Developmental Psychiatry: concepts, prevention, promotion & tertiary intervention

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CHW Developmental Psychiatry Team

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Developmental Psychiatry Clinic and Partners:
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Health Warning:

Developmental Psychiatry or Mental Health of ID/ASD is
• underfunded,
• limited research,
• complex,
• relies on collaboration of all involved

Outline

1. Concepts of ASD:
   – Category (disease), Dimension or Developmental Disorder?
2. Mental Health Comorbidity in ASD
3. Challenges in MH and ASD/ID
   – Developmental models of mental health
4. CHW Developmental Psychiatry Team Activities
   – Emotion based Social Skills Training for ASD (EBSST),
   – Developmental Psychiatry Clinic and Partnership,
   – Training Curriculum Project and Framework,
   – CHW School-Link,
   – Drug Audit of Developmental Psychiatry
5. The future of Developmental Psychiatry with NDIS
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.


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,
Skewed gaussian distribution of Social Intelligence/Empathy (Gilberg)
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
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.

Implications of a Developmental Model

• Normative: makes sense to all disciplines, family and young people, rather than medicalising expertise
  • 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, sensory modulation
  • 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
• Most treatments are development enhancing & attracts multi-skilled physicians
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

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EBSST: Skills for Life (1994-2014)

• Based on developmental theory that skills are learned in specific sequence including those of emotional recognition, theory of mind & problem solving
• Mental Health is correlated to Social Skills
• Emotions Development Questionnaire is a sensitive measure of change & has potential to prove the developmental sequence
• Now two group versions of intervention for
  – high function ASD and
  – for ASD with mild ID
• Clinical cohorts, pre/post outcomes; large control trial (n=350)
• Partnership with NSW DEC to provide a social emotional curriculum in schools for children with ASD
• Whole of school program for Mild/Mod ID

Current Developments to expand implementation:
• Publishing the manuals, Ipad App, Smart Board and On-line Training
What makes for a Quality of life in ASD?

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’
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%
  – Eureseis, 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)
Problems of psychiatric Diagnosis

• No studies of diagnostic reliability
• Do they have the same validity?

• Problems of identifying symptoms and signs of psychiatric disorder
• Lack of international consensus
Both diagnostic ICD & DSM manuals identify special problems of eliciting phenomenology in ID/ASD

1. **Subjective mental phenomena cannot be reliably elicited < 7 years or IQ < 45.**
   - debate over the age 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 to “hearing voices”,

5. **Diagnostic overshadowing**: failure to identify 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

• No advice on how to tackle these special problems
  – apart from consulting “an expert”.
# 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

<table>
<thead>
<tr>
<th>Rank</th>
<th>Disorder</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Impulse Disorder</td>
<td>21%</td>
</tr>
<tr>
<td>2.</td>
<td>Anxiety Disorder</td>
<td>19%</td>
</tr>
<tr>
<td>3.</td>
<td>Schizophrenia and other psychoses</td>
<td>18%</td>
</tr>
<tr>
<td>4.</td>
<td>Depression</td>
<td>14%</td>
</tr>
<tr>
<td>5.</td>
<td>Bipolar Disorder</td>
<td>12%</td>
</tr>
<tr>
<td>6.</td>
<td>Obsessional Compulsive Disorder</td>
<td>11%</td>
</tr>
<tr>
<td>7.</td>
<td>Personality Disorder</td>
<td>8%</td>
</tr>
<tr>
<td>8.</td>
<td>Sleeping Disorder</td>
<td>4%</td>
</tr>
<tr>
<td>9.</td>
<td>Eating Disorder</td>
<td>3%</td>
</tr>
<tr>
<td>10.</td>
<td>Tourettes</td>
<td>2%</td>
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</tbody>
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## 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

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

**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?

- 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.
MHPs in C&A with ID/ASD are different & need different approaches eg ADHD & other Developmental Disorders

- Are MHPs in C&A with ID different to those with average IQ? Eg:
  - 30-40% of C&A with severe ID have ASD (compared 1% in the average pop).
- Is Significance/meaning or validity of diagnosis 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 depression & 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.
MHPs in C&A with ID are different eg ADHD & other Developmental Disorders

Further ADHD is associated with other developmental disorders. Eg:

- ADHD and Developmental Coordination Disorder each occur at a rate of 7%, but co-occur in 50%.
- ADHD in 50% of teenagers with ID plus ASD vs 15% with ID without ASD (Bradley 2006)
- ADHD is found in 78% of PDD in clinic population (Lee & Ousley, 2006)
- Genetic studies confirm linkage between ID and ASD 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 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
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 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
The Mental Health Context

- 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: Australia Disability is 40% funded & is 29th/29 in OECD.

- C&AwID: 40% MHPs; 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
- 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;
Brief History of Developmental Psychiatry Partnership: DPP: an initiative to improve MH for C&A with ID

- Child Psychiatrist MH+ID
- Monthly Clinic at Grosvenor Hospital (ADHC)
- Lesley Watson Head of CT SBIS joined Conjoint Developmental Psychiatry Clinic
- CAMHS Clinical Psych #2 funding
- Funding ceased
- Conjoint paediatric clinic at CHW
- CAMHS Clin Psych (ID & ASD) funding
- ASD 2 day Workshops
- Training Curriculum Partnership Project in MH&IDD
- EBSST school based interventions
- CHW School-Link funding

Much is achieved sharing resources, with minimal funding
CHW Partnership Initiatives  2007
The Training Curriculum Project

• Partnership project between Dept of Psych Med at the CHW & Statewide Behaviour Intervention Service, ADHC: Leslie Whatson

• 4 years funding from 3rd National MH Plan and ADHC for project manager (Donna White)

• developed a 2 day interdisciplinary curriculum.
  – a literature review
  – clinical experience of ‘what works’ in tertiary multidisciplinary multi-agency clinic
  – areas of demand for training
  – a stakeholders survey of areas of intervention-focused learning;
  – evaluations and 3 month outcomes on workshops;
  – commissioning 28 chapters, independently reviewed for a textbook.
  – 6 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.


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 ‘bio developmental psycho social cultural model’ framework that
  – informs multidimensional assessment
  – provides a context for understanding behaviour
  – alternative approach for understanding developmental psychiatric disorders eg ADHD & ASD
  – assumes multi causal mechanisms to disturbance and disorder
  – emphasis on multimodal skill building/positive psychology
  – Requires multidisciplinary/multiagency collaboration
- A specialist MH service for C&A with ID needs close collaboration multi disciplinary/agency team,
  – with a healthy tension between developmental models versus deconstructive (illness) models.
- Problem Solving service systems should have:
  – tiers, with greater expertise for difficult to solve problems,
  – rules of interagency collaboration & a
  – complex case conference final pathway: combines clinical judgement & resource management
- Specific Prevention Promotion & Early Intervention approaches (generic MH strategies not applic)

Some components of PPEI should include:

- Universally available specialist parent child management training
- Emotional literacy programs in schools
- Multidisciplinary skill building skills
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
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.
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
CHW School-Link: focus on MH for C&A with ID and Developmental Disorders

(2009- current) Jodie Caruana & Hebah Saleh

Aim to improve MH outcomes through:

• **Awareness & Advocacy:** Newsletter/Educational Resource

• **Multidisciplinary Teaching & Professional Development:**
  – Approx 25 presentations a year

• **Promotion Prevention & Early Intervention (PPEI):**
  – Effective intervention of Stepping Stones Group Parent Training in 23 partner schools for ID & ASD
  – Partnership MySay for SSTP
  – Promoting PPEI models
  – Developing Mental Health First Aid Intervention for SSPs

• **Clinical Partnership:**
  – Complex cases discussion groups

• **Pathways to care**
  – Using Developmental Psychiatry Partnership to enable local partnerships, provide advice and support the growth of tertiary expertise
  – Publishing information for consumers, families, carers and advocates

• **Leadership to develop services, funding and expertise in MH& ID/ASD**
  – ACI Network of ID, Supporting Interagency partnerships: MOU for MH&ADHC, CAMHS ID Partners Meetings, partnership with 3DN (UNSW)
Developmental Psychiatry Team, Dept of Psych Med, CHW, SCHN (DPT)

Developmental Psychiatry Clinic (DPC)

Children’s Team of Statewide Behaviour Intervention Service, ADHC, NSW FACS (SBIS)

Collaboration outside of DPC

Developmental Psychiatry Partnership (DPP)

A unique resource in NSW of clinical expertise

Collaborative research with funding and in-kind donations

Include NSW Department of Education and Communities

Multidisciplinary, multiagency expertise, clinical & administrative

Strengthened relationships between health/MH, ADHC

1. CHW School-Link

2. Promotion, Prevention and early Intervention Initiatives

3. Training Curriculum Project

4. ASD Emotion Based Social Skills Training (EBSST)

5. Enabling CAMHS ID Committee, JCMHD

6. Cross agency partnerships and pathways to care b/w Disability, Health & MH

7. Regional Cases using CAPTOS

8. Complex Case Review Committee

9. Participation in ACI Disability Network

10. Expanding access to DPC

11. DPC Evaluation

12. Supporting Prof Troller & 3DN, UNSW

13. Supporting play therapy & trauma informed therapy & systemic clinic

14. Partnerships with NGOs
What enables Professional and interagency Collaboration: A review of the constructs by DPP

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

“Westmead Autism” is a team of staff from the Children’s Hospital at Westmead, their family & friends, running the City to Surf IN COSTUME to raise awareness and funding for the work done by the hospital for children with Autism and Asperger’s Syndrome. Batman, Superman, Mrs Incredible, Wonderwoman, Poison Ivy, Dora and Wally will be part of Westmead Autism, inspired by children with Autism and Asperger's Syndrome and their families.

At the Children’s Hospital at Westmead we treat patients who have Autism and their families to try to help them have good mental health and a good quality of life. My team at the Children’s Hospital helps children with Autism and their families through patient care and research. Our doctors and allied health professionals run an outpatient clinic and see children with Autism to help with issues such as anxiety, depression, behaviour support, and social skills training. Video conference technology is used to link the team of doctors and allied health professionals with clinicians and families around rural and remote NSW affected by conditions including Autism. A research program in Emotion-based Social Skills Training is being run to use evidence-based treatment methods to teach emotional understanding, perspective taking skills, problem solving, and emotions management. I am inspired every day by the patients I see and my team of staff who give them excellent patient care. Every dollar I raise will go to continuing the world-class services for Autism we provide at the Children’s Hospital at Westmead. Our aim is to make this intervention available to any young person with ASD. Help us reach our target!!

https://city2surf2014.everydayhero.com/au/dr-david-for-autism1
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