

# Developmental Psychiatry: MH for C&A with ID & ASD

## History, Concepts, Challenges and the Future

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### Acknowledgements

**CHW Developmental Psychiatry Team**

**Centre for Emotion Based Social Skills Training for Autism,**

Michelle Wong, Belinda Ratcliffe, Tom Butterworth, etc; [www.ebsst.com.au](http://www.ebsst.com.au)

**CHW School-link** : MH liaison with schools that cater for Intellectual & Developmental Disorders

Jodie Caruana, Hebah Saleh, Newsletter/Educational Resource and website: [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au);

### Developmental Psychiatry Clinic and Partners:

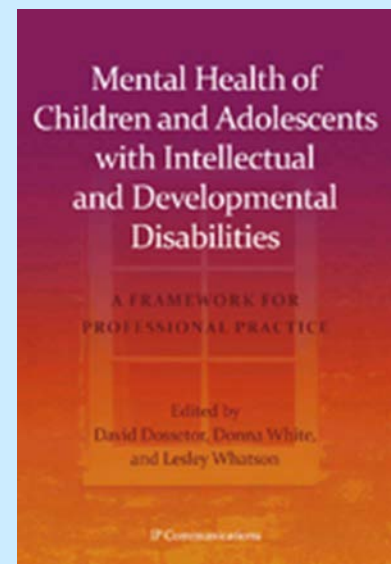
Statewide Behaviour Intervention Service, ADHC eg Lesley Watson, Donna White,  
A Hanson, K Van Seville

**Department of Education and Community** eg Katrina Worrall, Jan Luckey;  
Coreen School

### Publication:

Dossetor D, Donna White, Leslie Watson (Eds).

Mental health for children and adolescents with intellectual disability:  
a framework for professional practice. IP Communications: Melbourne. 2011.



# Health Warning:

Developmental Psychiatry or Mental Health of ID/ASD is

- underfunded,
- limited research,
- complex,
- relies on collaboration of all involved

## Outline

1. Case Example(s)
2. Difficulties of diagnosis
3. Developmental framework
4. Aetiology of ID MH
5. Diagnoses and comorbidities of ASD
6. Audit of meds
7. The development of Collaboration
8. The Future and potential models of services

# Case vignette with multiple comorbidities

- Michael was 14 years old with
  - a **complex developmental disorder of presumed genetic origin and major disruptive problems**.
  - small for age, skinny, red haired, with minimal eye contact, restless and fidgety.
  - Phenotypically looked a little like a boy with Williams Syndrome, though the gene probe negative.
  - **expressive dysarthria** esp for “R”s and “S”s due to problems of muscle tone & coordination
  - **problems of semantics and pragmatics**: eg when told to “put a sock in it”, he put a sock in his mouth.
  - **preoccupied with sad events**: death of great maternal grandmother 6 months ago, the cat that ran away 2 yrs ago and a friend who drowned 3 yrs ago.
  - didn’t like school, and complained of getting bashed;
  - did like soccer and had a few friends but none in his class.
  - **serious deficits in social relating skills** and understanding; at best he was ignored by peers.
  - **stereotypic interests** in cars and space.
  - significant **sensory sensitivities**.
  - All medical investigations were non contributory.
  - Mother described that **uncontrollable anxiety led to aggression and self injury**;
  - **school refusal and separation anxiety** & was also anxious about new people, open spaces & needles.
  - **depressed mood**: used to cry three times a day prior to treatment with sertraline.
  - unable to sit still, “**energy of a lithium battery**” but Ritalin had a powerful effect on calming down, improving language and communication and enabling him to attend school.
  - persisting **sleep problems**, and often stayed awake all night worrying about school.
  - problems got worse as term went on possibly due to increasing fatigue,
  - **muscle weakness and coordination** problems.
  - always had a problem with **bed wetting and soiling**.
  - **mild intellectual disability** with verbal skills >performance; over time his IQ was declining.

# Case vignette with multiple comorbidities

- His 16 year old brother who had the identical behavioural and developmental phenotype, had had multiple psychiatric admissions for decompensation and aggression; was diagnosed with mild ID, bipolar disorder, behaviour disturbance; loss of muscle tone, strength and coordination with variability of sleep pattern; was on a complex pharmacological and treatment regime. Has now developed memory loss and is being investigated for Frontal Lobe Dementia.
- His mother was warm hearted, caring and competent; his father was divorced and substance abusing with problems of verbal abuse, violence and excessive discipline; both boys were terrified of him. If he saw his father in the street he couldn't eat or sleep for 4 days, school refused for 10 days and had anxious ruminations and flashbacks.

# Case vignette with multiple comorbidities

- **Michael was diagnosed:**
  - mild ID;
  - Developmental motor dyspraxia disorder;
  - Enuresis & soiling;
  - Complex language disorder with specific receptive, expressive and semantic pragmatic problems
  - Pervasive Developmental Disorder nos (ASD)
  - ADHD
  - Depression;
  - various anxiety disorders:
    - separation, phobic, panic & general; selective eating disorder, PTSD,
  - relationship problems with his father
  - inadequate support from education for his special needs.
  - (recently found out that MGF has Bipolar Disorder)
  - Subsequently diagnosed with increasing peripheral muscle weakness and coordination problems and increasing memory problems.

# Treatment Management

- Treatment was multi-component to meet his multiple problems & included:
  - skilled mothering;
  - court protection from father;
  - a case conference to coordinate and value different agencies' contributions
  - intensive weekly skill-based psychological home-based treatment from ASPECT
  - occupational therapy sensory assessment for sound & tactile sensitivity
  - splints for writing;
  - advocacy in school: integration funding; social valorisation and an individual program eg he was made library monitor for recess.
  - Regular swimming in a swim club for disability
    - recently won a gold medal in the Special Olympics for 50m Freestyle (31secs) in Newcastle.

# Treatment Management

- Medication included:
  - Ritalin helped his developmental & educational performance, & emotional regulation;
  - Amitriptyline helped ADHD, enuresis, soiling, emotional regulation incl anxiety, such that he could access anxiety management skills better, and increased appetite
  - Risperidone helped aggression, anxiety and appetite;
  - clonidine to help sleep at night;
  - valproate to enhance mood stabilisation.
- Orthopaedic intervention included serial plasters to ankles for his shortened achilles tendons secondary to toe walking.
- Of note, his brother had had a similar complex psychotropic drug experience but later in the course of his problems, in a secure mental health unit, he particularly benefited from mood stabilisers including lamotragine and propranolol.
- Michael's psychiatric disability improved from the range of interventions, but he found new stability in a special educational school with greater understanding of his morbidities, where he has received regular awards for good behaviour.
- His younger sister has now presented with a very similar and disabling presentation.

# Brief History

- **1960s** many children with ID were institutionalised at birth
- **1980** UK “No child should be brought up in a hospital”
- **1987** NSW: Funding for Care of PWID transferred from Health to the Social Model (Welfare Services):- including medical, assessment and therapy services
- **1990** Training Resource Unit brought specialist behavioural (ABA) approaches to ID
  - Gradual transfer of assessment services back to paediatric health
- Rise of recognition of MH in ID
  - **DM-ID (2007)**: textbook of diagnosis of mental disorders in persons with an ID
  - **DC-LD 2001** (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation) (Royal College of Psychiatrists)
- **2013 LEFT BEHIND**: Monitoring the social inclusion of young Australians with self-reported long term health conditions, impairments or disabilities 2001 – 2011: the gap has widened
  - Young disabled Australians were five times more likely than their non-disabled peers to experience long-term unemployment and entrenched multiple disadvantage: defined as experiencing disadvantage in at least three areas - income, work, education, safety and support and health - for two years or more
- **2013**: pilot NDIS



# Context

- MH of C&A with ID is a public concern
- 30-50% of C&A with ID have signif MH probs; only 10% receive specialist help for MHPs (Einfeld and Tonge, 1996)
- Burden equivalent to Schizophrenia
- MH for C&A with ID is 14% of MH burden (Emerson & Hatton 2007)
  - 25% of CAMHS in UK is ID or Autism
- 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?

# Don't blame poor old Mental Health

- MH = 35% health burden; gets 10% health funding .
- Child MH = 35% MH burden; gets 7% MH funding
- CAMHS Staffing = 40% of need
- 15 years MH priority, % of MH budget is the same.
- PWC report: Aus Disability is 40% funded & is 29<sup>th</sup> /29 in OECD.
- C&AwID: 40% MHP; 10% (4%) get specialist MH help  
(Einfeld & Tonge)
- MH for C&A with ID = 14% of MH burden (Emerson & Hatton 2007)
  - 25% of CAMHS is ID or Autism in UK
  - The MHPs & the burden of care affect QOL
  - 3% of health & 8.75% of MH burden of care has no recognisable MH funding
- No specialist MH&ID service
- but MOU between MH&ADHC (Nov 2010)
- Canberra Roundtable on MH&ID (May 2013) agreed
  - principals of access for PWID for mainstream services
  - subspecialty MH skills needed
- **Health Economics indicate MH intervention is cost effective:**
  - \$3mill ave cost of a completed suicide
  - Lifetime Cost of someone with ASD \$1-2Mill;

# Why is it so difficult to help C&A with ID & MH?

## Why is there no designated mental health service for MH & ID?

**Discourse Analysis** with colleagues and trainees identified some of the differences of MHP for C&A with ID from mainstream MH.

- The context of developing the Training Curriculum Project,
  - developed a 2 day interdisciplinary curriculum.
  - 3 years funding from 3rd National MH Plan and ADHC for project manager (DW)
  - partnership project between the Department of Psychological Medicine at the CHW with Statewide Behaviour Intervention Service (SBIS), ADHC (LW).
- **Observations came from:**
- a literature review;
- clinical experience of '*what works*' in tertiary multidisciplinary multi-agency clinic
- areas of demand for training from SBIS;
- a stakeholders survey of areas of intervention-focused learning;
- evaluations and 3 month outcomes on workshops;
- commissioning 28 chapters, independently reviewed for a textbook.
- 4 2-day workshops to >500 clinicians in 2009/10:
  - evaluation and feedback from the curriculum was positive
  - at three months clinicians reported it had made a difference to clinical practices.

# **The findings**

## **8 problems for MH in ID**

- 1. Ambiguous Terminology**
- 2. Dichotomous/Divisive Concepts**
- 3. Problems of diagnosis of MHP in adult with ID**
  - **Reliability of identifying MH Symptoms**
- 4. Disparities in Diagnosis in DSM/USA & ICD/UK**
  - **Reliability of identifying MH Disorders**
- 5. Need for Special Diagnostic Skills**
- 6. Differences *defining* MHPs & Services in C&A with ID**
- 7. Differences & different approaches needed for MHPs in C&A with ID eg ADHD & other Dev Disorders**
- 8. Other problems in MH for C&A with ID**

# 1. Ambiguous terminology

- a lack of an internationally accepted language:
  - Eg. “Mental Retardation” is used in USA.
  - “Learning Disability” is used in UK,
    - whereas this term is used in America is for Specific learning problems.
    - In Australia you are never sure what problems this term is used for?
- agency/discipline specific jargon causes communication confusion;
  - 125 abbreviations in common usage were readily identified and
  - no workshop attendee could accurately interpret all.

***Finding :***  
***conclude that there is no evident common language.***

## 2. Dichotomous & Divisive Concepts

- **Challenging Behaviours** is a concept of poor social adaptation
  - implies an environmentally caused or maintained problem
  - needs a **linear behavioural approach** to intervention (ABA)
  - the primary model used by Disability Services.
- **VS** **Psychiatric Disorder** is an alternative concept to poor social adaptation
  - implies a disease model
  - identified by **syndromal clustering** of features
  - requiring the expertise of mental health services.
- Both models acknowledge bio psycho social factors.
- Research indicates that they frequently co-occur
- Yet some practitioners work only with one of these concepts.

**Professional discrimination** against ID still occurs: illustrated by the comment:

- *“if the patient can’t talk then they can’t have a mental disorder”.*
- A lack of interest, knowledge or experience is an effective way of avoiding providing a service

**Research:** Most condition specific research is limited to Mild ID

- Little agreement on how MHPs are different in the earlier stages of mental development

# 3. Probs of diagnosis of MHP in adult with ID

MHP defined “a diagnosable illness that significantly interferes with an individual’s cognitive, emotional, or social abilities.”

Experts assert that “those with ID have the full spectrum of mental illness, but usual diagnostic criteria are difficult to apply”.

Methodical approaches to diagnosis are a recent development.

## 1. DM-ID (Diagnosis of mental disorders in persons with an ID) ( 2007)

- Diagnostic and statistical manual for people with ID was developed by an international, (mostly American), expert group.
- Each chapter 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.

*“This manual of diagnosis gives people with ID entitlement to MH services”*

- Clinical usefulness study (2006): a field trial 900 patients, 80 clinicians from 11 countries:
  - user friendly and more specific than the DSM-IV-TR (text revision 2004).

## 2. 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.
- emphasising “it is not the criteria that need alteration but a different method of eliciting the necessary information”.

# Both diagnostic manuals identify special problems of eliciting phenomenology in ID

1. ***Subjective mental phenomena cannot be reliably elicited < 7 years or IQ <45.***
  - Hence the debate over the age at which depression or psychosis can be identified in children.
2. ***Difficulty articulating abstract or global concepts***
  - eg depressed mood because of limited cognitive and verbal skills.
3. ***More likely to give answers to please*** the interviewer.
4. ***Intellectual distortion*** for example saying “yes” to “hearing voices”, without understanding the implication of question.
5. ***Diagnostic overshadowing:*** failure to identify co-morbid psychiatric disorder attributing disturbance to the underlying ID.
6. ***Baseline exaggeration or intensification*** of existing maladaptive behaviour; eg. an increase in SIB under a time of stress.
  - A significant stressor can be an anniversary of a loss that carers may not identify, or a change of a teacher or other staff, or a classroom or accommodation or of family visits.
7. ***Stress on coping with a lack of cognitive reserve leads to disintegration, disorganisation or psychotic behaviour*** implying
  - such a major stress response does not constitute a mental illness (although adjustment disorders are part of DM-ID).
8. ***Delusions & hallucinations are frequently difficult to distinguish from a range of normal developmental phenomena*** eg:
  - concrete thinking, pretend friends, stereotypic thinking and imagination, especially in ASD.
9. ***Irritability & explosive anger may be common problem of challenging behaviour but associated with depression & mania.***



# Both diagnostic manuals identify special problems of eliciting phenomenology in ID

## Findings:

- *“Families and professionals alike are at risk of diagnosing serious psychiatric disorder where none exists.”*
- *Non specialised doctors (GPs) fail to identify mental disorder; eg depression in this pop*
- *There is no advice on how to tackle these special problems*
  - *apart from consulting “an expert”.*

# 4. Disparities in Diagnosis in DSM/USA & ICD/UK

**Tsiouris et al, (2008) DSM/USA**

**Large study of 4468 clients/service users,  
¾ in out of home residential settings,  
The main DSMIV psychiatric diagnoses**

1. Impulse Disorder 21%
2. Anxiety Disorder 19%
3. Schizophrenia and other psychoses 18%
4. Depression 14%
5. Bipolar Disorder 12%
6. Obsessional Compulsive Disorder 11%
7. Personality Disorder 8%
8. Sleeping Disorder 4%
9. Eating Disorder 3%
10. Tourettes 2%

## **Psychiatric Disorder in 60%.**

Diagnoses found not included:

Adjustment Disorders; PTSD; Substance-related disorders; Sexual & Gender Identity Disorder; Dementia; Mental Disorders due to a General Medical Condition Nos.

None of C&A eg Learning Disorders; Motor Skills Disorders; Elimination Disorders; Pervasive Developmental Disorders; ADHD & Disruptive BD; Somatoform & factitious dis; Attachment Dis; Stereotypic movement dis incl. SIB; Behavioural Phenotype of Genetic Disorders

Disorders

**Cooper et al, (2007) ICD/UK**

**Epidemiological study by 1023 adults >16, mild, mod, severe ID.  
Using PAS-ADD checklist & PAS-ADD 10, (Costello et al, 1997),  
Using Algorithms to produce ICD10 Diagnoses**

1. Psychotic Disorder 4.4%
2. Affective Disorder 6.6%
3. Autistic Spectrum Disorder 7.5%
4. Anxiety Disorder 3.8%
5. Organic Disorder 2.2%
6. Pica 2%
7. Hyperkinetic Disorder 1.7%
8. Personality Disorder 1%
9. Alcohol/substance abuse 1%
10. Obsessional Compulsive Disorder 0.7%
11. Sleep Disorder 0.6%
12. Other mental ill-health 1.4%

**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%**

**>50% of Problem Behaviour had Psychiatric Disorder**

# Reasons for disparity of diagnoses identified and of their frequencies?

- A lack of uniformity of diagnostic concepts and thresholds
  - Different rules on co-morbidity
- Different diagnostic and schools of psychiatric thought
- No research to establish an international consensus
- reminiscent ADHD in the 1980s
  - ADHD was diagnosed in USA at rates x10 that in UK,
  - before international collaboration clarified the concept and dimension of severity which is dealt with differently in the different diagnostic systems.

# 5. The Need for Special Diagnostic Skills

Special skills are needed to make a psychiatric diagnosis in people with ID eg in Depression.

- Most patients with ID and depression in a clinic population do not meet the required diagnostic criteria for DSM or M-ID (Hurley, 2008).
  - Pts with ID & depression do not complain of depressed thoughts & few report suicidality.
  - still have depressed mood, sadness, crying, anhedonia & withdrawal which distinguished from anxiety or bipolar disorder
- GPs' capacity to identify depression in ID in routine assessment was compared with long term paid carers' and a specialist psychiatric assessment. (Torr et al, 2008).
  - **GPs failed to identify depression, even with the carers present.**
  - Carers identified the consistent features of depression: mood (6 items), loss of interest (5 items), loss of social interaction and communication (8 items) using a 53 item checklist. Depressed thinking was not a reliable feature reflecting limited communic'n skills.
  - GPs focussed more on sleep, appetite, weight & general functioning.
  - In this cohort, expert opinion found that 30% had depression but 25% had a Pervasive Developmental Disorder.

## Findings:

- GPs are the gate keepers to specialist services, including MH.
- Both GPs & general psychiatrists will fail to provide the same level of case identification as a psychiatrist with special experience in ID.
- *Access to MH services for people with ID is disadvantaged by the lack of trained workforce.*
- *There is a need for further education & support for the recognition of subspecialty psychiatry skills in ID.*

# 6. Differences in defining MHPs & Services in C&A with ID

- C&A MH defines psychiatric disorder as: *any disturbance of beh or emotions sufficient to cause significant impairment to the child or their carers.*
- Epidemiological longitudinal studies indicates 40% have a severe MHPs but the Developmental Behaviour Checklist (DBC) measures symptom range & severity but *DBC doesn't translate to psychiatric disorders* (Einfeld & Tonge, 2006).
- **The additional impairment of Psych Disorder/Beh Disturbance in ID versus that of ID alone has not been quantified in a study.**
- **Disturbed behaviour may be due to Mental Illness, Mental Disorder, Developmental Disorder, Challenging Behaviour or Behaviour Problem.**
- **Which labels a clinician uses is substantially a subjective determination affected by profession, employing agency and different theoretical models.**
- ***MH is substantially underfunded and has prioritised services to severe mental illness and emergency intervention services for acute mental disorder.***
- The community message that “**Mental health is everyone's business**” suggests all child orientated services have to understand & manage MH problems.
- Aggression is the most common problem but by 10 years such behaviour is chronic problem that generally doesn't improve in psychiatric in-patient units.
- Most conditions are best treated in the community: with shared responsibility between families, neighbourhoods & all government departments.
- Juvenile Justice is often the default service for a lack of community based MH services.

## Finding:

**C&A MH also have problems with reliable identification of MHPs & prioritise to avoid responsibility for CB**

## 7. MHPs in C&A with ID are different & need different approaches eg ADHD & other Developmental Disorders

- The way MHPs in C&A with ID present are different to those with average IQ. Eg:
- 30-50% of C&A with severe ID have ASD (compared 1% in the average pop).
- The significance and meaning or validity of a diagnosis may be different for different levels of ID.

**ADHD in Mild ID: the diagnosis could be made reliably but there are differences in the predictive validity.** (Anstel et al, 2006).

- Prevalence is 30%, M=F, stronger factors of family functioning, & stronger association with dep & social impairment.
- Standard drug treatment is not as effective & patients are more prone to side effects

**ADHD in severe ID: there is a lack of research for reliability and validity,**

- is more affected by more general neurobiological factors as well as in the polygenic processes considered important in ADHD of average IQ.

## **7. MHPs in C&A with ID are different & need different approaches eg ADHD & other Developmental Disorders**

**Further ADHD is associated with other developmental disorders. Eg:**

- ADHD and Developmental Coordination Disorder each occur in community studies at a rate of 7%, but co-occur in 50%.
- ADHD is found in 50% of teenagers with ID plus autism vs 15% with ID without autism (Bradley 2006)
- ADHD is found in 78% of PDD in clinic population (Lee & Ousley, 2006)
- Genetic studies confirm linkage between ID and Autism indicating a commonality of development behind both.

**ADHD is particularly high in Behavioural Phenotypes:**

- Smith Magenis Syndrome 90%, Fragile X 75%, Williams Syndrome 65%, Charge Syndrome 50%, Neurofibromatosis 50%, VCFS 43%, Cornelia de Lange's Syndrome 40%, Soto's Syndrome 38%, Tuberose Sclerosis 35%, Turners Syndrome 24%.
- In Fetal Alcohol Syn ADHD is found in 49%, (ID in 55%, learning disorders 46%, ODD 41%, anger, mood disorders & sleep disorders in 50%)

Taking these observations suggests that

- ADHD in ID represents **a common outcome of impaired development of problems of developing coherence & efficiency of consciousness, rather than a specific disease process.**
- It is still helpful to identify co-morbid ADHD particularly based on the evidence and experience of the reduction of impairment from drug treatment.

**Finding: Developmental Disorders have high risks of co-occurrence, are highly genetic & may all relate to problems of developing neural complexity**



## 8. Other problems in MH for C&A with ID

- Different models for understanding MH are used by different disciplines & agencies.
  - Some agencies are individual centred & lack of family centred approach.
- A lack of recognition of the optimal range of the disciplines & agencies required
- A lack of inter agency collaboration with service cost shifting.
- A lack of service structure for more severe problems.
- A lack of attention to Prevention Promotion and Early Intervention (PPEI)
- Limited empirical evidence on the contributions from but need subspecialty skills: OT, physio, speech therapy, psycho-pharmaco therapy, family therapy & systemic practice which are all considered part of comprehensive treatment
  - (strong alternative therapy lobby)
  - (The best evidence is for parent training and behaviour therapy (Cochrane Review))

### **The resultant service failure:**

- Families experience a rotating front door of inexperienced community clinicians.
- Problems escalate without effective intervention.
- This provides some explanation why parental murder/suicide ideation is such a frequent presentation in the families of C&A



# Conclusions and progress so far

- **The scientific evidence in MH problems in ID is still in an early stage of development.**
- **Mental health for C&A with ID is different from adult psychiatry for ID & mainstream C&A psych**
- **A curriculum framework is necessary to establish a coherent service & interdisciplinary/interagency collaboration**
- **Specialised clinicians are positive on the impact that such services have on MHPs in partnership with families & child orientated agencies**
- **Developmental Psychiatry for in C&A with ID has much to contribute to mainstream psychiatry**

# Developmental Concepts

- *Richard Dawkins:*
- *Anomalies when rightly studied yield rare instruction; they witness and attract attention to the operation of hidden laws or of known laws under new and unknown conditions; and so set the inquirer on new and fruitful paths of research. (Henry Maudsley, 1880).*
- *The universal principle of development (Heinz Werner): where there is life there is development in a systematic sequence*
- *Development involves . . . ‘orderliness, sequentiality, and apparent lawfulness of the transition taking place from the birth or conception of an organism to the attainment of maturity’ (Zigler, 1963).*
- *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.*

# Implications

- These developmental observations remind us that all of human behaviour needs to be viewed from developmental framework.
- 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 neural connectedness

- The study of evolution has led to the appreciation of the importance of developmental processes in complex systems.
- In a similar way studying developmental psychiatry contributes our understanding the development of the mind:
- These developmental processes and their influence on mental phenomena distinguishes child and adolescent psychiatry from being a diminutive form of adult psychiatry.
- Development of the mind involves developing capacities of:
  - Identification of self and non self
  - Motor regulation and coordination
  - Selective attention
  - Communication skills
  - Emotional recognition, theory of mind
  - Mood regulation
  - Self concept
  - Reciprocal social interaction
  - Reality testing, perspective taking and problem solving
  - Good quality peer attachment
- What is the relationship between development of the mind and losing your mind?
- Rx of MH in ID is complex and attracts multi-skilled physicians

# Making sense of emotional and behavioural disturbance

- Behaviour is firstly determined by:
  - **Biology** incl genes, behavioural phenotypes & temperament
  - mediated by **developmental** stage/context
  - shaped by **chronological** or physical age
    - for example those changes in behaviour associated with puberty which improves in adulthood
  - shaped by the **environment**
    - the functional match or mismatch of the environment.
    - The influence of past and present life circumstances
- Optimally the environment **has to match** for both developmental and chronological age, enabling engagement both communicatively and with age appropriate social norms.
- Diff **trajectories** of development due biology & environment

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

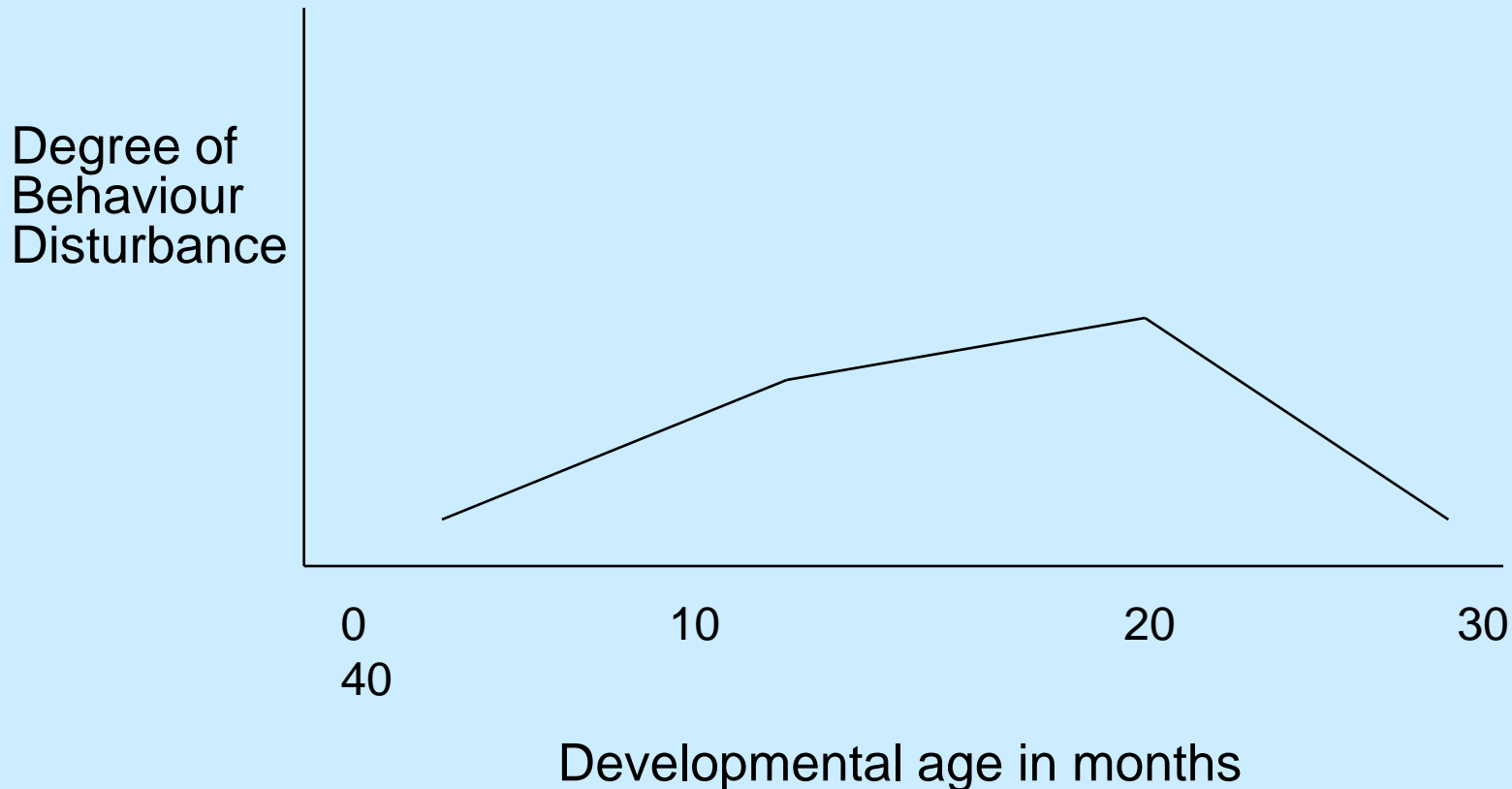
## **Assessment of problematic behaviour**

### *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



# ***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*



# Developmental contributions to Maladaptive Behaviour

- Increase with the rise of ‘**developmental toddlerhood**’ that resolves around the developmental equivalent of 2.5 – 3 years (Dossetor et al, 2004).
- influenced by temperamental and environmental factors
- Greatest environmental influence is the quality of **parenting** & other relationships
- further epidemiological rise in adolescence which settles in the 20s: Adolescents c ID also have a similar rise illustrating the **role of hormones**
- **Social role** changes in adol & post school; **Environmental Matching**:
  - can be highly disturbing if not suited to the needs
  - but also frequently leads to more stable & predictable demands that can help settle a YP with problems of flexibility and adaptability.
- IQ may not develop significantly after 16 years, but there are several other maturational and developmental changes. This is a source of hope for families struggling to provide for a difficult teenager with ID

# Epidemiology: ID & MH

‘mental retardation’ in USA & ‘learning disability’ in UK

- Definition (DSM-IV):
  - an IQ below 70 or 2 standard deviations below average
  - significant limitations in two or more areas of adaptive behavior
  - evidence that the limitations were apparent before the age of 18
  - diagnosed by professional assessment of IQ, eg with Wechsler Intelligence Scale for Children (WISC-IV) (2003), & adaptive behavior assessment eg Adaptive Behaviour Assessment System- Second Edition (ABAS-II) (Oakland & Harrison, 2008), or other developmental/clinical assessment if administration of standard measures is not possible.
- Severe, moderate & profound ID: 1%
- mild ID: 2-3%
- rates of psychiatric disorder 40-50%
- about 4 times more frequent than populations of IQ.
- more frequent in moderate & moderate and severe ID than in those with mild ID

# Factors contributing to disturbance

- Predictors of Disturbance 7 years later:
  - previous behaviour disturbance (Einfeld et al, 2000)
  - family factors accounted of only 8% of the variance
- parenting a young person with ID is much more demanding
  - 7 hours a day 7 days a week
  - 50% parental burnout, anxiety or depression
  - limiting other family resources incl finance, outings and social activities.
  - most parents are deeply committed to their child with ID
  - Genetics of parenting may make it difficult to match parenting style
  - Practical support is more important than social support
- YP c ID are at greater risk of abuse and sexual abuse.
  - > 25% & related to the number of adult carers is exposed to.
- Other social factors
  - peer group rejection and lack of skill recognition influences self esteem.
  - Adolescence when differences to norms become more evident & appreciated.
  - Social & environmental factors can influence temperament & personality dev

# Factors contributing to disturbance

- **special predisposing factors include:**
  - communication difficulties and diminished problem solving skills;
  - sensory disability, hearing problems (17%) and visual problems (30%) often undiagnosed
  - neurological problems eg epilepsy in 25%; (Allington-Smith, 2006; [Szymanski](#) & [King](#), 1999)
  - physical illness predisposes to an exacerbation of behaviour, incl pain not communicated,
    - eg constipation, ear & sinus infections, dental problems, gastric ulceration & helicobacter infection, gastro-oesophageal reflux, nutritional deficiencies, obesity & the metabolic syndrome, endocrine problems eg hypothyroidism (Lennox et al, 2007)
  - limited coping strategies: when something goes wrong, shouting, aggression or SIB which will bring the attention of an adult when unable to find a solution; Such behaviour can become an automatic response when a young person feels uncertain or threatened.
  - family factors also influence teenagers with ID, such as parental depression or anxiety, or hostility or other problems of parental emotional regulation or more serious parental mental illness, parental lack of warmth, inconsistency, lack of supervision, neglect and abuse can affect development and emotional wellbeing
  - biological factors of the person with ID and its influence of family relationships.
    - eg in Smith Magenis, Lesch Nyhan Syndrome or Prader Willi, the behavioural phenotype has a stronger influence on family relationships than the other way round.
    - Curiously in Down's syndrome the temperament of the person with intellectual disability can either engender warmth and affection through their sociability, or create challenging relationships with a more autistic or less adaptable temperament (Dykens, 2000).

# Economic/Social Factors (Emerson, 2004)

- YP c ID have greater risk of living in chronic poverty.
- Poverty affects directly & indirectly through –ve impact on well-being of mothers & families.
- Poverty influences an increased exposure to adversity of family environment
  - eg as hostile parenting and adverse neighbourhood,
  - increase in life events with less available social capital.
- Relative familial/neighbourhood poverty associated with -ve outcomes for children in:
  - health, cognitive & social development, academic attainment & psychiatric disorder.
  - disadvantaged by access to services.
- associated with both internalising and externalising psychiatric disorder.
- little evidence of biological embedding causing this psychiatric disorder
- a clearer association to the exposure to adverse circumstances, levels of personal resilience and social capital, including quality of family relationships and child care/education: a sense of ‘collective efficacy’.
- Increased rates of law breaking relate to lower SES & increased detection.
- 10% in juvenile detention have ID, a serious over representation.
- Emerson also finds that not only do the disadvantaged have less access to health or mental health services but psychological treatments are less effective in this population.

# Biology and behavioural Phenotypes

- There are approximately 750 recognised genetic syndromes some of which are associated with behavioural phenotypes which can contribute to psychiatric presentations. Eg:
- **Self injurious behaviour** is seen in different syndromes: -
- **Smith Magenis Syndrome** SIB Head banging, nail biting and gauging, & insertion of objects in orifices with the serious behaviour disturbance, obsessiveness & inverted sleep wake cycle;
- **Prader Willi Syndrome** Chr15 translocation, with the compulsive eating, obsessive behaviours and ADHD
  - **Psychosis (25-40%)**, esp in uniparental disomy (80-100%).
- **Lesch Nyhan Syndrome** with the self injurious behaviour and lip chewing; abnormalities of purine or dopamine function in this pattern of SIB
- **Fragile X** unstable CGG sequence is *amplified*, & blocks synthesis of FMR-1 protein: Hand biting & ASD & ADHD
- **Velo Cardio Facial Syndrome** VCFS deletion of 22q11 with ADHD, social anxiety & OCD
  - 42% major psychiatric disorder in adulthood, incl **30% psychosis**, & 24% schizophrenia, (with stronger positive symptoms and weaker negative symptoms than is normally seen)
- Even in those with moderate or severe intellectual disability without identified genetic syndromes, post mortems show that 90% have abnormal anatomical structure, for example at level of dendrites and synapses
- Each behavioural phenotype enhances evidence on how genetics affect the development of the mind and its problems.



# Future Influence of Behavioural Phenotypes

A window on the mechanisms of the mind

- **FraX: Medically treatable?** m glutamate receptor 5 antagonists: R Baclofen, fenobam, Minocycline up to 70% improvements in sociability
- **CdL & SIB: Treat the medical problem:** 80% have GORD: Rx with omeprazole; others have middle ear infections, dental problems, eye problems, renal probs, perthe's disease of the hip; various genes assoc with cohesin protein; ASD (30%), less stereotypic features & more social & communication features on ADOS (subtyping ASD); CdL also has problems of set shift changes & visuo spatial tests. eg a sorting test, where if the rules of sorting are increased to more than one category, they make greater mistakes and get angry, assoc with exec function deficits.
- **Prader Willi (PWS): Different mechanisms for different symptoms** hyperphagia assoc with intrauterine starvation, OCD symptoms related to developmental age assoc to skin picking, ADHD; Shift set change probs: with greater routines are more aggressive. One intervention of a visual/card warning of change has been used to reduce levels of aggression.
- **Different Beh Phenos have different obsessions:** CdL show increased ordering, completeness, cleansing, checking and grooming than expected for ASD. Smith Magenis have repetitive behaviours/obsessions about people, familiar or strangers, as well as extreme impulsiveness.
- **Williams Syn:** ADHD, musicality & Anx/phobia partly syn related & partly other factors.
  - Chr 7 ? a vulnerability to hyperacusis & some phobias eg to sirens/thunderstorms. Hyperacusis may provoke a startle response.
  - Fear of falling/heights may relate to probs of gait, balance & coordination
  - Other phobias may be linked to non specific genetic factors, FH or Anx, parent's fear reinforcement

**There are multiple models of behaviour/symptoms, not just syndromes: and when may these models apply to idiopathic cases of ID & MHPs?**

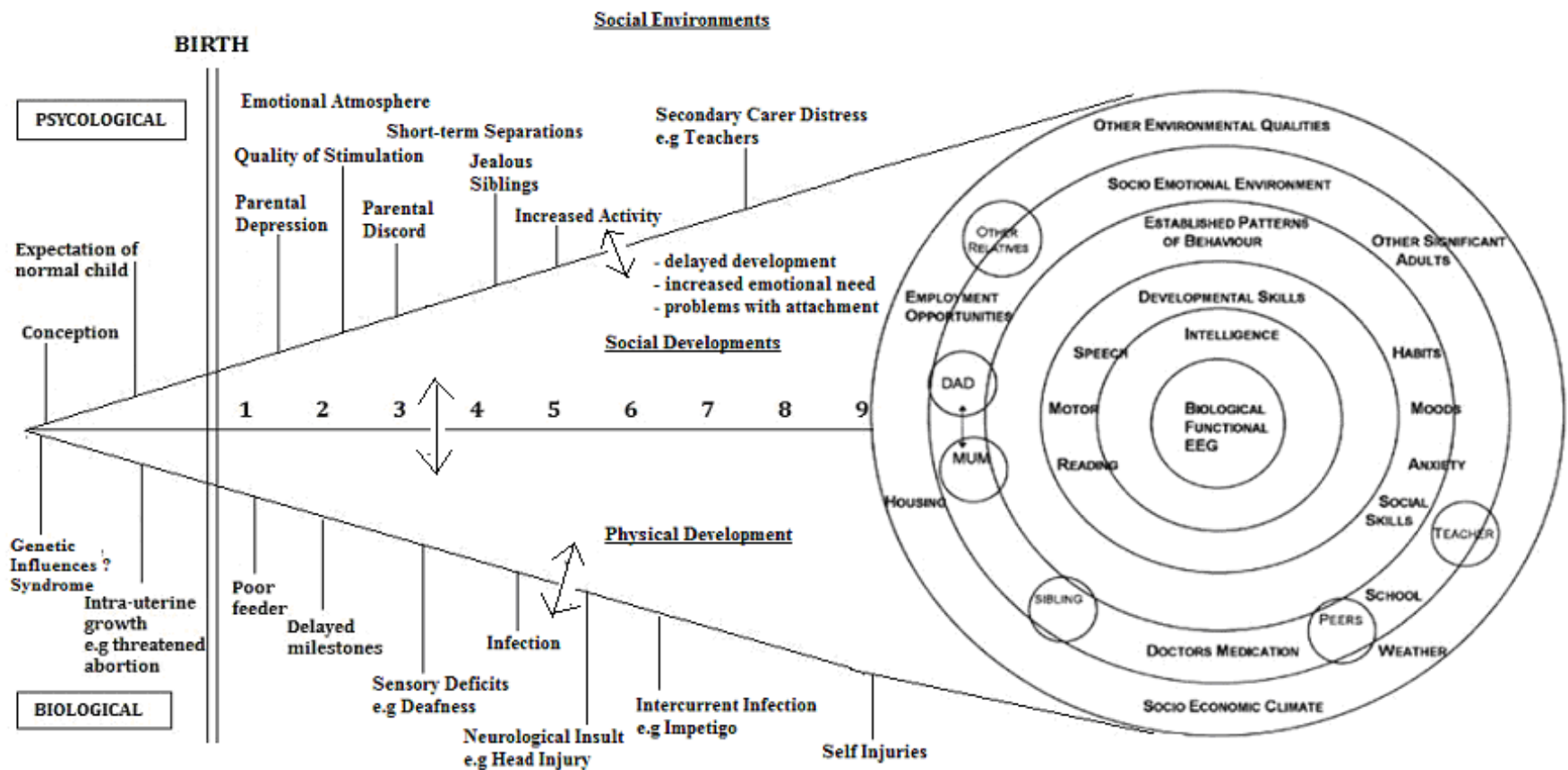
# Assessment

- Questionnaires eg Developmental Behaviour Checklist (Einfeld & Tonge, 1996) can aid the eliciting of less common symptoms,
- nothing replaces the comprehensive assessment by a clinician; includes:
  - a detailed examination of: presenting problems,
  - with predisposing, precipitating, perpetuating, and protective factors;
  - developmental history and profile;
  - medical and psychiatric history;
  - family history of developmental and psychiatric problems;
  - evaluation of the functioning of the family, with an assessment of each parent
  - a mental state examination of the adolescent +/- other members of the families
  - general medical & neurological examination and investigations as indicated.
  - Information from multiple informants:
    - the adolescent, different members of the family, representatives of school and other professionals such as medical practitioners and psychology and disability teams.
  - Formulation of the clinical predicament, including differential diagnosis,
  - may lead to further assessments from other disciplines in MH and disability clinicians, & the testing of the provisional diagnosis through intervention.
  - The norm is more than one psychiatric disorder plus other disabilities & medical problems, & a complex and challenging context from problems of family adaptation & problems of providing an adequate environment to meet his needs
  - Intervention is normally a collaborative process with key partners in the person's network contributing to multimodal intervention.



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

After Brofenbrenner, 1979



# **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 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**

## Child Psychiatry

**Community based**  
**Biased to Sociology**  
**Concerned about emotional deprivation**  
**Diagnosis based on epidemiology**  
**Treatment bias to psychotherapies**  
**Attributing responsibility to families & communities**

```
graph TD; A[Psychiatry of Intellectual Disability] --> C[Developmental Neuropsychiatry]; B[Child Psychiatry] --> C; C --> D[The social acceptance of difference with biological variation]; C --> E[Integrating medical sciences with social psychology];
```

**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**

# Psychiatric Disorder in with ASD

## Literature review

- 70% diagnosed with Psychiatric Disorder (Simonoff et al, 2008)
- Mood Disorder 53%; Anxiety/OCD 50% adult lifetime rates (Gillott et al 2007)
- Typically ASD occurs with multiple disorders (Wilson et al 2012)
- 70% being bullied, having no friends, not fitting in;
- 60-75% needed access to services, MH Services tend to exclude ID or ASD (We Belong, 2012)
- 68% parents stated educators not well informed
- 100,000 have ASD & MHP in Australia (Warren 2012)
- “People with ASD fall between the cracks of disability service provision” (Stronger together: a new direction for disability services 2006-16)
- UK Epidemiological Study of Adults with ASD found 1% prevalence, characterised by M>F, solitary, single status, low/no qualifications, lacked financial awareness eg for allowances, under supported by services, in rental/social accommodation, but no increased use of mental health services (Brugha et al, 2007)

# Psychiatric Disorder in Kids with ASD

- 50-80% school aged ASD, 41% >1 (Simonoff et al, 08)
- 20% ID only >50% ASD +ID (Bakken et al, 2010)
- **Increased rates of**
  - Anxiety 11-84% , incl phobias, physical anx, separation, social, GAD, OCD, often co-occur
  - ADHD, ODD, CD,
  - Tics 22% Tourettes 11%
  - Enuresis, encopresis
  - Motor coordination disorders, Language disorder
  - Depression/Mood Disorder, Bipolar Disorder,
  - Schizophrenia, Catatonia
  - SIB, Pica
  - Somatisation disorder
  - Stereotypic behaviours (eg blood curdling screaming)
  - Disorders of eating
  - Sensory processing disorder, (excluded from DSM5)
- **Reduced rate of**
  - Substance abuse; Cigarette Smoking
- **Clinic Population:**
  - 95% had 3 or more conditions,
  - 75% had 5 or more (Joshi et al 2010)

# Psychiatric Disorder in ID: differences

- Some psychiatric disorders are much more prevalent
  - Anxiety Disorder, Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder, Disruptive Behaviour Disorder, Pervasive Developmental Disorders and Autistic Spectrum Disorder (Einfeld et al, 1996; Borthwick-Duffy, 1994).
- Substance abuse is less frequent.
- depression, eating disorders and psychosis are not significantly more frequent than controls without ID. Levels of depression are controversial because of the difficulties of reliable identification (Emerson 2003).
- Rates vary with IQ

# ASD & ID

- more frequent in young people with ID.
- 70% of all those with ASD have ID
- half of those with ID have an Autistic Spectrum Disorder.
- ASDs are a dimension of disability in twin studies (Constantino et al, 2000)
- all levels of impairment from ASD are equally genetic.
- Even mild degrees of ASD lead to poorer prognosis & “treatment resistance”
- Of those with ID that present to a clinical service for MHP 75% have ASD
  - because of the association of other developmental problems
  - and partly from the problems of adaptability inherent in ASD
- an association of ADHD & ASD:
  - ADHD in 78% of a clinic pop of PDD (Lee and Ousley 2006).
  - 50% teenagers with ID & ASD had ADHD, compared with 15% of those with ID alone (Bradley, 2006)

# ASD & ADHD

- Some social impairment & inability to make friends is common in ADHD, but is that ASD?
- Treating the ADHD with stimulants can improve social functioning & sometimes makes worse
  - improvement of concentration & thinking can make the stereotypic rigidity more intrusive and handicapping,
  - Russell Barclay's rule of thumb: someone with ADHD is prone to function socially 2 years behind his chronological age
- Even mild ASD can be highly handicapping in adolescence and one should actively elicit the features
- The first time diagnosis of ASD in adolescence
  - late recognition of a major impairment by clinical and education services.
  - the level of ASD can become greater in adolescence.
    - Eg twin studies of Autism show that the later the monozygotic proband of an autistic twin is followed up, the more likely they are likely to have developed ASD.
    - a third of YP with a language disorder are found to develop significant ASD later in the course of development (Bishop et al, 2008).
  - Yet ASD is another disorder common in children and adolescents that is seldom identified in adults!

## Clinical presentation:

Teenager appears to be suffering from “storm and strain” with irritability and a low mood with an unrecognised ASD. Well meaning people empathise with his/her problems, failing to see the egocentric handicap of the teen who has an idiosyncratic capacity for arguing with anyone, ‘sticking to his principle’, yet lacks any objective capacity for sustainable reciprocal relationships or empathy.

Failure/late recognition of ASD leads to harm to family relns with caring, struggling parents, with inept teenager unsupported, in refuges, on the streets, subject to disadvantage & abuse.



# Autism & ASD

## Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

proposes **Autism Spectrum Disorder** will include Autistic Disorder, Aspergers Syndrome & PDD nos publication in May 2013

### **A. Persistent deficits in social communication and social interaction**

across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. **Deficits in social-emotional reciprocity;**
2. **Deficits in nonverbal communicative behaviors used for social interaction;**
3. **Deficits in developing and maintaining relationships,**

### **B. Restricted, repetitive patterns of behavior, interests, or activities**

as manifested by at least two of the following:

1. **Stereotyped or repetitive speech, motor movements, or use of objects;**
2. **Excessive adherence to routines,**
3. **Highly restricted, fixated interests**
4. **Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects**

**C. Symptoms must be present in early childhood** (but may not become fully manifest until social demands exceed limited capacities)

**D. Symptoms together limit and impair everyday functioning.**

Must meet criteria A, B, C, and D:

### **Severity Level for ASD**

Level 1 'Requiring support'

Level 2 'Requiring substantial support'

Level 3 'Requiring very substantial support'

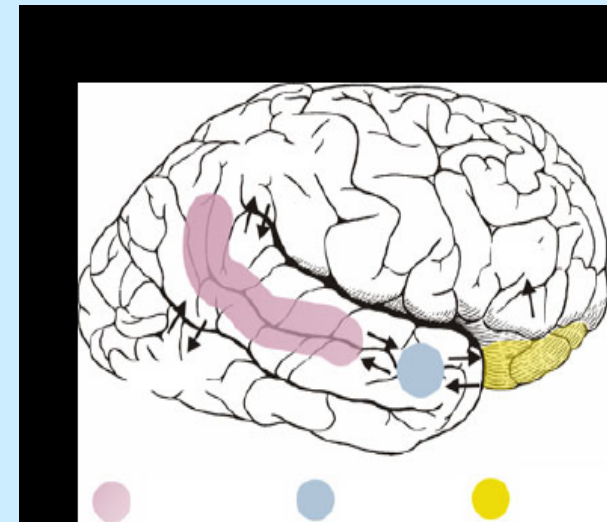
# Clinical Diagnosis

- NSW Gold Standard is 2 Clinicians with experience agreeing according to DSM/ICD
  - Research Assessments
- Diagnostic instruments: ADI-R, DISCO, ADOS, 3Di, SRS
- All instruments have their problems especially when compared against other reliable instruments.
  - ADI-R concentrates on deviancy
  - DISCO promotes a developmental frame of these domains.
  - ADI-R, DISCO not practical in clinical practice

ADI-R identifies a **single issue as the diagnostic feature of Autism: lack of reciprocity...**  
**Pervasively in social interaction, communication and interests.**

# ASD is a Neurodevelopmental Disorder

- Strongest predictive validity of any child psychiatric diagnosis
- No single cause identified
  - Predisposed by polygenic and other neurobiological factors
- Due to underconnectivity of the “social brain”
  - Superior Temporal Sulcus,
  - Amygdala,
  - Orbital Frontal Cortex &
  - Fusiform Gyrus (Pelphrey, Shultz et al, JCPP 2011)
- Severity is dimensional not categorical
- Or is it developmental?



# Social Responsiveness Scale (SRS)

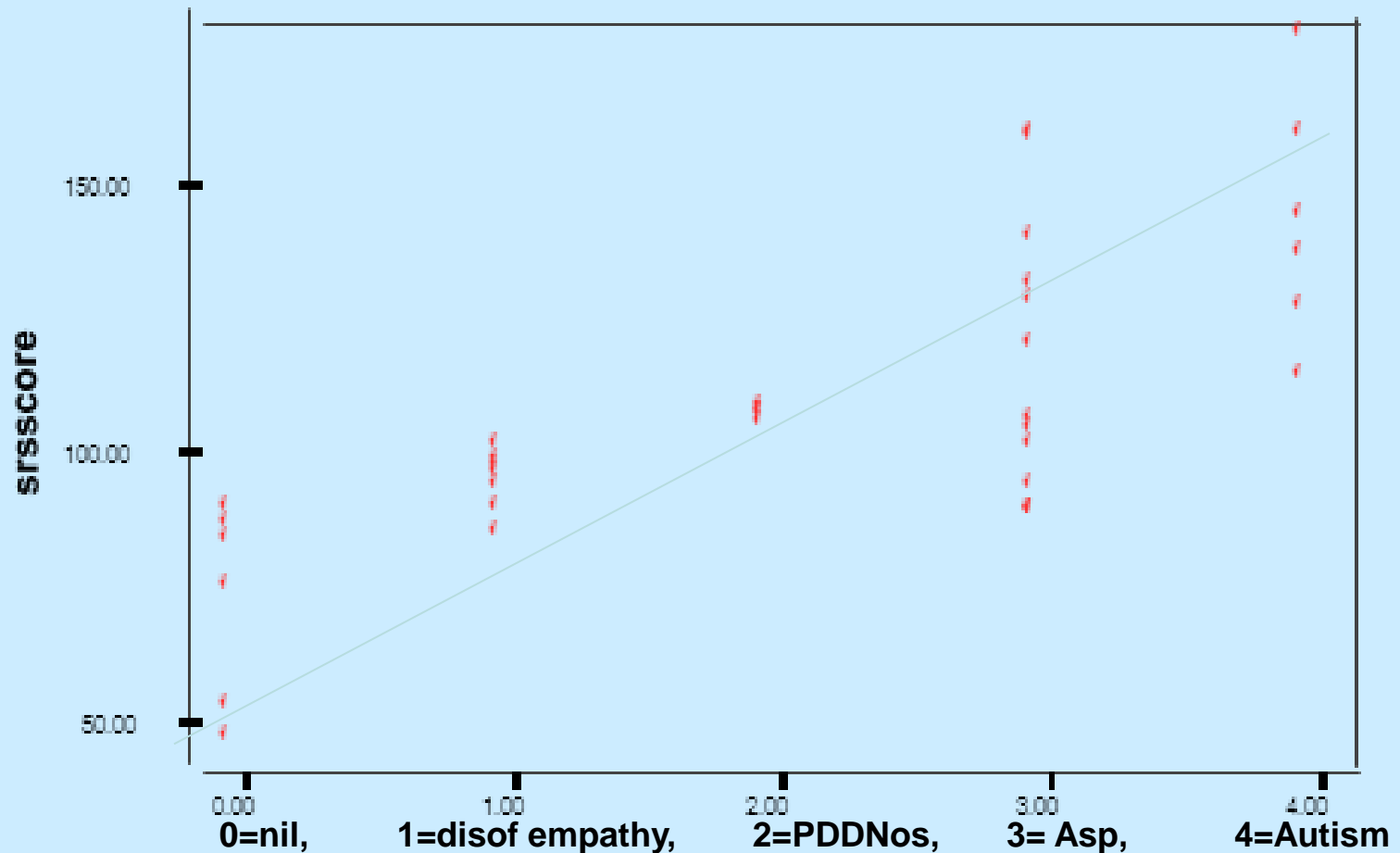
- 65 item questionnaire of developmental and behavioural
- filled by anyone who knows the subject well
- From twin studies, **SRS** has shown the dimensional nature of autism
- The whole dimension is as genetic as the category of autism.
- Scores (even below the autism threshold) contribute to the genetic contribution to disturbed behavior on CBCL.
- 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.

Constantino JN, Przybeck T, Friesen D, Todd RD (2000). Reciprocal social behavior in children with and without pervasive developmental disorders. J Dev Behav Pediatrics 21:2-11.

Constantino JN, Todd RD (2000). The genetic structure of reciprocal social behavior. Am J Psychiatry 157: 2043-2045.

# Scattergram: SRS Score vs ASD Clinical Diagnostic Category

N=33



The SRS score correlated with the category of Autistic Spectrum Disorder diagnosis:  
**Pearsons Correlation = 0.75,  $p < 0.0001$**

SRS score did not relate to IQ category: Pearsons Correlation = -0.021,  $p = 0.90$  (NS)

Despite high correlation with ASD category, in individual cases SRS also showed large variation between informants of clinical relevance,

## **Evidence of a developmental framework:**

### **Social communication: the primary variable for ASD**

- factor analysis of social communication items of ADI-R resulted in
- a 3 factor solution of symptoms:
  - Affective reciprocity, (?1st year)
  - Joint attention and (?2nd year)
  - Theory of mind. (?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 theory of mind.
- Shows a developmental progression of Autistic Features

Tanguay, Robertson Derrick 1998 JAACAP 37:271-277

# 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.

# ASD: the specific disorders of social development

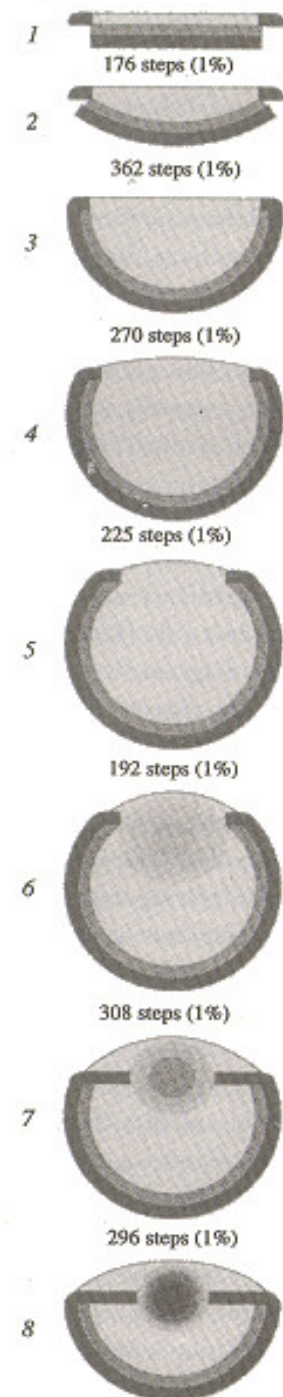
- A specific delay in socio-emotional development (social intelligence) behind general intellectual development
- Autism is social development skills < 2 years
- Aspergers is social development skills < 4.5 years
- A normative view of the biological causes of delays in developing peer relationships
  - help young people, families understand and accept:
  - specific strengths and weaknesses;
  - increased need for social support and guidance
  - Still make and need attachments, love and care like one of younger social age
  - but difficulties making friends with age related peer
- Social development: due to increasing complexity of networks/mechanisms, no single cause.
- Developmental Models simplify complexity and make understandable,
  - Vs biological models deconstruct brain function but are seldom clinically useful



# 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



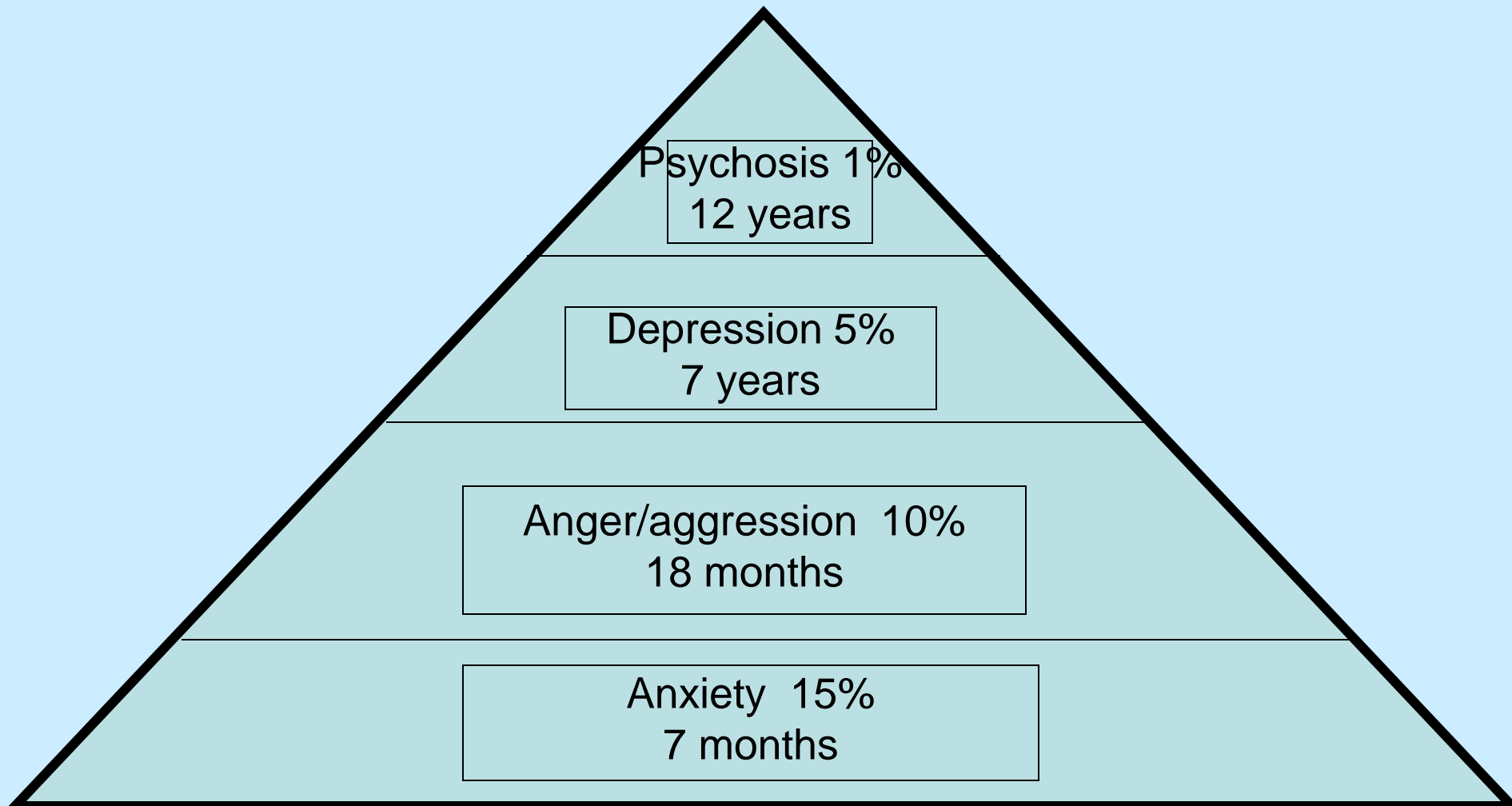
# The Evolution of the 'Photon Catcher': Implications for Social Development & Autism

- 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.

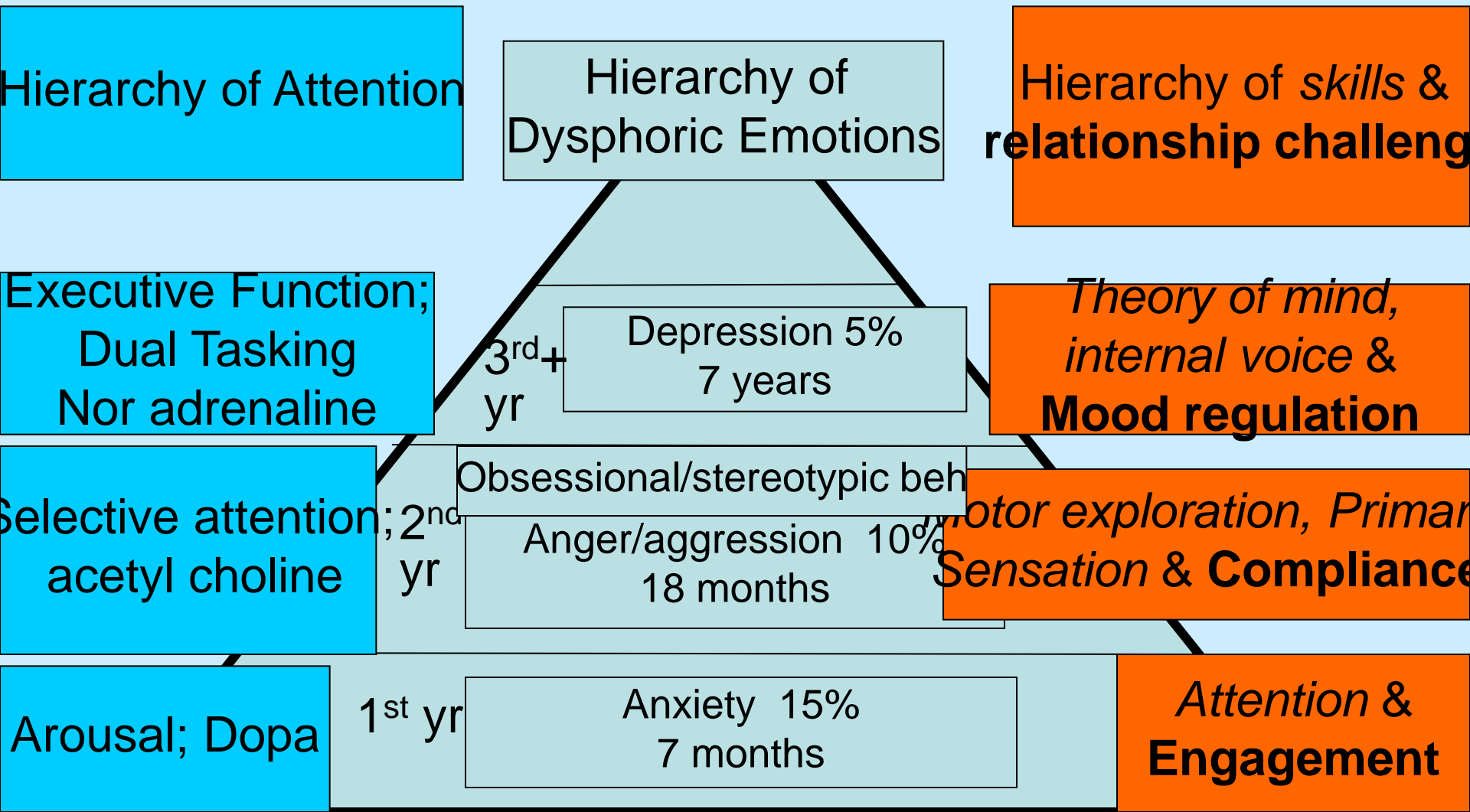
# Alternative contributing concepts: DEVELOPMENTAL HIERARCHY OF EMOTIONAL DISORDERS

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 and the developmental age at which this symptom is first recognized

Dossetor D, 2004 *Clinical Child Psychology & Psychiatry*. 9(3), 443-451.



Developmental Sequences:  
DEVELOPMENTAL HIERARCHY OF EMOTIONS, ATTENTION,  
INDEPENDENCE AND RECIPROCAL SKILLS



# Case vignette: Laura

- Laura 15 year old with Velo Cardio Facial Syndrome (VCFS) 22q11.2 chromosomal deletion
- parents have become concerned about recent changes in her mood and behaviour. She had been compliant and conforming until a year ago.
- now secretive and argumentative at home, meeting strangers in the park and had gone missing on one occasion, leading to police involvement.
- parents had observed recent episodes of crying, altered sleep and concentration, declining grades, irritability and thoughts of worthlessness. She had taken an overdose of her mother's tablets a month before, and from her diary her mother discovered that she was unhappy, saw herself as handicapped, wanted social acceptance and a boyfriend. She also worried about getting pregnant. She was struggling academically in a mainstream school with declining grades, and finding it difficult to maintain friendships.
- Assessment: moderately depressed with problems of peer acceptance. Her borderline ID was illustrated by being 3-4 years behind in her academic skills with problems in maths, reading and sequencing,
- she also showed a social naiveté of a 7-8 dev age and was impulsive and easily led astray with no insight into potential consequences & in keeping with the neuropsychiatric assessment of problems of executive functioning.
- She had had years of medical reviews and interventions for the physical problems of VCFS:
  - gastric reflux, low muscle tone, chronic constipation, ear infections and conductive hearing loss, cleft palate surgery and pharyngoplasty, speech therapy and scoliosis surgery.
- Her parents were knowledgeable and thoughtful, having run the local VCFS society. Her older brother had had ADHD and a troubled adolescence, with defiance of his parents, dropping out of school early & experimentation with illicit drugs, now at university.

# Laura's Psychiatric Management:

Intervention involved:

1. individual counselling to
  - (a) improve capacity for trust,
  - (b) provide CBT to help her low moods,
  - (c) skill building approaches to teach emotional understanding, and problems solving approaches to improve social learning.
2. She also benefited from a SSRI for her depression.
3. Family counselling  
focussed on understanding needs from a developmental perspective & to build up trust & communication so that she could accept her greater developmental need for parental support & guidance necessary to help her fulfil adolescent roles safely, eg as having friends & going to parties
4. Liaison with school  
enabling greater understanding & support both academically & socially.

# Longterm prognosis

- School is where most people with ID are identified
  - by the age of 22, the vast majority (74%) of mild ID were no longer known to disability services (Richardson & Koller 1985).
  - a 1946 cohort study showed that by the age of 43, many had achieved normal roles, although less than those without intellectual disability (Hall et al, 2005).

	Adults with Severe ID	Adults with mild ID	Adults with no ID
Current unemployment	79%	33%	11.4%
Obtained qualifications	4.3%	3.6%	59%
Home Owner	14%	53%	83%
Marriage	14%	73%	94%
Children	7%	61%	85%
Meet friends or relatives six or more times a week	36%	34%	45%
Go to pubs/clubs/social activity	73%	65%	72%
Satisfied with social contacts	71%	69%	74%

# Psychosis in VCFS

- Sharon 16 yr girl with VCFS presented to ED: with a decline in functioning for 2 months with paranoid delusions that neighbours were watching her and seeing through walls and talking about her. Convinced she was pregnant (despite evidence excluding), talking to imagined presence “stop looking at me”, attacking the neighbour, difficulty getting to bed, recurrent states of agitation and argumentativeness. She was exhibiting poor self care, suicidal ideation, poor sleep and agitation. She also declined in performance in school, attacked teacher; perseverating on wanting to have a birthday party or go to a disco, not wanting to take medication and how she will be good if she can stop taking medications.
- On Examination:
  - somewhat unkempt; problems with hygiene; agitated, banging walls and shouting;
  - “I am not crazy, I was just acting”; “I am only in hospital to have a pregnancy test”
  - Very Anxious, Appears to be hearing voices;
  - Risk of harm to self and reputation; Very limited insight.
- Context
  - Year 11; SSP School for last 2 years as unable to cope with academic & social demands of mainstream school;
  - Living with father and two brothers, one of who had VCFS and OCD.
  - Continued conflict between father whom she lived with & mother who also has VCFS & a HO psych admission, remained feckless & was undermining of F and Rx



- **Past History**
  - VCFS, Pharyngoplasty @6yrs and received speech therapy, problems with teeth, gait, foot pain and constipation
  - Decline in IQ from Borderline Intellectual Disability 1999; V<P, (better on abstract reasoning/problem solving, weak on Maths; performing 3 years behind) to Moderated Intellectual Disability in 2006
  - Sexually assaulted a few years previously
  - Treated by Psychiatrists for 18 months for voices and behaviour: Past Treatment: Risperidone, Quetiapine, Seroquel, Fluoxetine
  - Tends to hear voices at night and when agitated/anxious.
- **Diagnosis: Schizophrenia and Moderate Intellectual Disability**
- **In-patient Treatment over 12 weeks**
  - Unable to participate in group activities due to social anxiety and reluctance; progressive participation made a therapeutic target
  - Fluvoxamine maintained and started on Abilify and subsequently added Stelazine,
  - Oral contraceptive pill, to suppress menstrual symptoms
  - Cognitive Behavioural Therapy: visual aids to reassure against delusion, relaxation,
  - copes better if managed firmly with limited choices and clear rewards.
- **On Discharge**
  - Regular Psychiatric follow up
  - SSP Education, plus special support,
  - Problems with participation in school, both academically and socially
  - Support from DADHC for in home behaviour management and respite care
  - Will need long term multi-agency support
  - 2 years later reported hallucinations disappeared for first time; minor improvement in socialisation

# Solutions for MHPs for C&A with ID

**Our educational research identified the need for a coherent curriculum for MH for C&A with ID.**

**This included:**

- **A framework that is applicable for all professionals working with C&A with ID**
- **In the context of the family life cycle for a child with ID**
- **With a focus on the quality of life for child with ID and family**
- **Within a developmental framework that**
  - **informs multidimensional assessment**
  - **provides a context for understanding behaviour**
  - **an alternative approach for understanding developmental psychiatric disorders eg ADHD & ASD**
- **That assumes multi causal mechanisms to disturbance and disorder**
- **Puts an emphasis on multimodal skill building/positive psychology**
- **Requires multidisciplinary/multiagency collaboration**
- **A specialist MH service for C&A with ID which needs a multidisciplinary/multi-agency team that works closely together.**
  - **with a healthy tension between developmental models versus deconstructive (illness) models.**
- **Problem Solving service systems:**
  - **needs to be tiered, involve greater expertise with difficult to solve problems,**
  - **have rules of interagency collaboration &**
  - **a final common pathway of complex case conference, combining clinical judgement & resource management.**
- **Specific Prevention, Promotion and Early Intervention approaches are needed as generic MH strategies are not applicable.**

**Some components of PPEI should include:**

- **Universally available specialist parent child management training**
- **Emotional literacy programs in schools**
- **Multidisciplinary skill building skills**

# What makes for a Quality of life in ASD/ID?

Aim for a 'good enough' quality of life: "how satisfied are you with your life as a whole?"

QOL is pretty similar and fairly good for most (75%+/-20)

- Eg in the face adversity; chronic ill health, fast or slow learner; rich or poor
  - reasonable health,
  - being connected to other significant people, valued relationships
  - being linked to a community
  - contributing a worthwhile role, a sense of purpose, independence and productivity
  - having a hope for the future.
- Psychiatric Disorders are an important influence on quality of life
- **QOL for a child or adolescent with ASD/ID: limited research has similar domains**
- **for the young person with Autism QOL still involves (Cummins):**
  - **a sense of belonging, of friendship, or friendliness or shared activity**
- For the alienated, hostile, neglected young person living in a refuge, family relationships, despite their problems, are still the most important (NSW Commissioner for Children).
- For someone with an intellectual disability developmental achievement such as walking or functional communication is as valuable to them, as to an ATAR of 99
- Clinicians contribute to improving the QOL of young people with ASD and their families?
- Despite the challenges a growing literature shows how children and families can get it 'right'

# Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:

## A framework for professional practice.

Dossetor D, White D, Whatson L. Melbourne: IP Communication. 2011

**Foreword: Tony Holland. Introduction:** Training Curriculum Project: an interprofessional education program.  
White

### Pt 1 Foundations

1. Aiming for a **quality of life**: what makes for a 'good enough life'. Dossetor
2. **A common language** for understanding disability, development, emotions and behaviour. Caithness & Moore
3. **Structured assessment** of mental health problems in children and adolescents with intellectual disability. Ellis & Einfeld
4. **A paediatrician's approach** to the assessment of a child with intellectual disability or autism. Macdessi
5. Disabilities and **multicultural** issues. Baassiri & Carroll

### Part 2 Focus on Family and Carers

6. **Breaking the news of diagnosis**: facilitating adjustment and acceptance. Silove.
7. Children with developmental disability: is **providing care a burden**? Small
8. Promoting parent readiness for change: **a motivational interviewing approach**. Watson & Grice
9. **Cognitive behaviour therapy for carers** of children with intellectual disability and challenging behaviour. Patterson
10. **Brothers and sisters** with a disability: rewarding or challenging? Small
11. Understanding and responding to challenging behaviour: valuable contributions from **attachment theory**. Hansson
12. Challenging behaviour and change in intellectual disabilities: **family therapy, families and the wider system**. Rhodes & Watson
13. **Parent's Perspectives**. Carroll, Tye, Ollerenshaw, Eris & Brewer

# Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:

## A framework for professional practice.

Dossetor D, White D, Whatson L. Melbourne: IP Communication. 2011

### Pt 3 Interventions to promote skill development

- 14. Using a **sensory diet** to mediate behaviour of concern and to increase children's participation in daily activities. Mora & Chapparo
- 15. **Communication** for life: promoting communicative competence for mental health and well-being. White
- 16. **Building life skills** in children with intellectual disabilities. Grahame
- 17. Developing **emotion-based social skills** in children with autism spectrum disorder and intellectual disability. Ratcliffe
- 18. Promoting **healthy sexual lives** for young people with learning difficulties. Jones & Chivers
- 19. **Transition**: more than an event. Corfield & Brearley

### Part 4 Interventions to promote mental health

- 20. **Mental illness** and intellectual disability: the concepts, the evidence and the clinical skills. Dossetor
- 21. **Promoting resolution and safety**: a case study example. Whatson, Corfield & Owens
- 22. **Modifications of cognitive behaviour therapy** and counselling for individuals with intellectual disabilities. Grahame
- 23. **Regulation of arousal** in intellectual disability. Chenoweth
- 24. **Psychopharmacology**: the use of medication to treat challenging behaviour in children and adolescents. Zehetner

### Part 5 Integration of service systems

- 25. **A service model** for the mental health needs of children and adolescents with intellectual disability. Dossetor
- 26. A **special school community**: an inclusive setting for addressing the mental health needs of students with an intellectual disability. Caruana, Fleming, Saleh, Goltzoff & Dossetor
- 27. The community clinician and interagency **collaboration**. Burke, Martin & Dezilva
- 28. Conclusion. Dossetor

References

# **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 context of the Family Life Cycle Routes to breakdown with a child + ID:

## 4 common traps of caring & the ways to quality of life Nankervis K 2009

1. Failure of adjustment to a special/different child
  - Getting to know your child
  - Developmental attunement & special parenting skills
2. Failure to manage the main handicap: the Burden of Care to the family & carer indispensability
  - Adapting to the long term burden of care through sharing and support
3. Failure to look after the carer's wellbeing and family relationships
  - An individual vs their relationships: understanding systems
4. Failure to understand and manage psychiatric disorder
  - Understanding delayed and uneven development
  - Accessing specialist multidisciplinary skills

Four challenges should be focus of the spectrum of specialist services



# **An audit of 150 developmental psychiatry cases: Diagnoses, medication & outcome- a summary**

**The co-morbid psychiatric disorder is often > disabling than ID**

Each of ID & MH contribute 20-30/100pts functional impairment on CGAS

**Ave CGAS on presentation 35/100 (normal range 70-100)**

**Severity of emotional impairment should have MDT Assessment:**

Challenging behaviour and psychiatric disorder are overlapping and co-occurring concepts of psychosocial adaptability

**Average CGAS gain =20**

***Psychiatric disorder is the reversible component of disability;***

**Ave number of 3.5 psychiatric diagnoses**

**Common diagnoses:** ASD(70%), ADHD(63%), ODD(agg)(47%), Anxiety(45%), Depression(19%), Lability of Mood(16%), SIB (12%), Dev Coordination Disorder (10%), Sensory Sensitivity(6%), Sleep Disorder (5%)

**Other diagnostic categories:** other psych disorders, medical disorders, genetic/behavioural phenotypes, relevant environmental factors

Treated parental depression (18%)

**Ave number of medication/patient=2.2 (range 0-6)**

Anxiety & depression in those unable to describe, often assoc with ADHD, aggression or SIB.

**Psychotropic medication is an important part of MDT Rx**



# **Diagnoses, medication and outcome in a case series:**

## **How different is the psychiatry of children and adolescents with intellectual disability?**

### **Case notes audit of 150 outpatients seen in last 18 months**

- Introduction:
  - Problems of diagnosis in this population
  - My atypical clinical practice
- Methods:
- Results
- Conclusions

# Summary of background to the study

- Bad old days: diagnostic overshadowing meant psychiatric disorder was not identified.
  - Current Model: they are entitled to the same services and diagnoses as mainstream (ie for psychosis/major depression).
  - Research suggests high levels of co-morbidity
- vs** ICD restricts to a single psychiatric diagnosis.
- Childhood developmental disorders may be in DSM but in MH services in NSW they are not recognised as “serious mental illnesses” and access to treatment is poor

# Methods

Database created from file review of 150 cases

- Age
- Category of ID
- Presence of ASD
- Description of Diagnoses with attention to comorbidity
- Dimensional scoring of ASD, ADHD, Anx, Dep, Agg, SIB,
- Drugs given before seen, types and number
- Drugs given at last attendance, types and number
- Child Global Assessment Scale at presentation and FU

# Descriptive results

- N=150
- Ave Age = 12.8 yrs; SD+/- 3.7yrs; Range 4-23yrs
- Sex M:F= 101:49      2/3 are boys
- ID=103/150 (68%)      2/3 have ID
- ASD=119/150 (79%) 3/4 have ASD
- Of N IQ, ASD=37/47(79%) 3/4 of NIQ have ASD (10 no ASD)
- Average CGAS at presentation=35 (normal range 70-100)
- Estimated CGAS additional impairment from MHP=30
- Average CGAS gain from psychiatric Rx = 20; Range -5:30; n=66 cases
- Number receiving medication=139/150 (92%) Only 11 had no meds
- Average number of medication/patient=2.2 (range 0-6)

# Diagnoses

- In order of frequency used:

- ASD=106
- ADHD=94
- ODD (agg) =71
- Anxiety= 67
- Depression=28
- Lability of Mood=24
- Self Injurious Behaviour=18
- Dev Coordination Disorder=15
- Sensory Sensitivity=9
- Sleep Disorder=8
- Subtotal: 440

- **Ave no. of Diagnoses = 3.5**

**Other diagnoses include (85):**

**Other Psych Disorder:** Recurrent Confusional State, Other Organic Disorder eg ?Catatonia, decline in skills; Pica, Specific Lang Disorder, Separation Anxiety, PTSD, Dissociation, Somatoform symptoms, Episodic Dyscontrol, Sexualised Behaviour, Affect Related Voices, Hallucinations, Pseudohallucinations, Rigid/Obsessive +\ - Obsess Personality, Frontal Lobe Syndrome, Foetal Alcohol Spectrum Disorder, Blood Curdling Screaming, Offending Behaviour

**Physical Health Prob:** Soiling/constipation, Reflux, Eneuresis, Neurological Disorder/Movement Disorder, incl progressive decline, Epilepsy, TB meningitis, Traumatic brain injury, Hemispheric Pyrexia, Blind/Deaf, Obesity, wt loss, Immuno-defic, Eosinophilic Oesophagitis, Dental caries

**Genetic Disorder or Behavioural Phenotype** eg VCFS, Klinefelters, SMS, CHARGE, Sanfilippo, 6-pyruvoyl-tetrahydropterin synthase deficiency, TS, Various Deletions eg 2p;

**Relevant environmental factors:** Child Sex Abuse, Mo-Child Reln probl, Xs Dependency, Parental Coercion/abuse, Lack of Limits, Domestic Violence.

# Issues of Context

- Treating Parental Depression or anxiety disorder = 27
- Significant other Agencies (Statewide specialised services)
  - ADHC = 20 (Statewide Behaviour Intervention Service 10 incl 1 CJP)
  - DCS = 10 (Intensive Support Services 4 )
  - NGO = 9 (specialised or providing accommodation 5)
  - Telepsychiatry = 11 (most cases excluded from series)

# Correlations between diagnoses

With these frequencies expect intercorrelations?

- Male Gender correlates with: • ADHD\*, ASD\*
- Lower IQ correlates with: • PreCGAS\*\*\*, ASD\*\*\*, SIB\*\*\*, Agg\*\*, ADHD\*, NMeds\*
- ASD correlates with: • IQ\*\*\*, Anx\*\*\*, PreCGAS\*\* (but not ADHD)
- ADHD correlates • PreCGAS\*\*\*, Dep\*\*\*, Agg\*\*, NMeds\*\*
- Anx correlates with: • Dep\*\*\*, Agg\*, SIB\*, DCD\*,
- Agg correlates with: • PreCGAS\*\*, ADHD\*\*, Sensory\*\*, IQ\*\*, Dep\*, NMeds\*\*
- Dep correlates with: • SIB\*\*\*, Anx\*\*\*,
- SIB correlate with: • Pre-CGAS\*\*\*, IQ\*\*\*, Dep\*\*\*, Anx\*, NMeds\*\*,
- N of Meds correlates with: • PreCGAS\*\*\*, ADHD\*\*, Agg\*\*, SIB\*\*
- Pre-CGAS correlates with: • IQ\*\*\*, SIB\*\*\*, NMeds\*\*\*, ADHD\*\*\*, ASD\*\*, Agg\*\*
- Sensory correlates with: • Agg\*\*
- DCD correlates with: • Anx\*
- Labile Mood correlates with: • -

\*=p<.05; \*\*=p<.01; \*\*\*=p<.001

# Medications in current use

**No. of meds/pt=2.2 (range 0-6)**

- **Night Sedation:** 23pts • Clonidine 16, Melatonin 6, Chloral 4
  - **Stimulants:** 38pts • 33 Rit, Concerta 7, Dex 2
  - **Anxiolytics:** 62pts • Clonidine 56, Propanolol 2, Naltrexone 2, Benzos 2
  - **SSRIS:** 48pts • Fluoxetine 35, Fluvox 9, Sertraline 3, Cipramil 1
  - **Other Antideps:** 47pts • Amitriptyline 39, Clomipramine 2, Strattera 3, Mirtazepine 2, Venlafaxine 1
  - **Mood Stabilisers:** 42pts • Carbamazepine 30, Epilim 11, Lithium 1
  - **Major Tranquillisers:** 64pts • Risperdal 34, Abilify 18, Seroquel 9, Olanzapine 3
  - Also trialled but not current: Lithium 4, Buspirone 3, Amisulpiride 1, Chlorpromazine 1, Lorazepam 1
- Drugs tried before: Ave=3.4 Range 1-12 (sample of 79)**



# 1. Conclusions

- The presence of a co-morbid psychiatric disorder is often more disabling than the intellectual disability
- Each of ID & MH contribute 20-30 points to functional impairment
- **Psychiatric disorder is the reversible component**
  - It is a human rights/equity issue that mental health services cannot or do not consider this work core business
  - In NSW Paediatricians are more likely to be involved, & are helpful for complex medical co-morbidities; from whom most of my referrals come; need closer CAMHS partnership
- The level of additional impairment indicates MHP, 2<sup>nd</sup> work out what is the psych problem
- It is exceptional for single diagnosis to adequately describe a predicament, with ave 3.5 diagnoses

## 2. Conclusions

- Attention should be paid to anxiety and depression in those unable to describe
- Recognising co-occurring anxiety is often the key to successful Rx of ADHD, aggression or SIB.
- The severity of co-morbid anxious arousal has a range of valuable treatments to consider after SSRIs (which frequently cause behavioural activation as a side effect).
- YP with ID is deteriorating in skills, is more likely to have depression than psychosis.
- Up to 50% of parents have depression/anxiety/burnout/martyrdom which warrants prompt treatment
- In treating, more than one medication may be considered on the basis of co-occurring diagnoses, 1<sup>o</sup>, 2<sup>o</sup> & 3<sup>o</sup> treatments, drugs for different symptoms, or neurotransmitter theory.

# 3. Conclusions

The dimensions of behaviour identified from questionnaires eg Dev Beh Checklist, Aberant Beh Checklist are:

1. Self absorbed (x<Low IQ) (stereotypic)
2. Social relating (x<Low IQ) (empathy)
3. Abnormal communication (x< Low IQ)
4. Disruptive/Antisocial (x <**High** IQ)
5. Anxiety (<Low IQ)
6. Hyperactivity (?<Low IQ)
7. SIB (x< Low IQ)
8. ASD (?< Low IQ)
9. Depression (?<in Mild/N IQ)

The factors of behaviour questionnaires contribute to validating the main diagnoses & validating a developmental understanding of behaviour

However for less frequent diagnoses epidemiology may be too broad an approach for to validate less frequent diagnoses

# 4. Conclusion

- MH problems in ID/ASD
  - The main diagnoses are common and co-occur
  - Cause significant additional functional impairment
  - Are likely to be predominantly due to biological factors
- Medications
  - May have increased risk of side effects
  - But are an essential part of treatment
- Neurodevelopmental psychiatric disorders
  - are central to child MH&ID/ASD
  - Are not considered in adult mental health

Treatment can improve the quality of life of YP w ID

Any doctor worth his salt needs to be prepared to prescribe

# **The Developmental Psychiatry Team, Clinic & Partnership: Brief history, current capacity & future directions**

**Lesley Whatson, Head of Statewide Behaviour Intervention Team Children's Team (SBIS), ADHC Donna White, Anders Hanson, Deb Corfield, Lucinda Mora**

**Katrina Worrall Senior Psychologist with NSW Department of Education and Community (DEC), Bryan Smith King and Melissa Clements**

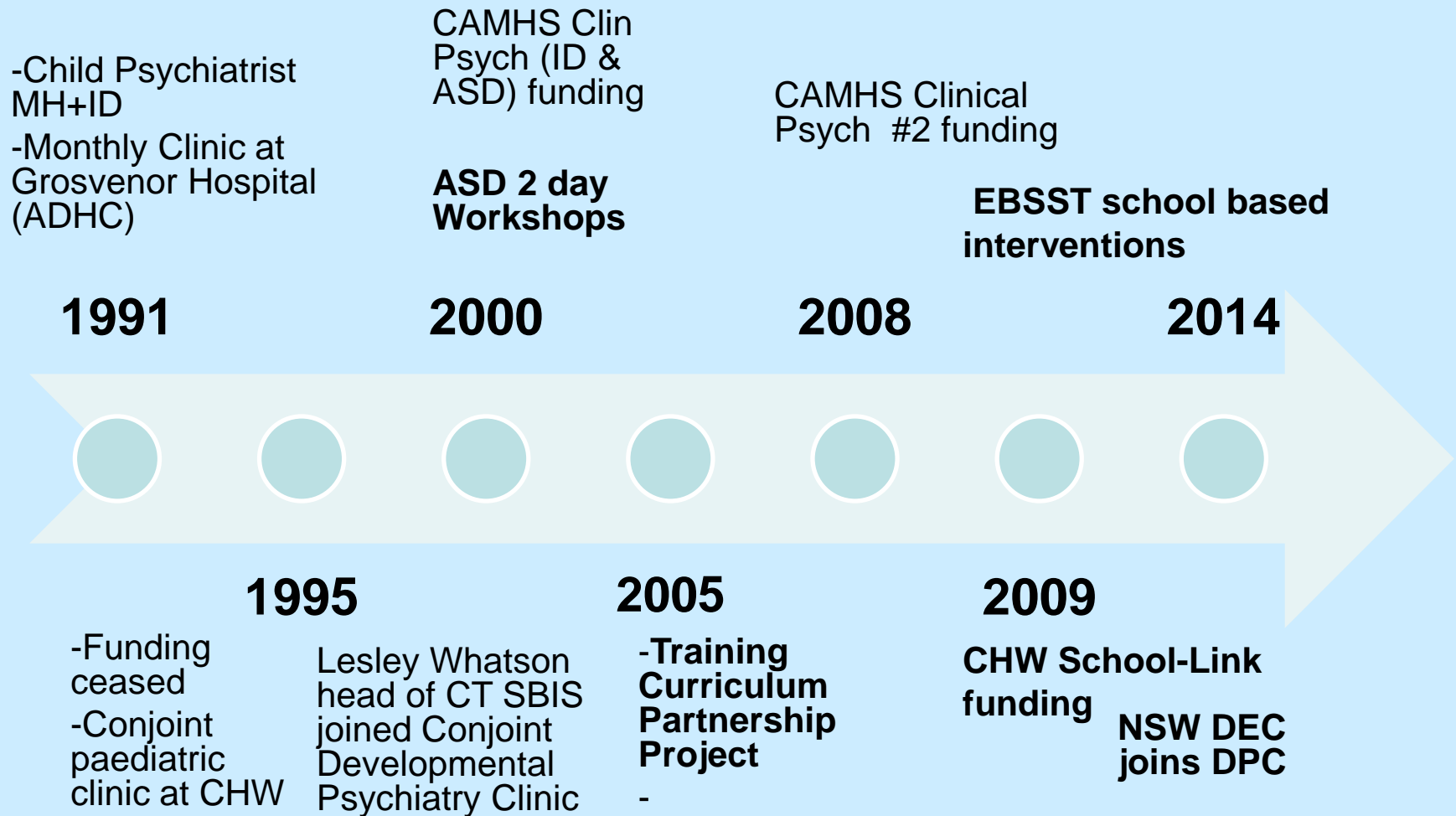
**Developmental Psychiatry Team: David Dossetor, Michelle Wong, Belinda Radcliffe, Phil Ray, Louisa Carroll, Sarah White, and the EBSST team**

**[www.ebsst.com.au](http://www.ebsst.com.au)**

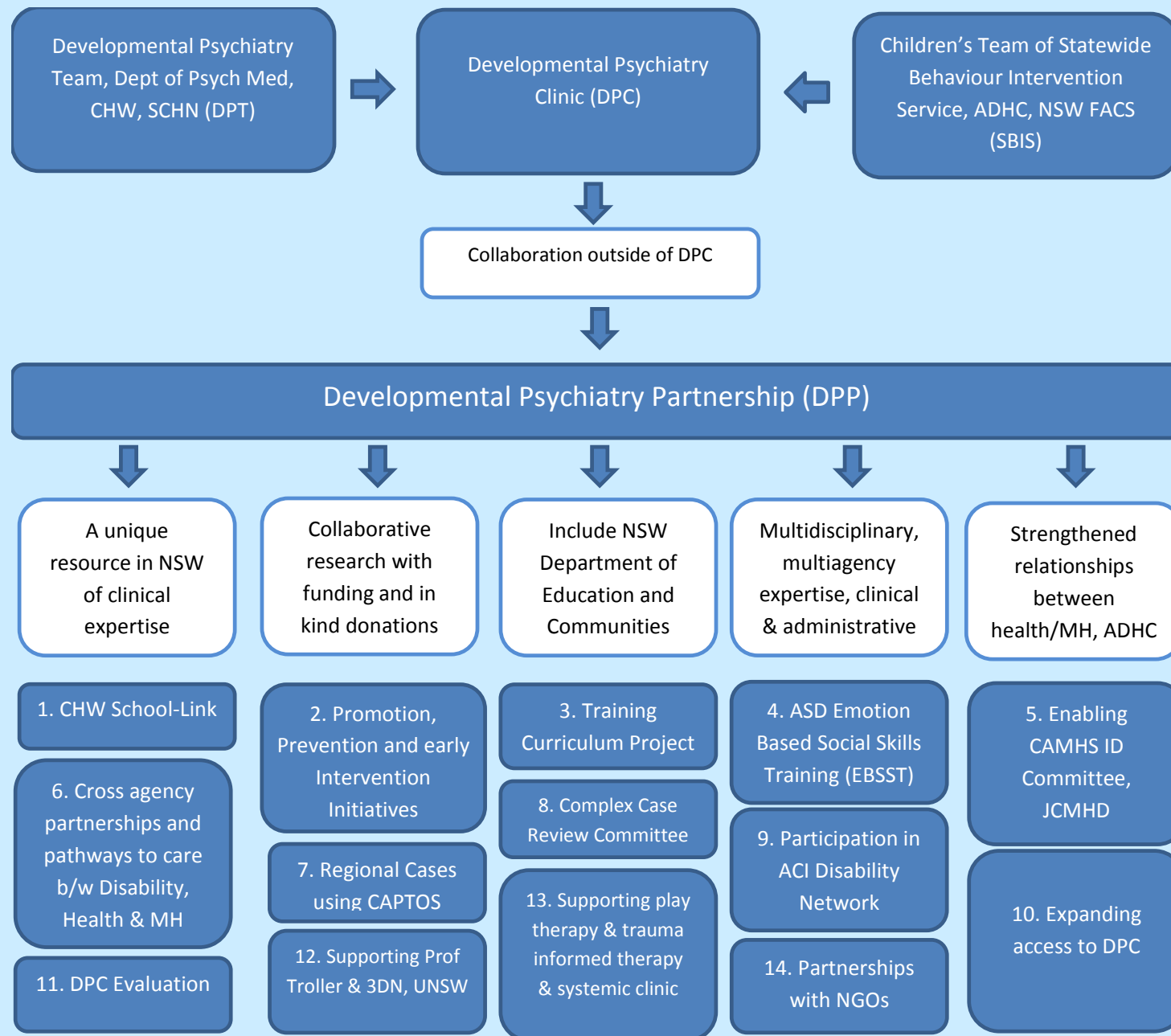
**CHW School-Link Team: Jodie Caruana, Hebah Saleh**

**[www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)**

# Brief History of Developmental Psychiatry Partnership: DPP: an initiative to improve MH for C&A with ID



Much is achieved sharing resources, with minimal funding



## THE HEALTH SYSTEM

The Health system is large and complicated and relies on people knowing what they want from it and being able to communicate that to the right people. It is a collaboration to assess when something is wrong and to solve problems to improve health. For people with an intellectual disability, a family member, advocate or a professional may help with communicating and understanding how to get care and how to make sure they are satisfied with the care they get.

### Summary

The health service is a complex system. Getting the best from the health service depends on getting to know clinicians you can talk to who can guide you to a service to meet your needs. If the health service does not help your health problems there are ways to access further help.

## QUESTIONS

It is helpful for people to write their questions about health and what they can do about their health, down when they are preparing for a health appointment.

Some of the forms which Doctors and other health professionals use are listed below. These questionnaires can help guide you and your clinician in assessment. Annual check ups are good practice.

•**The Centre for Disability Health** has useful documents for record keeping and communication: [www.cddh.monash.org/](http://www.cddh.monash.org/) under Products and Resources includes Personal Health Record, Pre-assessment questionnaire, and Depression Checklist.

•**Comprehensive Health Assessment Programme (CHAP)**  
[www.adhc.nsw.gov.au/data/assets/file/0019/228106/Health\\_Care\\_Policy\\_Att\\_12\\_CHAP\\_brochure.pdf](http://www.adhc.nsw.gov.au/data/assets/file/0019/228106/Health_Care_Policy_Att_12_CHAP_brochure.pdf)

•**Developmental Behaviour Checklist** (<http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html>) for behavioural problems or depression in children or adults with Intellectual Disability.

## THE IMPORTANCE OF A HEALTH HISTORY

In order for the Doctor to understand the health problems of their patients, they need:

- Details about past and present health problems
- Early life experiences of the patient and their family, including physical and psychological problems.
- Copies of other health assessments
- Medication details (current and past) with details about whether they were working and the effects they are having.

It is very helpful if there is a diary of sleep habits, seizure activity, stomach or bowel problems etc to help give a clear picture.

## BEING SATISFIED WITH HEALTH SERVICES

To have a good relationship with a Doctor, a patient needs to feel they understand each other and trust each other. This might take time and sometimes it means visiting a couple of Doctors until the relationship feels right.

A patient needs to feel they can ask questions about the treatment they are on, including its benefits for them and any side effects.

It is helpful to ask for a copy of the report from the visit to the health worker or Doctor, to assist in understanding and remembering the details of the visit and to pass it onto the next health worker appointment.

## COMPLAINTS:

When a patient remains dissatisfied with the hospital, its service or the staff, there are official ways to express concerns. It is best to go through this process in stages.

- Talk to the doctor in charge of your care
- In hospital talk to 'the patients' friend'
- Write to the Chief Executive of the Hospital or the GP Council..
- Write to or call the Health Care Complaints Commission
- Write to or call the Disability Discrimination Commissioner

## MORE ASSISTANCE:

Trust and communication are important characteristics of a good health service for a patient.

A patient should feel they can discuss their concerns with their Doctor or ask for another appointment with a different Doctor.

Social Workers, nurses, a patient advocate or 'the patient' s friend 'or the Carer Support Service can all assist with this.

### CONTACT

Name:

Address:

Telephone

:

Email:

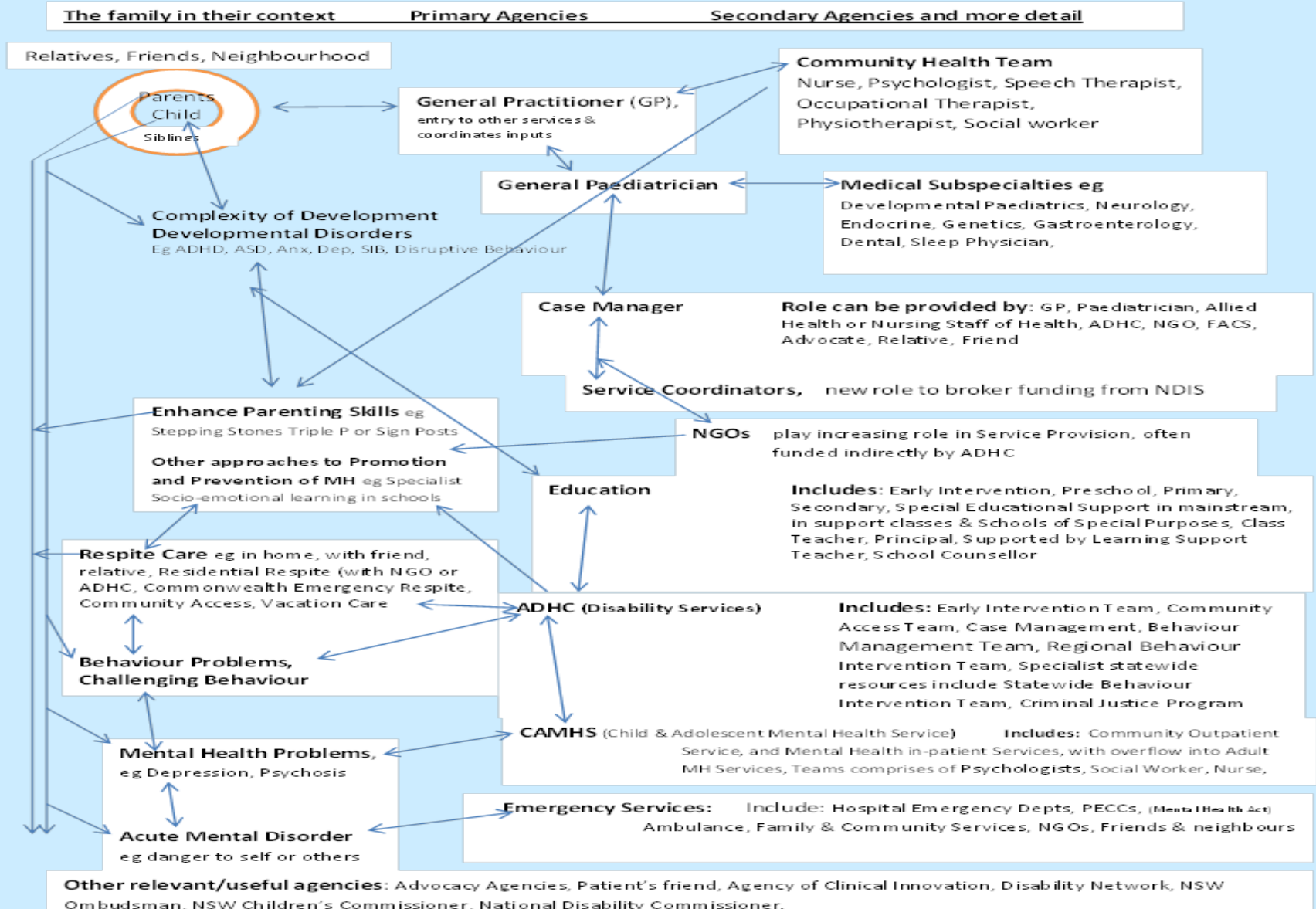


Emotional/Behavioural Disturbance is common in C&A with ID, and requires special skills in understanding and promoting coping skills, in the child, the parents and carers, and in professionals involved. A life course can lead to additional agencies having a contribution. The skill is to keep the support of helpful clinicians or agencies, as life becomes more complex. It takes skill to coordinate all the different agencies with each other.

**Spectrum of approaches incl:** Promotion of health & healthy habits, Prevention and Early Intervention, Assessment & Treatment

**Alternative funding systems incl:**

State funded services, Medicare Funded/Private Practitioners, Non-Government Organisations/Charities (NGOs), Disability Care Australia



# ***DPC Clinical framework***

- The Monthly Conjoint DP Clinic presented by Developmental Paed includes:
  1. young person, their family,
  2. care team from health, disability, education & NGOs
  3. Multidisciplinary Multiagency Tertiary Team review
- **Medical, and psychiatric skills.**
  - Health, mental health, multidimensional formulation and medication
- **Multidisciplinary allied health skills.**
  - Clin Psychology, OT, Speech Thx, Special Ed, pharmacy, case management;
  - skill building approaches to intervention;
  - enabling specialist skills in less experienced members of the treating teams.
  - specialised therapies eg EBSST, play therapy or trauma focused CBT
- **Family and System Skills.**
  - Different to mainstream, incl skill enhancement approaches.
  - the **cultural expertise**
  - **The system issues;** (can be seen in a separate special referral service).
  - the environment and the need to match environment to developmental/psychiatric need
- **Legal assessment of child protection, with abuse and neglect.**
  - an interface FACS and Intensive Support Services for young people in out of home care.
  - human rights/child protective legal elements eg service systems that are failing
- **High level of interagency collaboration.**
  - To influence each other's service systems for the needs of the child and family
  - match service provision with clinical need vs business funding formulas.
  - level of mutual respect from efforts to help with each other'.

# Developmental Psychiatry Team

- DPC and partnership has expanded
  - to cases discussed but not seen in clinic
  - Cases seen with cross team representation.
- Tertiary Referral Services:
  - >100 cases of ID/ASD/yr
  - 2 tier 4 specialist ID Health Services,
  - some NGOs, private paediatricians & psychiatrists
- Case Examples:
  - Consultations to YP stranded in Paediatric Wards or Emergency Departments or seeking in-patient admission
  - 15yo in our emergency dept for 36 hrs, while arrangements made for flexible funding package to restore care under extra medication in his home.

## Review by Centre for Disability Studies 2014

### What enables Professional and interagency Collaboration: A review of the constructs by DPC

1. A belief we can help
2. A 'good enough' quality of life
3. Reciprocity
4. A common language
5. Mutual professional trust & respect
6. Tolerance & patience
7. Creativity
8. Valuing different skills
9. Family centred practice
10. Life span & future orientated
11. A capacity to prioritise
12. Respect within own agency
13. Evidence-based approaches
14. Practice based expertise
15. An assumption of beneficence
16. Systemic approaches
17. Personal professional engagement
18. Service prioritisation
19. Support from senior management
20. Practically orientated

# What prevents a replication of Professional and Interagency Collaboration

1. Challenged by the severity
2. A lack of conceptualisation
3. Not willing to try
4. Lack of interagency open communication
5. A professionally egocentric view
6. Lack of MDT peer support
7. Despair
8. Professional isolation and stigmatisation
9. Decline of services
10. Business models rather than clinical need
11. Lack of pathways to care & service responsiveness
12. Lack of a system of prioritisation
13. Lack governance structure
14. Lack of recognition of the special population needs
15. Beginning with construction of rules and terms of engagement
16. Individual partners contributing as individuals
17. Lack of specialty professional skills and services



**Same questions as  
were followed in  
the interview  
schedule were  
covered in the  
focus group of 10  
core panel  
members**

# Outcomes

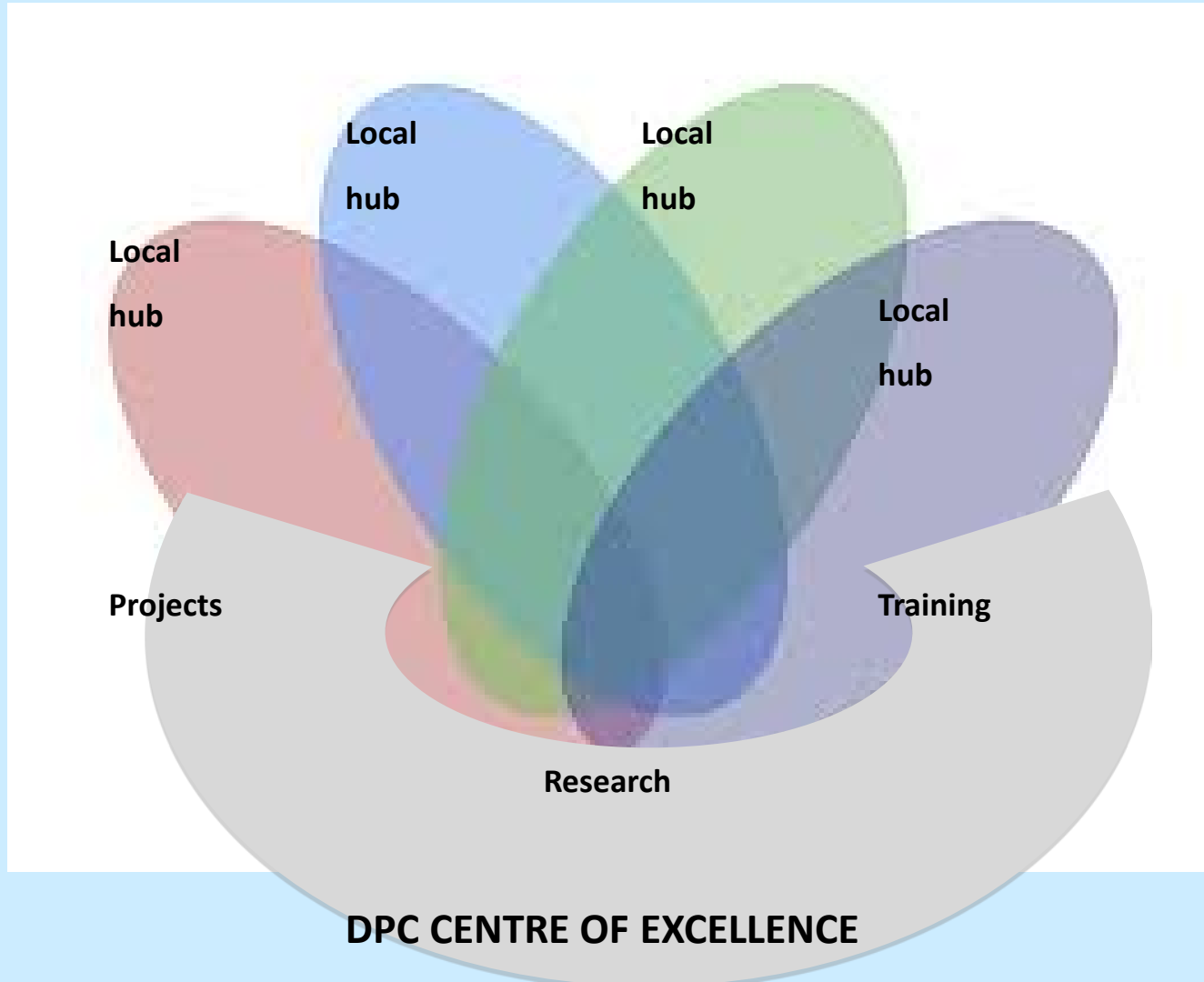
## What was working

- Responsive to NSW Disability Standards
  - Rights
  - Participation and Inclusion
  - Individual Outcomes
  - Feedback and Complaints
  - Service Access and
  - Service Management
- A beacon of hope
- **The Clinic has a *visible presence***
- Cross cultural sensitivity
- Team approach
- Collaboration
- Responsive core DPC meetings

## Areas for growth and development

- Promote ID and MH as professional area
- Expand/fund a state wide service
- Increase length of notice for DPU panel meeting
- Strengthen infrastructure of DPC : Advertising, marketing; research, educative role

# Major outcome: Refining the model in view of NDIS





# The Future of Multidisciplinary Multiagency MH & Developmental Disability Expertise in NDIS

## 1. The risk of loss to DPP service?

- by 2018 SBIS, ADHC(a key MH partner) will no longer exist in its current form.
- ***loss of a system of workforce training and building in innovative approaches to managing complex cases*** which will increase risk of institutionalisation.

## 2. How to enable maintenance of tertiary service capacity?

- Could NDS fund a Centre of Excellence including the 6FTE of the children's team of SBIS?

## 3. Possible new funding systems:

- Could NDS fund tertiary expertise and partnership with a number of the most significant NGOs?
- Will NDIS fund private enterprise/hospitals for complex behaviour problems?

Building interagency collaboration with professional respect and trust takes years.

How will 600 NSW Disability NGOs

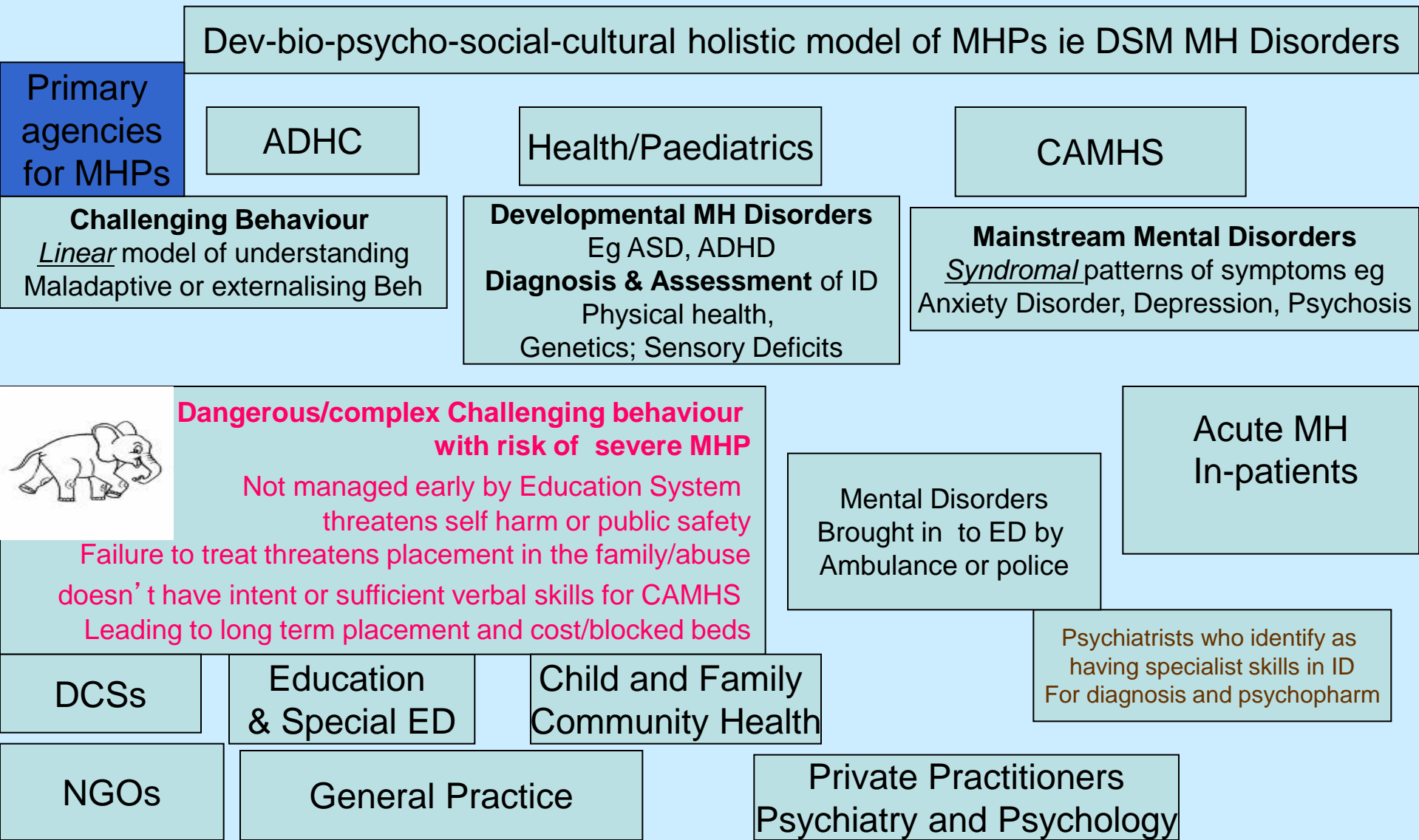
- collaborate and support positive, access to the complexities of the health/mental health system?
- enable capacity enhancement of the specialist health services for PWID.

NDIS relies on consumer or carer to advocate for funding for their needs

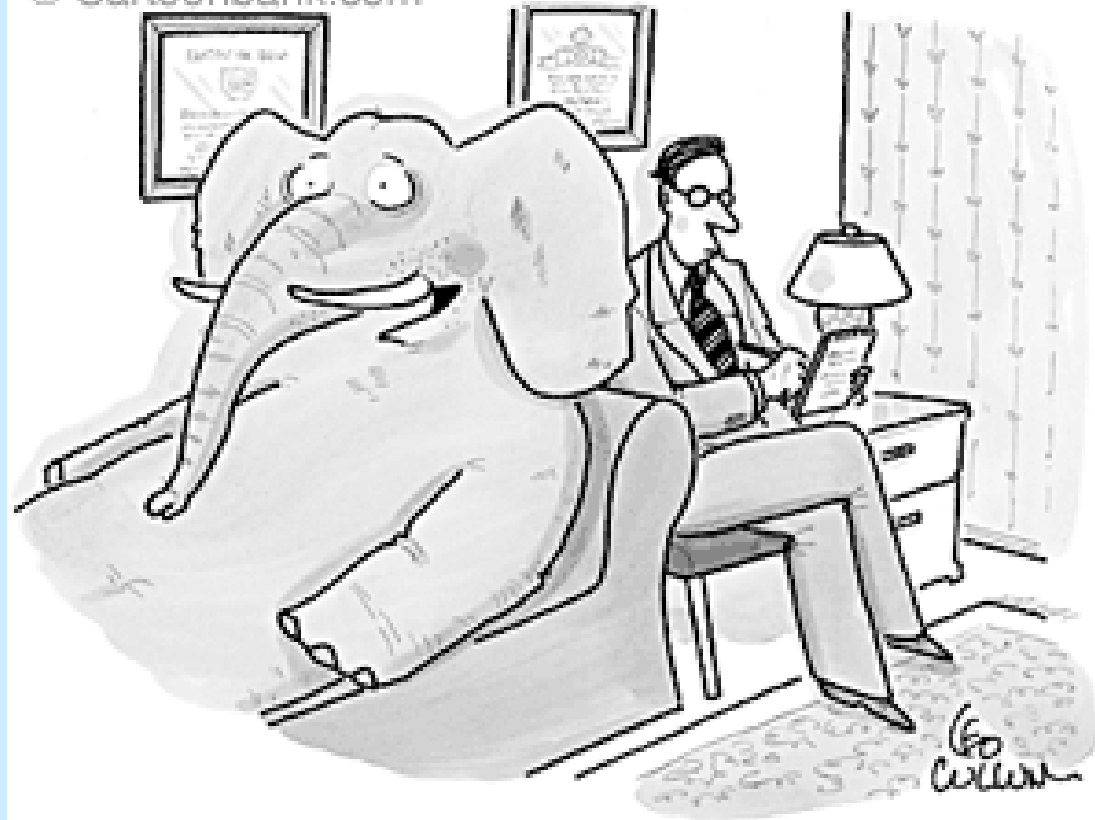
- Will they know what they need to enhance mental health/prevent mental health problems
- Will enhanced funding for services reduce the MH burden of care?

Post ADHC: who will provide tertiary clinical/disability expertise, fund innovative treatment approaches, provide emergency respite & accommodation for dangerous behaviour, in the context of developmental problems, and a family can no longer care?

# Understanding the pathways to care



© Cartoonbank.com



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

# 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;

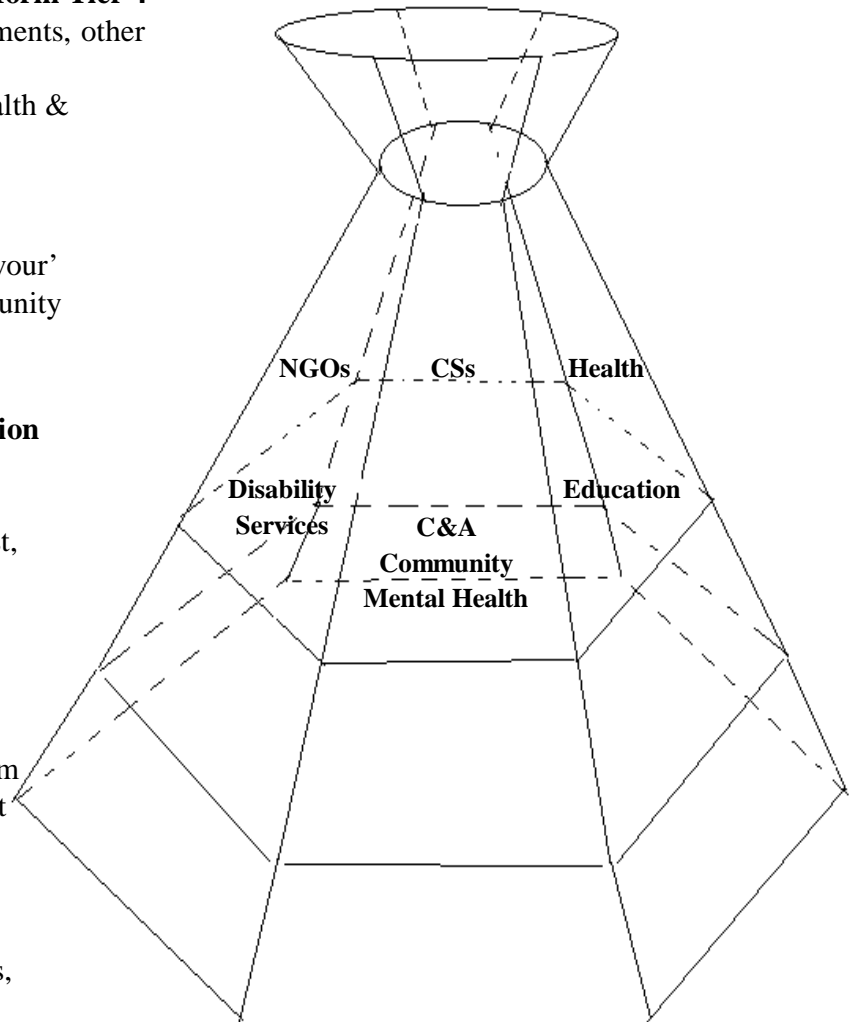
**Health:** GP, paediatrician or neurologist; MH Psychologist, SW, family therapist, psychiatrist; and

**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*

# Definitions of Mental Illness & Health in ID

## Guide to Services framework in Australia

Term	Service	Disturbance	Severity	Examples
<b>Mental Disorder/ Illness</b> (3 <sup>rd</sup> National Mental Health Plan)	Diagnosable Illness from DSMV Priority for <b>Mental Health Services</b>	Cannot fend for self Managed in community with short assessment IP admission Risk of stigma & social exclusion	Significant impairment and high risk of harm to self or others Major problems of reliability and validity of diagnosis	-Major Depression -Bipolar Disorder ·Schizophrenia ·Acute Mental Disorder
<b>Mental Health problem</b> (3 <sup>rd</sup> National Mental Health Plan)	Diagnosed from DSMV but seen as a developmental disorder (not a serious mental illness) Rx by <b>Paediatrics &amp; disability service</b> , +/- <b>specialist ID MH</b> . Not MH priority	Emotional/Behavioural Disturbance is as severe as impairment from ID. The combination makes for complexity and severity	Severe impairment, risks to caring framework esp in acute exacerbation <b>Needs high expertise multidisciplinary subspecialty collaboration of disability &amp; health</b>	-ADHD -ASD -ODD/CD -Depressive symptoms -Anxiety Disorders, OCD, etc -Lability of mood, -Panic disorder, Dissociation -Trauma based problems ·Usually several disorders
<b>Challenging Behaviour</b> (Emerson 2001)	Culturally Abnormal Behaviours <b>Disability Services</b> , ABA approach	the physical safety of the person /others is placed in serious jeopardy	Significant impairment, high intensity, frequency or duration Still big impact on Quality of Life	·aggression ·self harm -behaviour disturbance -stereotypy -habits, Pica
<b>Mental Health &amp; Wellbeing</b> (3 <sup>rd</sup> National Mental Health Plan)	A state of emotional & social wellbeing. Needs PPEI across <b>family, school, community</b> & interagency leadership, collaboration & research on approaches in special population	Promote individual resilience to cope with the normal life stressors	Chronic moderate severe EDBD probs. Aim to achieve potential & Quality of Life	Risks of poor attention, restless, behaviour, reciprocity, relationship connection, self esteem, autonomy, skills, participation, employability

# Health Economics of School Based Preventative Mental Health Intervention

- Parenting interventions for the prevention of persistent conduct disorders: OR 7.82
- School-based interventions to reduce bullying: OR 14.35
- School-based social and emotional learning (SEL) programmes to prevent conduct problems (CD) in childhood OR 83.73, £132cost/family. Knapp, McDaid and Parsonage 2011

## A Framework of MH Prevention for Mainstream Education?

NSW Dept of Education commissioned “the psychological and emotional wellbeing needs of children and young people: models of effective practice in educational setting” Urbis 2011

1. **MH Promotion is most effective for most students (80-90%)**
  1. School-based social and emotional learning in Primary
  2. Positive Psychology in Secondary
2. **Targeted prevention for high risk groups or identified cases (10-15%) eg Anxiety/Dep in teens: FRIENDS** (Barrett et al, 2006); **Stress Inoculation Training** (Hains & Szyjowski, 1990), and **MoodGym** (internet based, Caelear et al, 2009) **Resourceful Adolescent Program (RAP)** (Shochet & Ham; 2004) **Penn Resiliency Program** (Chaplin et al, 2006); **Interpersonal Psychotherapy-Adolescent Skills Training** (Young et al, 2006).
3. **Individualised Specialist Psychological Intervention (1-5%):** school counsellors with collaboration with CAMHS and other services

# Promotion, Prevention and Early Intervention (PPEI) for C&A with ID & Special Education.

1. Stop Think Do ([www.stopthinkdo.com](http://www.stopthinkdo.com))
2. The Paths Curriculum ([www.prevention.psu.edu/projects/PATHS.html](http://www.prevention.psu.edu/projects/PATHS.html))
3. Social Decision Making ([www.footprint.com.au](http://www.footprint.com.au))
4. The Alert Program ([www.alertprogram.com/](http://www.alertprogram.com/))
5. Stepping Stones Triple P ([www.triplep.net](http://www.triplep.net))
6. Emotion Based Social Skills Training ([www.ebsst.com.au](http://www.ebsst.com.au))
7. Signposts ([www.signposts.net.au/](http://www.signposts.net.au/))
8. Secret Agent Society ([www.sst-institute.net/](http://www.sst-institute.net/))
9. Mindfulness/Acceptance and Commitment Therapy ([www.actmindfully.com.au/](http://www.actmindfully.com.au/))
10. Cool Kids ([www.emotionalhealthclinic.com.au](http://www.emotionalhealthclinic.com.au))
11. Problem based Learning (PBL) ([www.pbis.org/](http://www.pbis.org/))
12. Kids Matter ([www.kidsmatter.edu.au/](http://www.kidsmatter.edu.au/))

# A Framework for PPEI in special schools for ID

- Key elements for children with ID include:
- **Specialised parent training programs** :improve family relationships and attachments, These could be part of admission to a special school, building a relationship with each family and their disability support team.
- **Behavioural Approaches**: the second best level of evidence of effect in ID, includes ABA and Contingency Approaches.
- **Development Promoting Programs**: matched according to developmental stage; widely accepted, and gradually establishing a scientific based (eg TEACCH):
  - **Augmented and Alternative Communication** for profound/severe ID & problems of motor and language dev: motor & attention skill dev and sensory exploration are pre-requisites of independent communication ; progresses onto object communication, followed by picture communication (White, Chapt 15 in Dossetor, White and Whatson, 2011)
  - **Specialised Social and Emotional Learning**: focus on the staged development of emotional recognition, theory of mind & problem solving (such as EBSST); need scaffolding from adults to facilitate internalisation of competencies to develop relationships before social skills
  - **Specialised Social skills Training**: Stop Think Do, The Paths Curriculum, Social Decision Making, The Alert Program are suitable SEL from an early stage, involving problem identification, identifying feelings and working out behaviours.
- **Targeted intervention** for anxiety and mood regulation: Cool Kids and ACT/Mindfulness ?a universal intervention or for high risk children (or suitable for both).



## A Framework for PPEI in special schools for ID

- **Individualised Approaches:** complex cases require specialised assessment & intervention; can be in classroom setting. Approaches include:
  - **Complex Learning and Developmental Disabilities:** CLDD provides an individualised multidimensional approach to understanding a child's problems with learning, using the Engagement Profile and Scale to increase engagement & modifying the learning process through dimensions of awareness, curiosity, investigation, discovery, anticipation, persistence and initiation, with a range of interventions; an interface between special ed and neuropsychology, using educational approaches ([www.complexld.ssatrust.org.uk](http://www.complexld.ssatrust.org.uk)).
  - **SPICE Model** (Dosen, 2003): The Dimensions of Social, Physical, Intelligence, Communication, Emotional (SPICE) are rated according to developmental age skills. Curran has used as an assessment tool to help design interventions for the MH problems of C&A with ID, in a special school-based project.
  - **Multidisciplinary School-based Clinics:** a number established in NSW in Special Schools but need evaluation; bring together expertise of a specialist MDT from disability, health NGOs. Include eg a paed, OT, a speech thx, clinical psych & psychiatrist & family/cybernetics therapist; brings a range of skills school staff can apply to both the presenting and future cases incl the management of high risk behaviour.
    - Giant Steps Psychiatry Clinic: in 6/12 15/16 highly disturbed kids now settled

# Demand and Staffing for MH&ID

- C&AwID: 40% MHP; 10% (4%) get specialist MH help (Einfeld & Tonge, 2006)
- MH for C&A with ID = 14% of MH burden (Emerson & Hatton 2007)
  - 25% of CAMHS is ID or Autism in UK
- RCPsych(UK) based on recognition of the human rights for PWID has recommended C&A MH staffing for ID (Learning Disability) is
  - 8 LD CAMHS clinicians/100,000 population &
  - 8 LD CAMHS IP beds for 1million population!
- In NSW the only way to make sense of these needs is to understand that most of the mental health provision is provided by ADHC and Paediatricians, as the CAMHS provision is so much smaller (?5%)
- The planned closure of NSW ADHC is closing the main MH resource for this population. The loss of expertise will lead to service breakdown and abandonment of C&A wID in hospitals

# Eyeball Health Economics and ABF

- DPT: .8 psych, 0.1 paed, 2 psychol, .4 OT 1 paed reg
  - (Plus cost of 6FTE at ADHC)
  - Cost \$800,000/PA (plus training, teaching, service leadership and research and research/donor funding)
  - 100 IDD MH Cases/year = \$8000/case
- Assume 5-20% cases are prevented from long term care or hospitalisation (at \$150-350,000/year/case)
  - Cost = \$1-5 Million on care costs in group home or hospital
- An improvement of 20/100 CGAS points in 50%
  - Estimate reduced costs by \$0.5-1million in care costs
- Approx returns: 10:1 (per year of care delayed)
- (Plus improved quality of life and family life including work participation)

**Conclusion:** high expertise multidisciplinary psychiatric team is likely to reduce care costs by approx 10:1 or \$10million of NDIS/Welfare saved per year for every \$1Million spent in multidisciplinary health.

Disability/Welfare Services cannot afford not to have multidisciplinary medical/psychiatric services.

# Newsletter

Quarterly Newsletter.

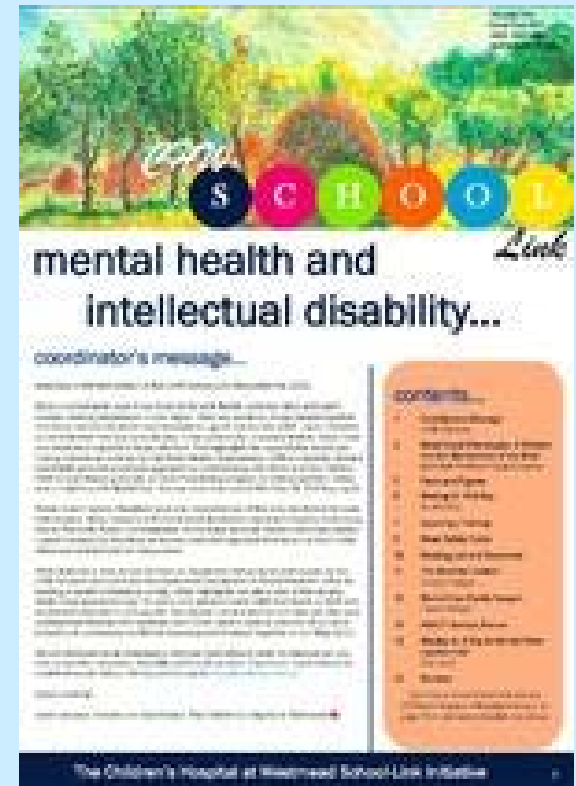
Contributions and any suggestions for content are most welcome to:

Hebah Saleh (editor) School-Link Officer  
[hebah.saleh@health.nsw.gov.au](mailto:hebah.saleh@health.nsw.gov.au)

*Sign up to our e-list to receive our quarterly newsletter and from time to time relevant emails about professional development opportunities.*

[www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)

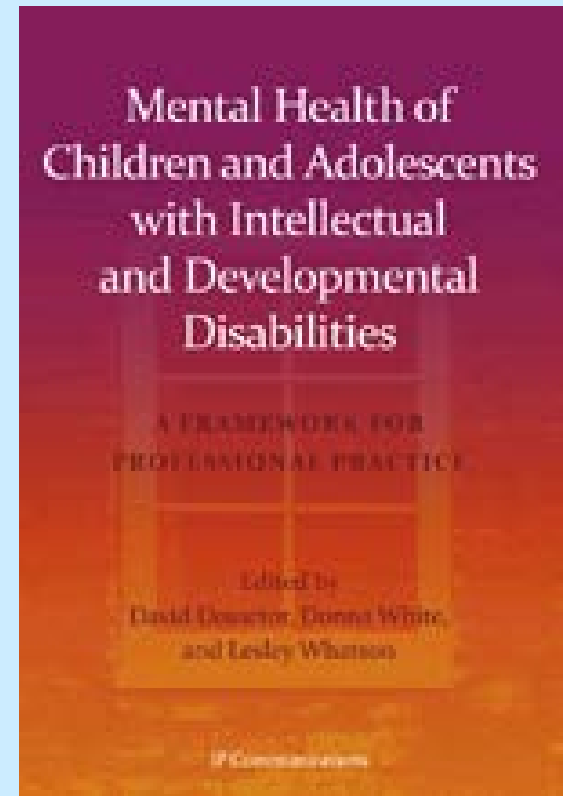
*MHPod; Psychiatry of ID*

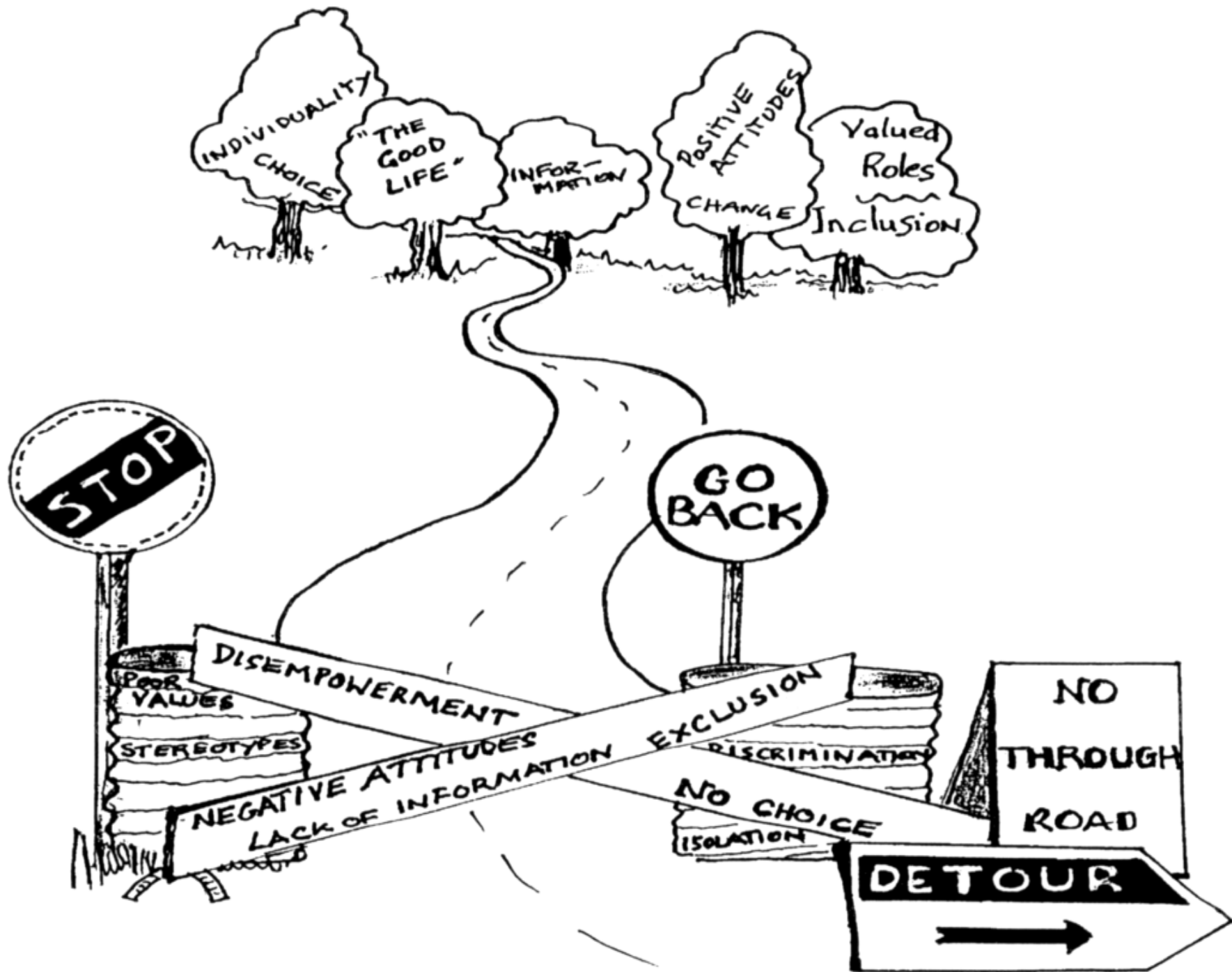


# Training Curriculum Project

*Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:  
A Framework for Professional Practice.*

Ask us for an order form.









## Superheros Run the City to Surf Raising Funds to Treat Autism Now!



"Westmead Autism" is a IN COSTUME to raise awareness of Autism Syndrome. Batman, Super children with Autism and At the Children's Hospital mental health and a good through patient care and Autism to help with issues is used to link the team of affected by conditions in based treatment method management. I am inspired every day by go to continuing the world intervention available to



<https://city2surf2014.everydayhero.com/au/ur-david-for-autism>  
<https://city2surf2014.everydayhero.com/au/team-westmead-autism>

# CHW School-Link newsletters/ Educational Resource: now Vol 5

1. How much should we worry about the Mental Health Needs of Children and Adolescents with or without Intellectual Disability?
2. Clarifying concepts of disturbance, disorder and mental illness in children and adolescents with intellectual disability.
3. Appreciating the more important things of life: Professor Trevor Parmenter 's Festschrift. (Ethics, QoL, Spirit, old age, concept development, intelligence, needs not disability)
4. Behavioural Phenotypes: A Window into the Mechanisms of the Mind.
5. How much do we value families and what impact does this have on children with intellectual disability?
6. Mental Health Problems: Disorders of Social Development caused by Maladaptation's of "Theory of Mind"? A Developmental Psychiatry View.
7. Fetal Alcohol Spectrum Disorders (FASD): Raising awareness of a preventable disability in our midst.
8. Moving to Learn, Learning to Move: the importance of motor development in mental health and intellectual disability.
9. Better Health Services for People with Intellectual Disability in NSW: *The Agency of Clinical Innovation Disability Network*.
10. Responsibilities and Rights for Consumers and their Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services in NSW.
11. Draft Health Guideline for Health Service Consumers with Intellectual Disability.
12. Health Economics for Mental Health and Intellectual Disability: Evidence based medicine and the growth of health economics of preventative mental health intervention.
13. The National Roundtable on the Mental Health of People with Intellectual Disability: A Summary.
14. Guidelines on the Pathways to Care for Children and Adolescents with Intellectual Disability and Challenging Behaviour and/or Mental Health Problems.
15. Diagnosis, Psychotropic Medication and Outcome of an audit of 150 child and adolescent neuropsychiatric patients.
16. Strugglers and Copers; Stress & expectations mediate onset of psychosis in VCFS



# **CHW School-Link newsletters/ Educational Resource: now Vol 5**

- Behavioural Phenotypes: A Window into the Mechanisms of the Mind.
- Families of children with intellectual disability?
- Disorders of Social Development: A Developmental Psychiatry View.
- Fetal Alcohol Spectrum Disorders (FASD):
- The importance of motor development in mental health and intellectual disability.
- Better Health Services for People with Intellectual Disability in NSW: ACI Network
- Responsibilities and Rights for Consumers and their Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services
- Draft Health Guideline for Health Service Consumers with Intellectual Disability.
- The growth of health economics of preventative mental health intervention in MH&ID
- The National Roundtable on the Mental Health of People with Intellectual Disability
- Pathways to Care for C&A c ID with Challenging Behaviour and/or MH Problems.
- Diagnosis, Medication and Outcome of an audit of 150 C&A neuropsych patients.
- Strugglers and Copers; Stress & expectations mediate onset of psychosis in VCFS

# CHW School-Link Newsletters: 3 issues/yr

## **Other topics**

**The coordinators message:** current items, including winning a Mental Health Matters Award, or Autism and Friends at the Movies

**Feature articles** eg: A Framework for professional practice, PBL, Grief, Play therapy, Fragile X, Neglect and the developing brain, sensory modulation, Mind matters, literature review of MH & ID, EBSST, Shared care family support, Stepping Stones.

**The medicine cabinet,** Judy Longworth Pharmacist: practical accounts of the medications used.

**A day in the life of:** eg carer of the year, a developmental paediatrician, school counsellor, an academic (Emerson), Cultural consultant, psychiatric registrar, chief paediatrician

**News Items:** conferences, research developments eg Stepping Stones Parent Training; key articles with brief reviews, book reviews eg Fetal alcohol Syndrome

## **Case Studies**

Responsibilities and Rights for Consumers and their Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services in NSW.

Draft Health Guideline for Health Service Consumers with Intellectual Disability.

**Conference Reviews:** IASSID, AADDM, SSPB, ASID, Resilience (CHERI)

**Illustrations from CHW Operation Art**

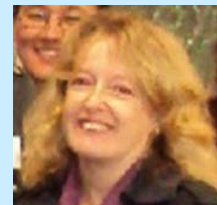
# Prevention Promotion and Tertiary Intervention:

Collaboration between mental health, disability and education to improve outcomes for children with ASD & intellectual disability and CHW School-Link.

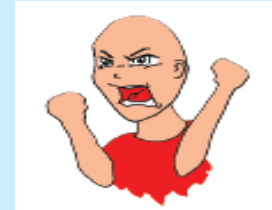
1. Emotion based Social Skills Training for ASD
2. Group Stepping Stones Parenting Intervention
3. CHW School-link and a framework for PPEI

**CHW team:** David Dossetor Director of MH & Child Psychiatrist in ID&ASD  
Michelle Wong & Belinda Radcliffe EBSST team  
Phil Ray Group Stepping Stones research lead  
Jodie Caruana & Hebah Saleh School-Link Team

**Disability Partner:** Lesley Whatson, Statewide Behaviour Intervention Service  
**NSW Dept of Education including 11 Government Special Schools**



# Emotion-Based Social Skills Training (EBSST): Skills for Life for Autism



**David Dossetor**, Project Sponsor

**Michelle Wong**, Clinical Psychologist, Project Manager **Don't miss her presentation**

**Belinda Ratcliffe**, Clinical Psychologist, Research

**Tom Butterworth**, Nikki Fellow, Clinical Psychologist in ASD

## Acknowledgements

### *Funders*

• 3<sup>rd</sup> National MH Plan, ADHC, Collier Foundation, Automobiles for Autism, Nikki Fellowship, City to Surf Westmead Autism Team

### *Partners*

• NSW Dept of Education, Statewide Behaviour Intervention Service (ADHC)

### *Contributors*

• Sandra Heriot, Victoria Grahame, **Louisa Carroll**, **Phil Ray**, **Tom Butterworth**, Lisa Brice, Amy Price, Alison Fettell, Sandy Vickerstaff, 64 school counsellors, and many more!

# EBSST: Skills for Life

- Based on developmental theory that skills are learned in specific sequence including those of emotional recognition, theory of mind and problem solving
- Research Development over 10 years
- Now two group versions for
  - high function ASD and
  - for ASD with mild ID

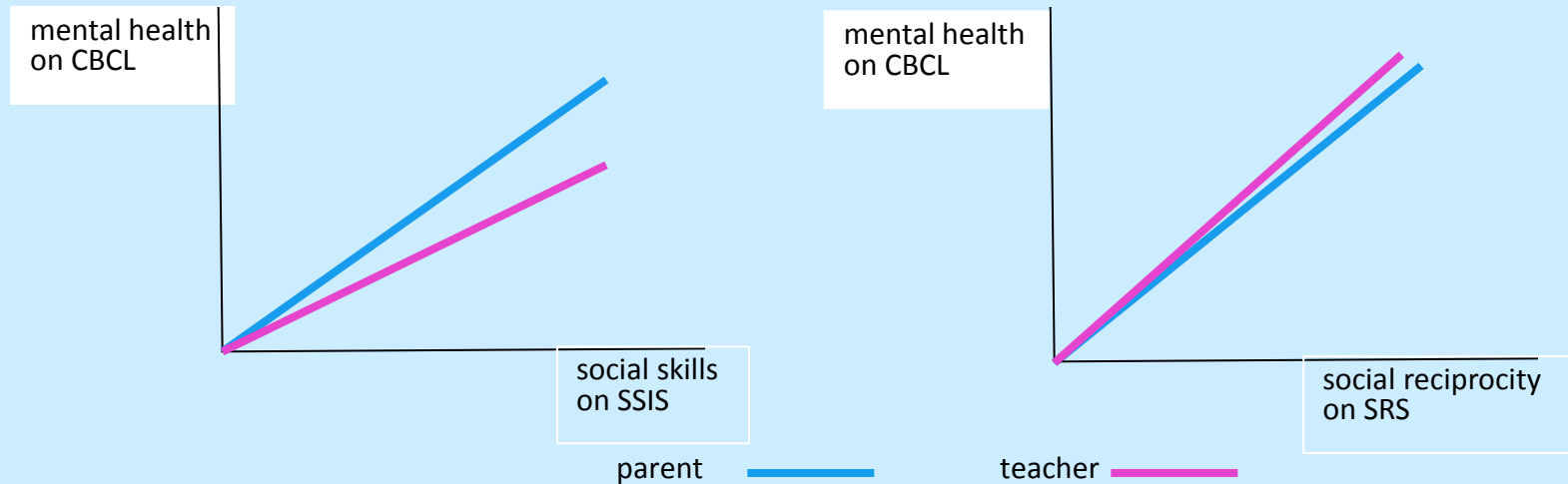
# EBSST Research Development

2004	2006	2008	2010	2012	2014
<b><i>Pilot Study</i></b> HFASD&AS <i>outpatients</i>					
	<b><i>RCT</i></b> HFASD&AS <i>outpatients</i>				
		<b><i>Pilot Study</i></b> ASD&Mild ID <i>outpatients</i>			
			<b><i>Controlled Trial</i></b> HFASD&AS <i>schools</i>		
			<b><i>Controlled Trial</i></b> ASD & Mild ID <i>schools</i>		
				<b><i>Pilot Study</i></b> EDBD <i>whole school</i>	

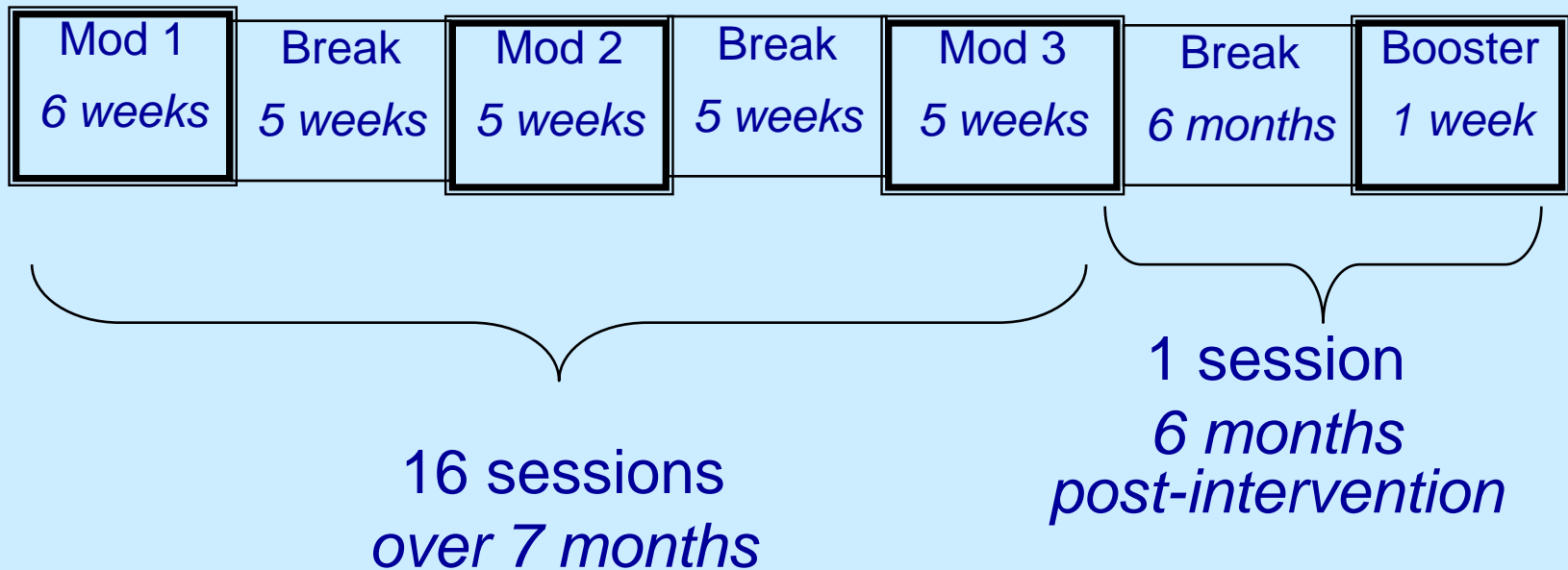
# Implications of Social and Emotional Deficits 2

Better social skills and social reciprocity is associated with better mental health in children with ASD. (n=292)

(Ratcliffe, Wong, Dossetor, Hayes, 2013)



# EB SST Session Format





# EBSST Content

Module	Child Group	Parent/Teacher Groups
1	Identifying emotions	Psychoeducation Emotion coaching Emotionally attuned parenting
2	Emotional problem solving Understanding others' thoughts and emotions	Emotional problem solving Promoting theory of mind
3	Managing emotions	Managing emotions
Booster	Review	Review

# Mod 1 – Identifying Emotions

The Feeling Worried Strength Bar 

3		very worried
2		worried
1		a little worried
0		okay

# Mod 3 – Managing Emotions

- Use my words
- Use my imagination
- Talk to someone
- Danger zone
- Problem solving
- Happy bag
- Do something I enjoy
- Relaxation
- Unhelpful to helpful thoughts



# Emotions Developmental Questionnaire (EDQ)

(Wong, Lopes & Heriot, 2009)

- Very limited emotion-focused social/emotional outcomes measures for children with an ASD
- Developed specifically to assess EBSST
- Grounded in theoretical constructs:
  - emotional understanding,
  - empathy/theory of mind,
  - emotion regulation &
  - parent emotion coaching skills.
- Construction: literature review, clinical consensus, piloting.
- 40 items, each tap different skills targeted in EBSST
  - E.g. Does ***your child*** talk to you about ***their*** not so good feelings (e.g. sad, worried)? (*item 8*)
- Parent and teacher versions

# EBSST in Schools Methods

## HFA School Study

- **41 School counsellors** nominated them & ASD Kids
- **217 children**, 8-12 years:

Treatment group (n= 106) vs.  
Delayed Treatment (n= 111)

Confirmed or suspected ASD

Validated with SRS

- Parents & Teachers also participated

- 64 School counsellors attended 2 days of competency based training to deliver *manualised* EBSST in small groups (3-8 participants).

## ASD & Mild ID School Study

- **14 school counsellors**
- **75 children**, 8-12 years -  
Confirmed or suspected ASD  
and Mild ID

Treatment group (n= 43) vs.  
Delayed Treatment (n= 32)

- Parents and teachers participated

# RESULTS

Outcomes of interest

1. Emotions Competence
2. Social Skills
3. Mental Health

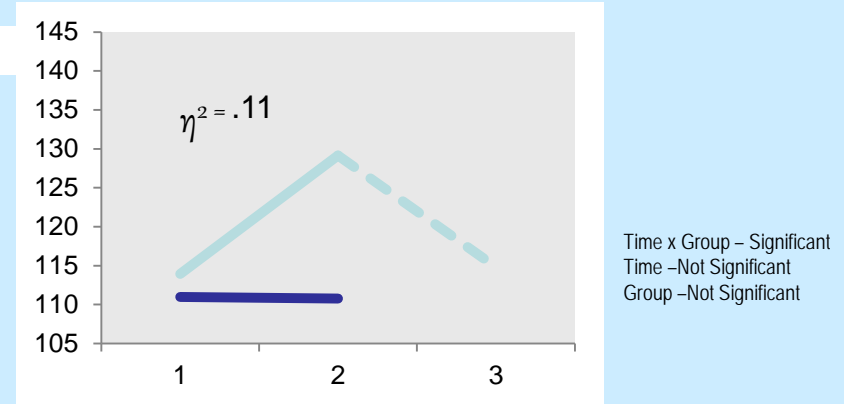
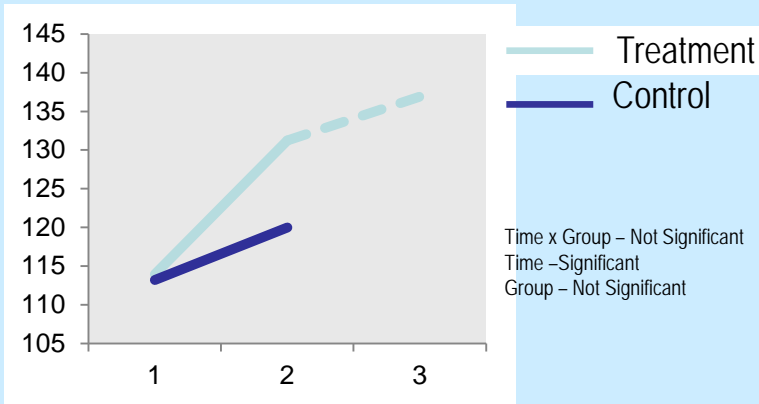
Parent and teacher reports for each measure.

# Emotional Competence

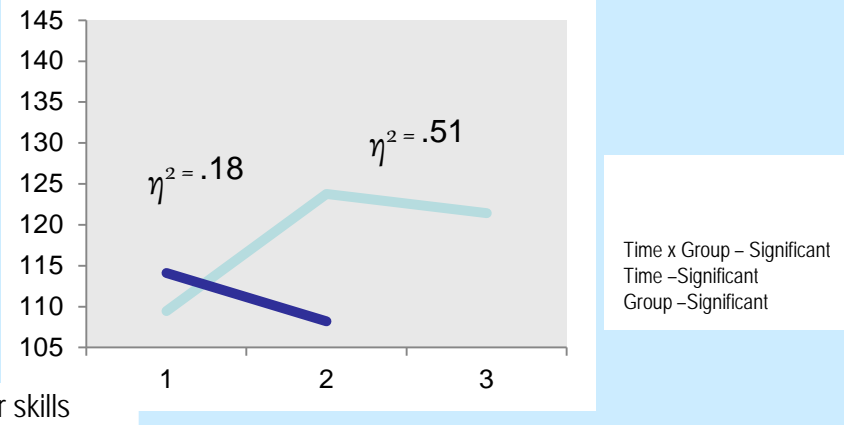
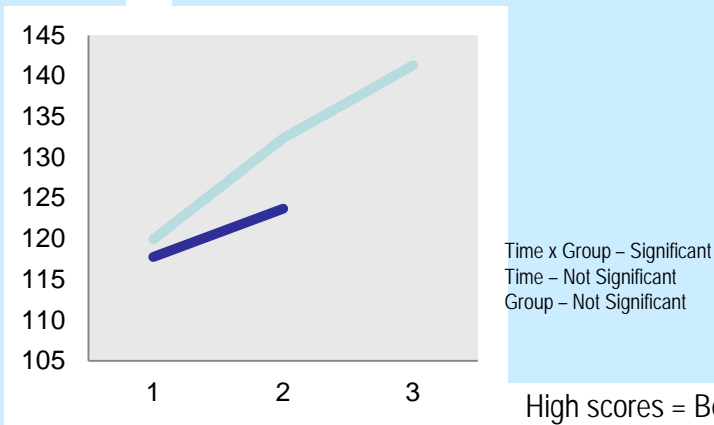
PARENT

TEACHER

ASD  
with ID



ASD  
without ID



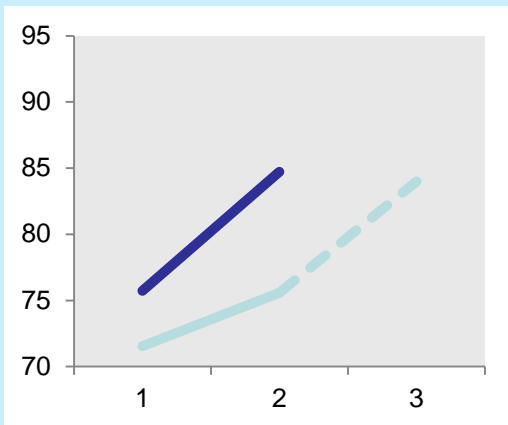
High scores = Better skills

# Social Skills

## PARENT

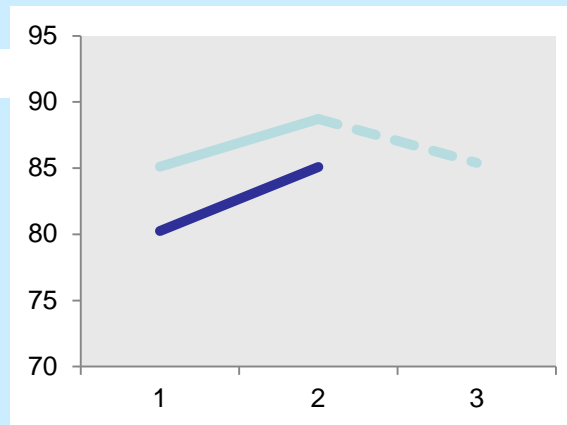
## TEACHER

ASD  
with ID



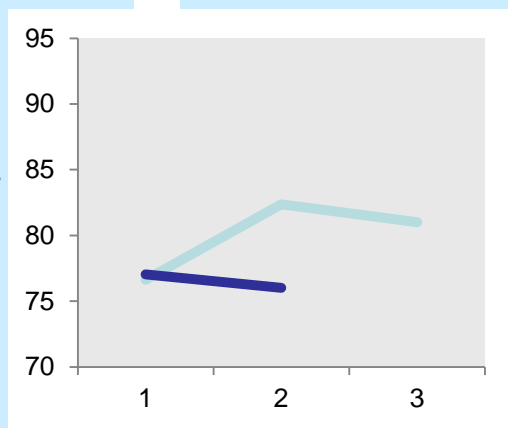
Treatment  
Control

Time x Group – Not Significant  
Time –Not Significant  
Group – Not Significant

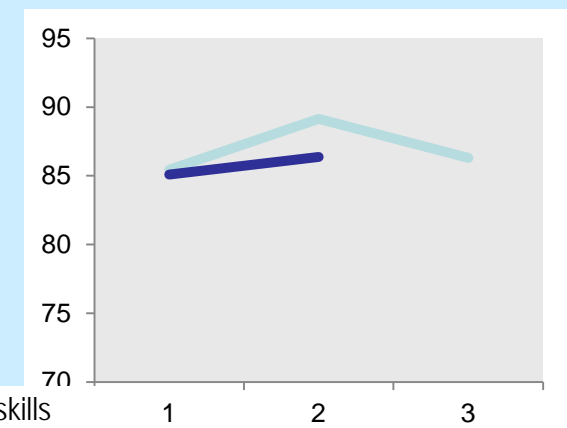


Time x Group – Not Significant  
Time –Not Significant  
Group –Not Significant

ASD  
without ID



Time x Group – Not Significant  
Time – Significant  
Group – Significant



Time x Group – Not Significant  
Time –Significant  
Group –Not Significant

High scores = Better skills

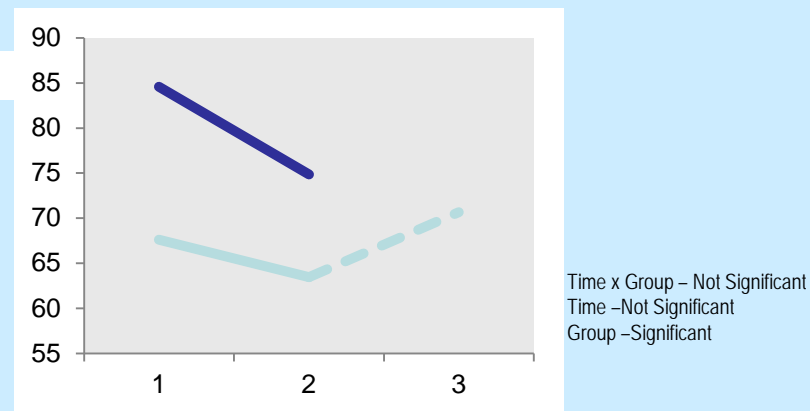
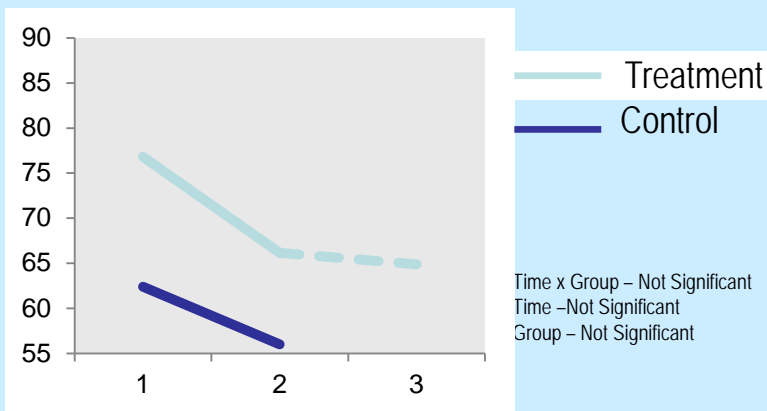


# Mental Health

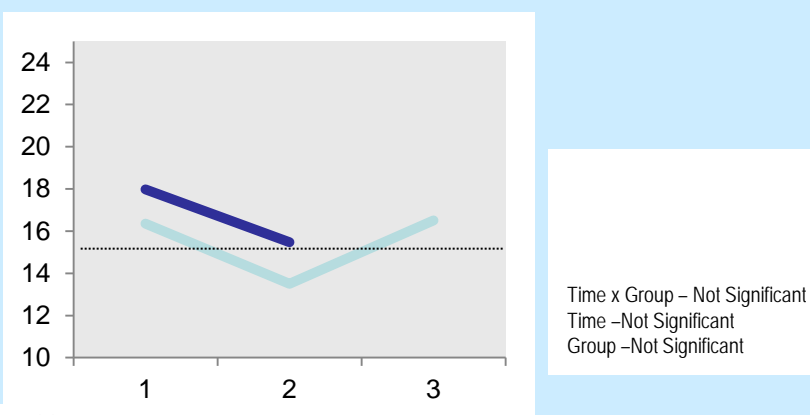
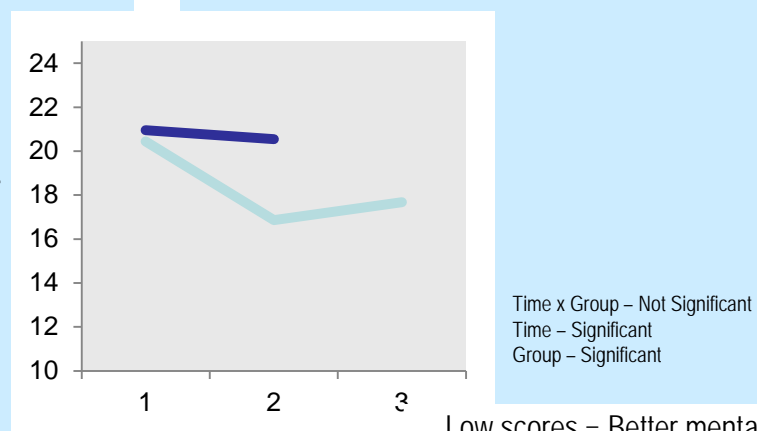
## PARENT

## TEACHER

ASD  
with ID



ASD  
without ID



Low scores = Better mental health

# RESULTS - Qualitative



# Qualitative Feedback - Parent


**“Thank you so very much for the opportunity to educate both my child and myself – we have learnt skills for life”**




- “When he has been fairly distressed he has used deep breathing to calm himself, he has spoken about how he was feeling and gotten his happy bag to get his mind off the problem”
- “We did a problem solving take away task at home – when the problem came up again he recalled the good choices to deal with the situation”





# Qualitative Feedback - Jack


**Children's Questionnaire**


 Please tick box


 Like     
  It is ok     
  Don't Like

- Do you like coming to the group?  



○		
---	--	--
- Do you like watching the videos?  


○		
---	--	--
- Do you like doing the role plays?  



○		
---	--	--
- Do you like doing the worksheets?  



○		
---	--	--
- Do you use the strength bar at home?  


○		
---	--	--

 Draw or write what you like about the group.



 Draw or write what you don't like about the group.



# Discussion

## Children with ASD without ID

1. Emotional competence - statistically significant improvements in schools. Gains maintained 6-months post-intervention. Large effect sizes.
2. Clinically significant improvements in teacher-reported mental health.
3. Controlling for mental health, significant improvements in teacher-reported social skills.

# Discussion

## Children with ASD and ID

1. First controlled study of a theoretically-based intervention developing emotion skills in children with ASD & ID.
2. Emotional competence: statistically significant improvements in schools, large effect size.
3. Positive trends
  - emotional competence (parent report)
  - social skills (parent & teacher report)
  - mental health (parent & teacher report)

# Future Directions

- Whole school large scale study
- Mainstream whole classroom delivery piloted
- EBSST App
- EBSST interactive whiteboard delivery
- Online facilitator training
- Publication and distribution





# RESULTS - Qualitative

- Counsellor feedback
  - “This is the best program I have ever done”
  - “Results have exceeded expectations”
  - “Children have made friends for the first time”
  - “Can we roll this out across the whole school!?”
- Feasibility

# DISCUSSION

- Positive trends across all measures
  - Significant results for emotion-based social skills (EDQ) (large effect size)
    - Sensitive to change in emotional development?
- Clinically significant improvement mental health for treatment group compared to control
- N.S results for overall social skills (SSIS)
  - ?Insensitive measure

# Clinical Implications

- Extra-ordinary partnership with NSW DEC
- Largest Australian school-based study involving children with HFA
- The only study of School based study in ASD & ID
- Both statistical and clinically significant benefit
- Wide scale implementation across education system

## **LIMITATIONS**

- Non-randomised
- 50% missing data
  - As expected in a field trial of this nature?

# Future Research Directions

- Whole Schools EBBST
- EBSST for interactive whiteboard
- EBSST for iPad
  - App #1 due in 12 months!
  - On-line training 24 months
- Ipad software for data collection (Collate)

# CHW School-Link [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)

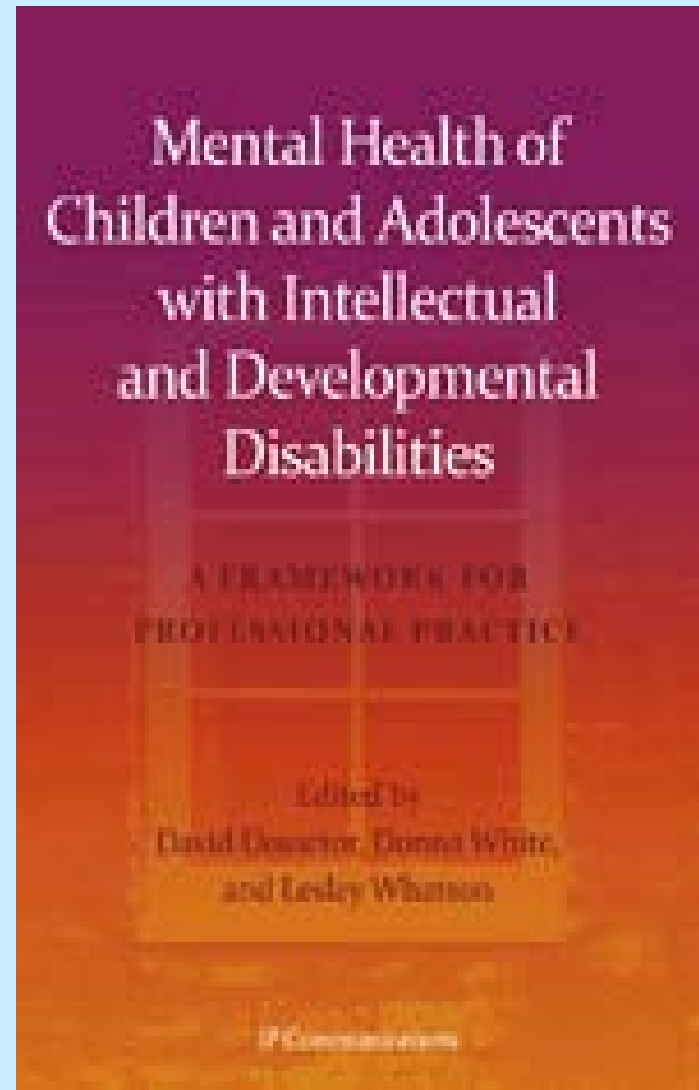
- NSW School-link promotes PPEI, Mental Health Education and pathways to care since 1999.
- 2009 CHW School-link funded (1.5 FTE)
- Focus on Schools for Special Purposes that cater for ID and other children with ID and ASD.
- Needs analysis showed a lack of PPEI, a lack of training and confidence, and a lack of pathways to care
- Partnership between Mental Health/Health, Education & Disability: steering group, project management & clinical collaboration
- Training workshops and a book,
- Newsletter 3 issues a year
- Research into MH PPEI for ID&ASD

# Book Alert!

*Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:  
A Framework for Professional Practice.*

- Dossetor White & Whatson, 2011
- [www.ipcommunications.com.au](http://www.ipcommunications.com.au)

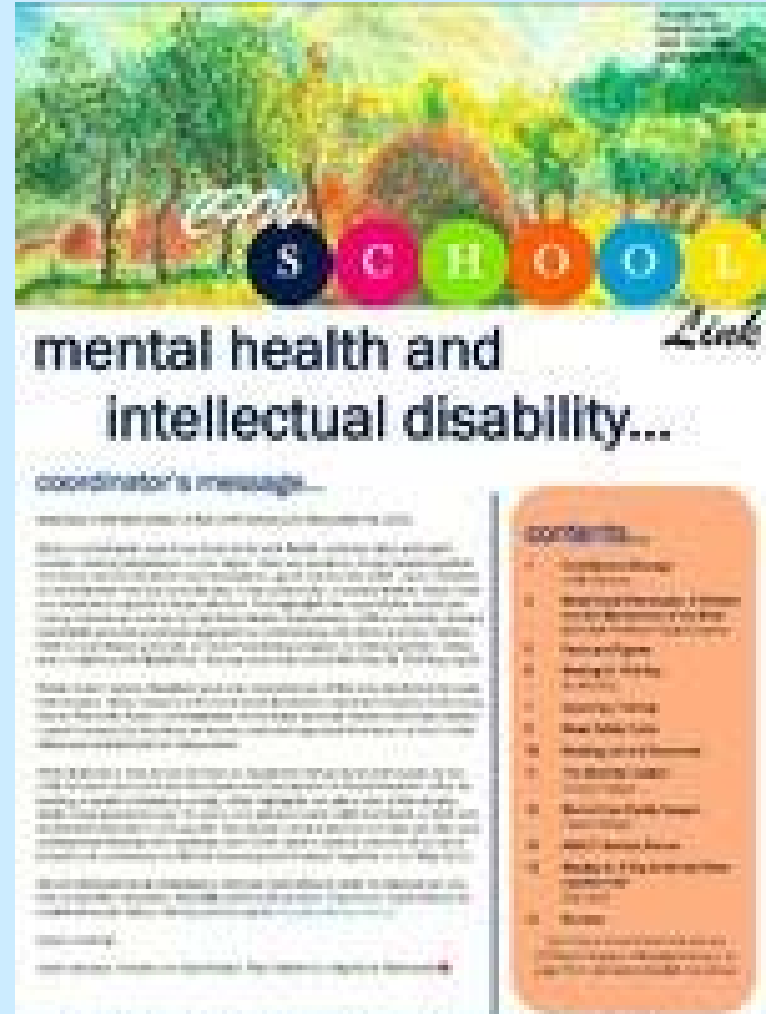
Email: david.dossetor@health.nsw.gov.au



# Newsletter

- Quarterly Newsletter. Contributions and any suggestions for content are most welcome to:  
[jodie.caruana@health.nsw.gov.au](mailto:jodie.caruana@health.nsw.gov.au)
- Sign up to our e-list to receive our quarterly newsletter and from time to time relevant emails about professional development opportunities*

[www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)



# Group Stepping Stones Triple P

- 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 assumes a complex understanding of beh probs, including:
  - **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.



# Introducing GSSTP

- Group Stepping Stones Triple P (Sanders et al, 2003; Harrison, 2006)
  - For parents of children with disabilities (2-12yrs)
  - The programs offer positive parenting supports that:
    - Build positive relationships with the child;
    - Teach children new skills;
    - Set rules and give instructions that their children will follow;
    - Respond to misbehavior;
    - Use discipline strategies that work
    - Plan ahead for risky situations
    - Have the parent develop self-care strategies
- No GSSTP studies within schools that cater for ID.
- Mini GSSTP pilot in 3 schools in 2010.

# Aims and Methods

- Add to the evidence of MH prevention for kids with ID
- Inaugural delivery of GSSTP in a school environment, (as opposed to clinical setting)
- Free training for participating schools
- Enable co-facilitation between disability and schools.
- Recruitment through school of parents of a child attending a special education school that caters for ID
- **89 participants recruited from 11 schools.**
- Pre/post testing by parents and child's teacher

# RESULTS

## Demographics: Children & Parents (complete data set)

### Children (as reported by parents)

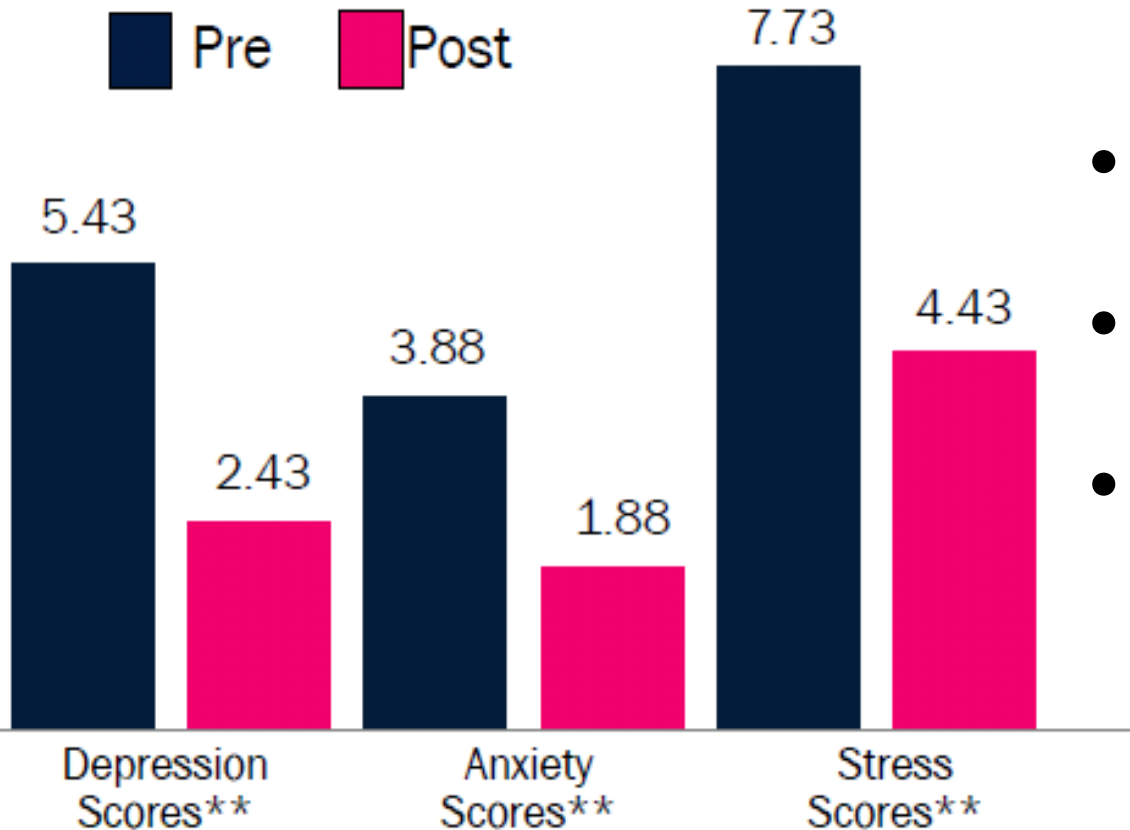
- 42 Male & 14 female = 56 / 89
- 37 ASD
- 22 ID
- 11 Other Neurological Syndrome
- 11 Other physical disability
- 40 had received services from NGO' s

### Parents

- |                           |              |
|---------------------------|--------------|
| • 33 Married              | • 2 Divorced |
| • 8 Separated             | • 1 Widowed  |
| • 7 Defacto               | • 1 Other    |
| • 4 Never Married/Defacto |              |

# Results Depression Anxiety Stress Scales DASS

## DASS 21 Scores Pre and Post GSSTP



- 56% reduction in depressive symptoms\*\*
- 52% reduction in anxiety\*\*
- 43% reduction in parental stress\*\*

\*= $\leq 0.05$       \*\*= $\leq 0.01$   
(significance levels)

# Results: Parenting effectiveness

## Parenting Scale

- Laxness: 19% decrease\*\*
- Overactivity: 18% decrease\*\*
- Verbosity: 22% decrease\*\*
- Total 19% decrease\*\*

## Parenting Tasks Checklist

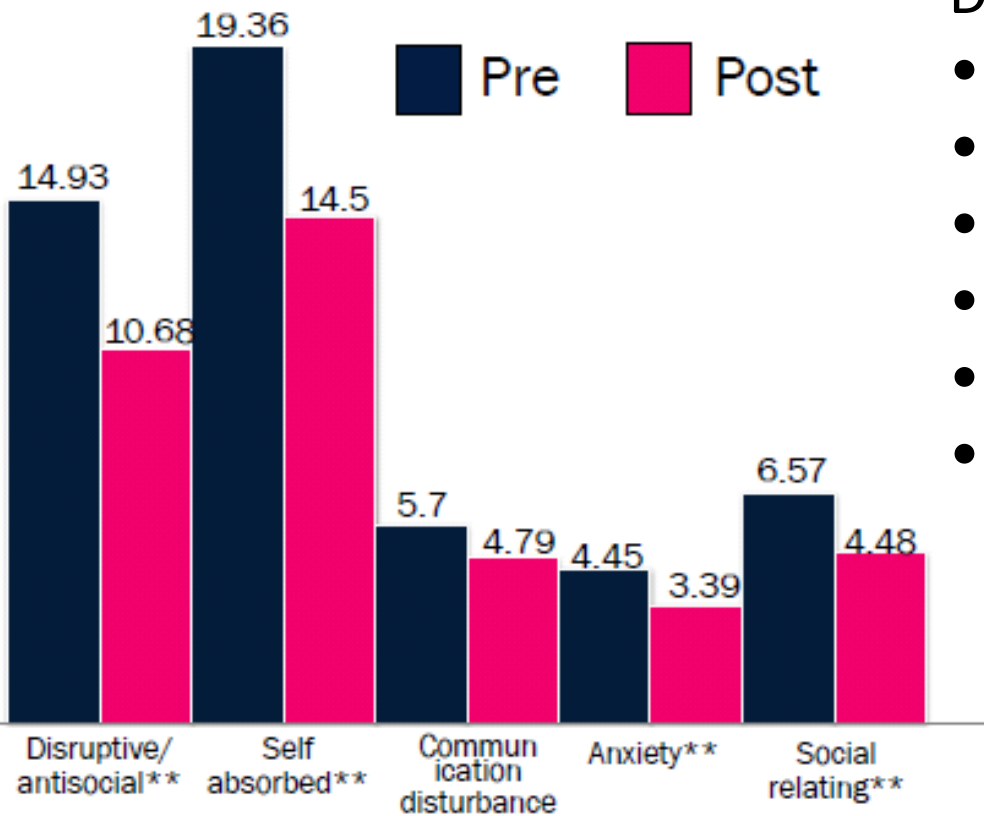
Highly Significant improvements in parents behavioural efficacy

- 11% increase in confidence between settings\*\*
- 19% increase in confidence related to gen beh management\*\*

\*= $\leq .05$       \*\*= $\leq 0.01$   
(significance levels)

# Results Developmental Behaviour Checklist - Teacher

Teacher DBC Scores Pre and Post GSSTP



\*= $\leq 0.05$  \*\*= $\leq 0.01$   
(significance levels)

Decreases in scores

- Disruptive/Antisocial: 29% \*\*
- Self Absorbed: 26% \*\*
- Communication Disturb: 16%\*
- Anxiety: 24% \*\*
- Social Relating: 32%\*\*
- Total: 25%\*\*

# Anecdotal Reports

"We learnt a lot of things from this Stepping Stones Triple P program to apply to our child and to improve his attitude. So thank you very much"

"Triple P Program was very satisfying for me I learnt a lot from it and I would do the program again if I was asked. P.S. The book is very helpful. Thank you".

# Conclusions

- School-based GSSTP is effective for children with ID & ASD.
- Reduced behaviour problems in the classroom.
- Parents stress levels were significantly reduced.
- Collaboration across government agencies to deliver better mental health outcomes for children and their parents/carers.
- Additional by-products of the groups included
  - increased parent peer support
  - improved parent/school relations
  - Improved ADHC/school relations.
- First study using an independent behavioural observer (teacher).





<http://www.macarthuradvertiser.com.au/story/245053/parents-gain-skills-to-tackle-tricky-kids/>

# Future Directions

- Focus on ASD in 2013
  - Almost 45 schools interested
  - 20 schools selected to attend training
  - 17 schools participating
- National Stepping Stones Trial NSW 2014
  - My Say: can SSTP make a public health and cost effective difference?
- A Stitch in time saves... 84: Evidence based medicine and the growth of Health Economics of Preventative Mental Health Intervention.

# Health Economics of School Based Preventative Mental Health Intervention

- Parenting interventions for the prevention of persistent conduct disorders: OR 7.82
- School-based interventions to reduce bullying: OR 14.35
- School-based social and emotional learning (SEL) programmes to prevent conduct problems (CD) in childhood OR 83.73, £132cost/family. Knapp, McDaid and Parsonage 2011

## A Framework of MH Prevention for Mainstream Education?

NSW Dept of Education commissioned “the psychological and emotional wellbeing needs of children and young people: models of effective practice in educational setting” Urbis 2011

1. **MH Promotion is most effective for most students (80-90%)**
  1. School-based social and emotional learning in Primary
  2. Positive Psychology in Secondary
2. **Targeted prevention for high risk groups or identified cases (10-15%) eg Anxiety/Dep in teens: FRIENDS** (Barrett et al, 2006); **Stress Inoculation Training** (Hains & Szyjkowski, 1990), and **MoodGym** (internet based, Caelear et al, 2009) **Resourceful Adolescent Program (RAP)** (Shochet & Ham; 2004) **Penn Resiliency Program** (Chaplin et al, 2006); **Interpersonal Psychotherapy-Adolescent Skills Training** (Young et al, 2006).
3. **Individualised Specialist Psychological Intervention (1-5%):** school counsellors with collaboration with CAMHS and other services

# Promotion, Prevention and Early Intervention (PPEI) for C&A with ID & Special Education.

1. Stop Think Do ([www.stopthinkdo.com](http://www.stopthinkdo.com))
2. The Paths Curriculum ([www.prevention.psu.edu/projects/PATHS.html](http://www.prevention.psu.edu/projects/PATHS.html))
3. Social Decision Making ([www.footprint.com.au](http://www.footprint.com.au))
4. The Alert Program ([www.alertprogram.com/](http://www.alertprogram.com/))
5. Stepping Stones Triple P ([www.triplep.net](http://www.triplep.net))
6. Emotion Based Social Skills Training ([www.ebsst.com.au](http://www.ebsst.com.au))
7. Signposts ([www.signposts.net.au/](http://www.signposts.net.au/))
8. Secret Agent Society ([www.sst-institute.net/](http://www.sst-institute.net/))
9. Mindfulness/Acceptance and Commitment Therapy ([www.actmindfully.com.au/](http://www.actmindfully.com.au/))
10. Cool Kids ([www.emotionalhealthclinic.com.au](http://www.emotionalhealthclinic.com.au))
11. Problem based Learning (PBL) ([www.pbis.org/](http://www.pbis.org/))
12. Kids Matter ([www.kidsmatter.edu.au/](http://www.kidsmatter.edu.au/))

# A Framework for PPEI in special schools for ID

- Key elements for children with ID include:
- **Specialised parent training programs** :improve family relationships and attachments, These could be part of admission to a special school, building a relationship with each family and their disability support team.
- **Behavioural Approaches**: the second best level of evidence of effect in ID, includes ABA and Contingency Approaches.
- **Development Promoting Programs**: matched according to developmental stage; widely accepted, and gradually establishing a scientific based (eg TEACCH):
  - **Augmented and Alternative Communication** for profound/severe ID & problems of motor and language dev: motor & attention skill dev and sensory exploration are pre-requisites of independent communication ; progresses onto object communication, followed by picture communication (White, Chapt 15 in Dossetor, White and Watson, 2011)
  - **Specialised Social and Emotional Learning**: focus on the staged development of emotional recognition, theory of mind & problem solving (such as EBSST); need scaffolding from adults to facilitate internalisation of competencies to develop relationships before social skills
  - **Specialised Social skills Training**: Stop Think Do, The Paths Curriculum, Social Decision Making, The Alert Program are suitable SEL from an early stage, involving problem identification, identifying feelings and working out behaviours.
- **Targeted intervention** for anxiety and mood regulation: Cool Kids and ACT/Mindfulness ?a universal intervention or for high risk children (or suitable for both).

# A Framework for PPEI in special schools for ID

- **Individualised Approaches:** complex cases require specialised assessment & intervention; can be in classroom setting. Approaches include:
  - **Complex Learning and Developmental Disabilities:** CLDD provides an individualised multidimensional approach to understanding a child's problems with learning, using the Engagement Profile and Scale to increase engagement & modifying the learning process through dimensions of awareness, curiosity, investigation, discovery, anticipation, persistence and initiation, with a range of interventions; an interface between special ed and neuropsychology, using educational approaches ([www.complexld.ssatrust.org.uk](http://www.complexld.ssatrust.org.uk)).
  - **SPICE Model** (Dosen, 2003): The Dimensions of Social, Physical, Intelligence, Communication, Emotional (SPICE) are rated according to developmental age skills. Curran has used as an assessment tool to help design interventions for the MH problems of C&A with ID, in a special school-based project.
  - **Multidisciplinary School-based Clinics:** a number established in NSW in Special Schools but need evaluation; bring together expertise of a specialist MDT from disability, health NGOs. Include eg a paed, OT, a speech thx, clinical psych & psychiatrist & family/cybernetics therapist; brings a range of skills school staff can apply to both the presenting and future cases incl the management of high risk behaviour.
    - Giant Steps Psychiatry Clinic: in 6/12 15/16 highly disturbed kids now settled





## Superheros Run the City to Surf Raising Funds to Treat Autism Now!



“Westmead Autism” is a IN COSTUME to raise awareness of Autism Syndrome. Batman, Super children with Autism and At the Children’s Hospital mental health and a good through patient care and Autism to help with issues is used to link the team of affected by conditions in based treatment method management. I am inspired every day by go to continuing the world intervention available to



<https://city2surf2014.everydayhero.com/au/ur-david-for-autism>  
<https://city2surf2014.everydayhero.com/au/team-westmead-autism>

# Violent 10year old with Aspergers

- Dennis, a 70kgm 10year old boy with Asperger's and ADHD of normal intellect.
- Recurrent episodes of violence causing concern to his general paediatrician for the last 2 years
- Initially managed as an outpatient, getting more serious and of greater duration leading to a crescendo of problems and recurrent attendances of Emergency Services and presentations to the local general hospital in a non-metropolitan area.
- Episodes of anger and aggression lasting for several hours at a time with multiple minor injuries to his parents and destructiveness to the home, with holes in the wall & destruction of furniture.
- The most dangerous incident is when he took a hammer to his mother's hand leading to a fracture, and attempts to stab her with a screwdriver.
- The recent event required Ambulance and Police, the use of capsicum spray and handcuffs, and transport by a Police paddy wagon to the ED.
- In the ED with special nursing support for 6 days. The paediatrician was too worried to admit such violence to a paediatric setting. He was deemed too young for an adult MH ward (the LHD has no CAMHS IP unit). He was seen by a psychiatric registrar who consulted his consultant. This did not progress the situation.
- On Day 2 in the ED I was contacted as on call at CHW by the paed requesting an urgent admission to Hall Ward, the only designated Mental Health Unit in NSW eligible to take those under 12. Hall Ward was full over the entire period. The main Children's Hospital was also full, so a transfer to a paediatric setting was also not even possible, even if that was considered appropriate. I provided telephone advice on medication and adding Olanzapine 10mg tds which helps aggression and stereotypic rumination.
- There were considerable urgent multi-agency discussions, particularly with FaCS who were unable to provide any alternative accommodation.



- I offered an urgent Outpatient assessment 2 days later. His family were not able to take him home for fear of assault. He was brought to my consultation by the family from the ED of the district hospital and taken back afterwards. Clonidine, Amitriptyline and Carbamazepine for ADHD, Anxiety and mood lability were introduced over a few weeks.
- There was a case conference involving the Assertive Outreach Team of CAMHS of the neighbouring LHD. Two weeks later there was a further multi-agency, multi-disciplinary case conference involving 20 people. This focused on improving acute sedation management regime with a capacity for this to be done by the Emergency services to avoid Police containment based on the medication advice for the acute management.
- At OP FU 4 weeks after the initial consult, medication regime had avoided any further acute/dangerous episodes. His level of improvement means that that alternative behavioural approaches and communication may have a greater capacity when previously they were functionless because of the frequency and rapidity with which he exploded.
- After being out of school for most of the year, a new placement had been found in a multi-categorical class starting at 1 hour per day and progressing to FT.
- The family are highly committed to their only child but parent training interventions was without benefit. As mother was in such danger from the assaults, the father had ceased work to be the primary carer. Both parents had become quite dejected and an antidepressant for the father successfully treated his level of burnout and depression.
- **Conclusion:** This case is not uncharacteristic & illustrates the severity of behaviour that can occur from ASD in the context of ADHD and Anxiety despite the best endeavours and good will of local generic services. This case used a huge array of local resources and services found situation difficult to contain and place child in under a paediatric service. Input from a psychiatrist, & psychologist skilled in ASD led to improved pharmacological management modifying the trajectory and enabling the young person to return home.



