Mental Health for Children and Adolescents with Intellectual Disability: Establishing a framework for professional practice

The theory and the practice

The Training Curriculum Project & ACI Disability Network & Health Services for ID

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Acknowledgements & resources:


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CHW School-link Newsletter and website: www.schoollink.chw.edu.au

Extended version of talk available on MH-Pod at Institute of Psychiatry
The Context & Challenge

• MH of C&A with ID is a public concern
• 30-50% of C&A with ID have significant MH probs; only 10% (4%) receive specialist help for MHPs (Einfeld & Tonge)
• 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, Rx & education & income
  – 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)
• PWC report finds that Disability is funded to 40% of the level of need & Australia is 29th/29 in OECD.
  • Improving funding would improve GDP through increased employment of the 400,000 people with disability(2010).
• Context of no designated mental health service for MH&ID
Training Curriculum Project

• **Partnership**
  – between Statewide Behaviour Intervention Service, (Lesley Whatson) & Developmental Neuropsychiatry Team, CHW

• **2007 received funding for a project manager (Donna White)**
  – 2 years from 3rd NMHP plus 2 years from ADHC

• **developed a 2 day interdisciplinary curriculum.**

• **Process**
  – 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.
    *Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:*
    **A Framework for Professional Practice.**
    *IP Communications 2011*
  – 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.

• A network of skilled academically orientated clinicians
What impedes Training & Service Development for MH for C&A with ID?

Method

- **Discourse Analysis** with colleagues and trainees identified some of the differences of MHP for C&A with ID from mainstream MH.
  - from the research, formal feedback and networking
The findings
8 problems for MH in ID

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

- Mental health accounts for 35% of the health burden and receives 10% of the health funding.
- Child mental health is 35% of the mental health burden and receives 7% of the MH funding.
- Staffing levels for C&A MH are at 40% of basic predicted need.
- Over the last 15 years Mental Health has been a national and state health priority and we are now on our 4th NMHP.
- At the end of 15 years Mental Health still receives the same proportion of the health budget!
- When mental health is struggling to have a coherent mainstream adult mental health service, it is hard to get services for Children and adolescents, let alone children and adolescents with developmental disabilities.
2. 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.
3. 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 comments:
- “if the patient can’t talk then they can’t have a mental disorder”.
- “Autism is an exclusion criteria for a mental health service”

- 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

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<td>Large study of 4468 clients/service users, ¾ in out of home residential settings,</td>
<td>Epidemiological study by 1023 adults &gt;16, mild, mod, severe ID.</td>
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<td>The main DSMIV psychiatric diagnoses</td>
<td>Using PAS-ADD checklist &amp; PAS-ADD 10, (Costello et al, 1997), Using Algorithms to produce ICD10 Diagnoses</td>
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<tr>
<td>1. Impulse Disorder 21%</td>
<td>1. Psychotic Disorder 4.4%</td>
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<td>2. Anxiety Disorder 19%</td>
<td>2. Affective Disorder 6.6%</td>
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<td>3. Schizophrenia and other psychoses 18%</td>
<td>3. Autistic Spectrum Disorder 7.5%</td>
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<td>4. Depression 14%</td>
<td>4. Anxiety Disorder 3.8%</td>
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<td>5. Bipolar Disorder 12%</td>
<td>5. Organic Disorder 2.2%</td>
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<tr>
<td>6. Obsessional Compulsive Disorder 11%</td>
<td>6. Pica 2%</td>
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<td>7. Personality Disorder 8%</td>
<td>7. Hyperkinetic Disorder 1.7%</td>
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<tr>
<td>8. Sleeping Disorder 4%</td>
<td>8. Personality Disorder 1%</td>
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<tr>
<td>9. Eating Disorder 3%</td>
<td>9. Alcohol/substance abuse 1%</td>
</tr>
<tr>
<td>10. Tourettes 2%</td>
<td>10. Obsessional Compulsive Disorder 0.7%</td>
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**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

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?

- Research diagnostic tools identify lower levels of disorder than specialist clinicians seeking to understand disturbance.
  - EBM vs Expertise
- A lack of uniformity of diagnostic concepts and thresholds
  - Different rules on co-morbidity
- Different diagnostic and schools of psychiatric thought lie behind these discrepancies.
- The research process to establish an international consensus is yet to be investigated and funded

This is reminiscent of the 1980s when ADHD was diagnosed in USA at rates x10 that in UK, before international collaboration clarified the concept and the dimension of severity which is dealt with differently in the different diagnostic systems.
5. The Need for Special Diagnostic Skills

Special diagnostic 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 be quantified in a study. (Audit 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

In the provision of MH services for C&A with ID other problems include:
- Different models for understanding MH are used by different disciplines & agencies.
- Some agencies are individual centred & lack of family centred approach.
- A lack of clinicians with evidence-based practice expertise, and experience in both MH & ID (strong alternative therapy lobby).
- An increased association with complex medical problems.
- 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 OT, physio, speech therapy, psycho-pharmacotherapy, family therapy & systemic practice which are all considered part of comprehensive treatment. (The best evidence is for parent training and behaviour therapy.)

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.
- The only domains with cochrane levels of evidence are
  - Parenting skills
  - Behavioural intervention skills (limited longer term follow up)
- Specialised expert clinicians are positive on the impact that such services have on MHPs in partnership with families & child orientated agencies, but little research has been done
- 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
- Developmental Psychiatry for in C&A with ID has much to contribute to mainstream psychiatry

**Part II:** The framework for professional practice and some service developments for C&A with ID in NSW
Framework 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

Foreword: Tony Holland.

Introduction: Training Curriculum Project: an interprofessional education program. White

Pt 1 Foundations
2. A common language for understanding disability, development, emotions and behaviour. Caithness & Moore
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 an Family and Carers
7. Children with developmental disability: is providing care a burden? Small
10. Brothers and sisters with a disability: rewarding or challenging? Small
11. Understanding and responding to challenging behaviour: valuable contributions from attachment theory. Hanssson
12. Challenging behaviour and change in intellectual disabilities: family therapy, families and the wider system. Rhodes & Whatson
13. Parent’s Perspectives. Carroll, Tye, Ollerenshaw, Eris & Brewer
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


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

• Essential skills of MDT

• Cross Discipline Skills versus Subspecialty Skill
  – Nurses to case manage & support children & families through health/disability service
  – 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 common traps & challenges of caring for a child with ID through the family life cycle

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<tr>
<th>Common traps</th>
<th>Main challenges</th>
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<tr>
<td>1. Failure of adjustment to a different child</td>
<td>1. Getting to know the child: specialist parent skills training</td>
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<tr>
<td>• Attunement and developmental understanding and special parenting skills</td>
<td>2. Sharing the burden of care: practical support &amp; innovative respite</td>
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<tr>
<td>2. Failure to share the care of a different child</td>
<td>3. Managing the system</td>
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<tr>
<td>• Adapting to the burden of care</td>
<td>• Accessing specialist disability services</td>
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<td>3. Problems of psychiatric disorder</td>
<td>• Caring for the carer and family</td>
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<tr>
<td>• Seeking special multidisciplinary help</td>
<td>4. Understanding delayed and uneven development</td>
</tr>
<tr>
<td>4. Failure to look after the carer’s well-being and family relationships</td>
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**“Ontogeny repeats phylogeny”:**

Systematic sequences occur in evolution & embryology & development

- **The universal principle of development** *(Heinz Werner):*  
  - where there is life there is development in a systematic sequence

- **Orthogenic principle:**  
  - development progresses from relative globality & lack of differentiation to increasing differentiation, articulation and hierarchic integration.  
  - both individual and context differentiate, leading to a development-transactional approach. Real development is complex & involves relations constantly changing or transacting with its environment.

- Skills in a developmental domain occur in sequence.

- Regardless of the cause for delayed acquisition of skills progress follows the same sequence of gaining competence.  
  - eg, head control precedes sitting skills followed by standing and walking  
  - preverbal noises precede single words followed by short word sequences.

- These sequences are governed by rules of developing mathematical complexity at a level of nerve connectedness
The main challenges:

4. Understanding delayed and uneven development

Assessment of problematic behaviour

Domains of Development

   • 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

Degree of Behaviour Disturbance

Developmental age in months
The main challenges:

4. Understanding delayed and uneven development

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

- **Examples**
  - If specific language is delayed there is greater risk of ID or prob 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*.
**Principals of MH treatment in ID**

- Seeing maladaptive behaviour in its developmental context provides a self evident clinical language.
- Development of the mind is complex & developmental sequences of behaviour provides a normative approach which simplifies scientific complexity.
- Behaviour can be understood from multiple theories. Eg
  - ADHD may be seen as the delayed development of mental coherence and efficiency and a genetic disorder that responds to stimulants
  - ASD can be seen as the Specific Delay in Social Development as well as a complex neurobiological disorder of the development of the social brain
- Most treatments focus on developmental support and enhancement
- Scientific method provides a deconstructive approach to the internal environment
- Neurobiology is focusing on what biological substrates contribute to developing competence, often driven by research in behavioural phenotypes
- Multidisciplinary teams need sufficient trust to consider alternative models
In a similar way studying developmental psychiatry contributes our understanding of 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, sensory modulation
- Selective attention
- Communication skills
- Mood regulation
- Self concept
- Reciprocal social interaction
- Reality testing and perspective taking
- 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
Contributions to 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
Expanding Domains for understanding behaviour

• Impairment,
  – the biological substrate, evidence esp from behavioural phenotypes;
    • Genetics, neuroimaging of development of circuitry, cellular connectivity and
      connections, neurochemistry, physical well-being, behavioural phenotype, 
      temperament

• disabilities
  – cognitive capacities
    • Neuropsychology, communication, sensory motor, perception, behaviour 
    • contribution of developmental & psychiatric disorders (esp. ADHD, ASD) personality 
      & psychosis

• handicaps: 
  – environment related.
    • Applied Behaviour Analysis 
    • Attachment, family and community relationships & access 
    • the quality and influence of services systems 
    • the wider political, economic and policy environment

• Diff trajectories of development due biology & environment, 
• the match & capacity to cope with their environment
• The influence of past and present life circumstances 
• All influence quality of life outcomes! (After Holland 2010)
Actual Components of the Framework for C&A MH & ID

1. Partnership with parents and advocates
2. Agency of Clinical Innovation Disability Network
3. Supporting the promotion of pilot Tier 4 services
4. Partnerships with Child orientated agencies
5. Building specialised services and agency partners
6. Improving education in MH & ID
7. Building the evidence for prevention & early intervention
8. Building other collaborative relationships
Partnerships with Clients, Parents and Advocates

• Maria Heaton, NSW Carer of the Year Award 2012, Chair of the ACI Disability Network and Mother of 12yo Tristan, who has Lissencephaly spoke at a recent conference about her son who has profound disability, significant deafness and blindness, and depends on a gastrostomy for feeding. “He communicates more than he lets on” Maria says. Yet with appropriate care and stimulation is as happy, and loving a boy as any, with a range of interests such as swimming, tickle games and TV.

• She also talked of the problems she dealt with eg
  – doctors saying Tristan would be dead by 3 months,
  – of getting services adequate to his needs, which generally require 3 monthly renewal of “emergency” support, rather than recognising his long term needs.

These examples illustrate what is at stake for people with IDD to have right to freedoms, choice and a quality of life.
Agency of Clinical Innovation: Disability Network

- Set up following NSW Gov discussion paper & working group on Health Needs of People with ID and Evaluation by PWC
- Participation from Consumers, Carers, NGOs, ADHC, Health, MH, policy officers and clinicians and other interested parties
- Framework of 4 subcommittees, coordinated by an Executive Committee: to advise on framework and priorities of health services for people with ID
- Framework of 5 Tiers of service provision
- Oversight of the 3 new Tier 4 pilot specialist health services for ID at Kogarah MRID with Regional Outreach, Centre for Disability Studies enhanced General Practice, and Fairfield with multicultural transition: each funded for $450,000
- Developing guidelines: ‘pathways to care for children and adolescents with intellectual disability and challenging behaviour & mental health problems & ‘responsibilities & rights using Health’
NSW Service Framework for people with ID & their carers

**Tier 1**
Ministry of Health
Strategic health, policy and population health

**Tier 2**
Primary Health and Community Care
Regular health checks; ??Disability CNCs to facilitate

**Tier 3**
Specialist Health Services
A. IP care
B. OP care
Include: MH, Dental, Endocrine, genetic, neuro, Corrections health & Justice Health etc

**Tier 4**
Specialist ID Service
MD Assessment of C, Ad, Adol
Med management of complex cases
Liaison & collaboration
Partnership with other subspecialties
Leadership and education for other tiers
Consultation for acute hospital consultation

**Tier 5**
ACI ID Disability Network
Academic Units incl Chair in MH&ID;
Medical School Education; online Ed

**Partnerships**
ADHC
Carer/Advocates
NGOs
Education
- Pathways to care
- Responsibilities & Rights
- Policy & Guidelines

**Specialist Prevention, Promotion and early intervention needing review and development**

Evaluation of services
Escalation processes
Clinician competency assessments
Continuing Med Ed
Complaints & discrimination
Developments in MH/ADHC Reln

MOU between ADHC & Health (Mental Health) (Jan 2011)
- Requires senior management cross agency meetings with feedback to an implementation committee
- Subcommittee for CAMHS ID.

ADHC Funded Chair of MH & ID @UNSW (5yrs, Julian Trollor)
- Workshops & On-line Educational Program for MH & Disability
- Building a research agenda
- Influence RANZCP: established a special interest group
- Hosted AADDM conference with Jackie Small @ UNSW

Funding in ADHC has improved clinical professional skills and collaboration, esp with a MH priority

AHDC funded 1 year Fellowships in MH &ID through the institute of psychiatry

ADHC funding a chair in ID & Behaviour Support
Building collaboration

• SWSLHD/Met South ADHC collaboration
  – Example of the complexity of the cases, eg with uncertain diagnosis of difficult to treat schizophrenia

• SBIS, DEC & CHW have a monthly joint tertiary clinic & a mutually supportive partnership that has been growing over 10 years, with a focus to try & enable greater local collaboration.
  – Developmental Psychiatry Team now has 2 clinical psychologist, pt OT, paediatric registrar
EBSST: Specialised Social Emotional Learning
“Developing Skills for Life”  Developed 2004 -2012

David Dossetor, Sponsor, Michelle Wong, Project Manager, Belinda Ratcliffe,

- **Funders**: 3rd Nat MH Plan, ADHC, Collier Foundation, Automobiles for Autism
- **Partners**: Dept of Education, Statewide Behaviour Intervention Service (ADHC)
- **Contributors**: Sandra Heriot, Victoria Grahame, Louisa Carroll, Lisa Brice, Amy Price, Alison Fettell, Sandy Vickerstaff, 64 school counsellors, and many more!

- Based on developmental theory that skills are learned in specific sequence including those of emotional recognition, theory of mind and problem solving
- Now two group versions for
  - high function ASD and for ASD with mild ID
- Clinical cohorts, pre/post outcomes
- DEC Partnership to provide a social emotional curriculum in school
- Whole of school program
- Developing the use of white board and Ipad technology
CHW School-Link: MH of students with ID

PPEI, skill building and pathways to care for MH&ID

- **Partnership & Collaboration:** Jodie Caruana, Hebah Saleh plus DEC & Schools; ADHC & SBIS; Developmental Neuropsychiatry Team

- 2009 **Needs Analysis** “Leading the way” of 58 SSPs that cater for ID

- **Awareness raising and education:**
  - Conferences & workshops
  - Developing educational materials eg via MH-Pod at IOP available
  - Free electronic CHW Newsletter [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au) to register

- **Partnership Piloting of Stepping Stones** in 14 SSPs that cater for ID
  - Dramatic improvement in children’s behaviour, parent wellbeing and style
  - Parent school reln, support and child minding groups

- **Cross agency Complex Case Discussions** with School Counsellors, SBIS, CHW, CAMHS & ADHC for SSPs that cater for ID
  - SWLHD & Regional NSW via teleconferencing.
  - Demonstrating improved competency and confidence and helping build cross agency relationships
Diagnoses, medication and outcome in a case series of 150:
Diagnostic overshadowing--> Equality is MH→ examining complexity?

• Each of ID & MH contribute 20-30 points to functional impairment (on CGAS 0-100)
• **Psychiatric disorder is the reversible component**
• The level of impairment indicates MHP(ave 35), 2nd work out what is the psych problem
• Complex comorbidity with ave 3.5 diagnoses
  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
• Ave no. of meds: 2.2,
• Look for anxiety and depression in those unable to describe
• co-occurring anxiety is often the key to successful Rx of ADHD, aggression or SIB.
• YP with ID is deteriorating in skills, is more likely to have depression than psychosis.
Take home message

• Kids with ID are challenging but rewarding
• Special needs in family care, service provision both mainstream and specialised, MD specialist skills, collaboration, clinical research, political power and partnership to make it happen
• NSW has started down the road, with a long way to go

Parents gain skills to tackle tricky kids
By Scott Dougherty