Developmental Psychiatry: the current context, a case audit of diagnosis and drug prescribing Quo Vadis with the NDIS

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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

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

Developmental Psychiatry Clinic and Partners:
Statewide Behaviour Intervention Service, ADHC: Lesley Whatson, Donna White, A Hanson, K Van Sebille

NSW Department of Education: Katrina Worrall, Jan Luckey; Coreen School

Publication:
Dossetor D, Donna White, Leslie Whatson (Eds).
Mental health for children and adolescents with intellectual disability:
a framework for professional practice. IP Communications: Melbourne. 2011.

Illustrations from CHW Operation Art
• “Meet Jessica” animation for MH awareness raising in schools & community services
• Train the trainer to >1200 teachers, school counsellors and clinicians in 28 sites in NSW
• 2016 NSW Mental Health Award for collaboration from Way Ahead, MHCC
• Training materials now freely available on website & recorded for NSW teachers as CPD
Health Warning:

Developmental Psychiatry or Mental Health of ID/ASD is

• underfunded,
• limited research,
• complex,
• relies on collaboration and clinical consensus

Brief Outline

1. Context
2. What will NDIS do for the services for C&A with emotional & behavioural problems?
3. Diagnosis and Drug Audit of 150 cases
4. Psychiatric Comorbidity in Developmental Psychiatry Clinic
The state of play in service provision

- Between 1/20-1/50 families have a child with an ID.
- EBD in 40%; 10% (4%) get specialist MH help; a greater effect than the ID on the family. (Einfield & Tonge)
- Such psych disorder constitutes 14% of the burden of all childhood psychiatric disorder, and with ASD it is 25%. (Emerson & Hatton 2007)
- The human rights of PWID: should expect equitable access to MH Services, ie 3-4x greater access than a neurotypicals
- They are more likely to attend EDs and less likely to access outpatient services (Trollor)
- Survival of PWID increased, but life expectancy of 15-25 yrs less.
- Quality of services affects mortality & social inclusion eg employment and the sustaining of family care
- With increasing affluence, the gap of social inclusion and achievement of PWID is widening.
- The MH of PWID is a health, social, and political issue
Developmental Psychiatry

• Support for professional specialisation & funding of community based services has been slow since the deinstitutionalisation

• 1st world countries are at different stages of awareness & implementation of service provision (Centre of Disability Studies)

• RCPsych recommends 5-6 specialised CAMHS clinicians/ 100,000 pop, & 3-4 Specialist CAMHS inpatient beds for severe ID /1Mill pop & 3-4 for mild

• Australia: there is a ‘dawning of recognition’ of the need for specialised services to be embedded in Mental Health Frameworks. (CDS)

• Some states are recognising the need as ‘a health issue’ with position papers

• Some states & territories capacity building has begun with pilot models

• Severe levels of impairment from MHPs additional to ID (eg. CGAS 30s)

• A range of different complex problems
  • eg extreme repetitive self-injurious behaviour, extraordinary levels of anxiety and hyperactivity and insightless rage and violence sometimes driven by stereotypic preoccupation.
Brief History

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 approaches (ABA) to ID (Diagnostic Overshadowing)

Division of concepts and agencies between disability for behavioural disorders vs mental health services for major mental illness

Rise of recognition of MH in ID

DC-LD 2001 (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation) (Royal College of Psychiatrists)

2013 (Centre for Disability Research and Policy, USYD) 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; premature mortality 20years

2013: pilot NDIS and now the full roll out

• Consumers: without specialised MH expertise we fail to meet disability MH needs (Canberra Roundtable)(2013) agreed
  • principals of improved access for PWID to mainstream services
  • subspecialty MH skills needed
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 29th /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

• Health Economics indicate MH intervention is cost effective:
  • $3mill ave cost of a completed suicide
  • Lifetime Cost of someone with ASD $1-2Mill;
  • Emotional Social Intervention in primary schools has an 84:1 return on expenditure
# Definitions of Mental Illness & Health in ID

Guide to Services framework in Australia

<table>
<thead>
<tr>
<th>Term</th>
<th>Service</th>
<th>Disturbance</th>
<th>Severity</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Mental Disorder/ Illness</td>
<td>Diagnosable Illness from DSMV Priority for Mental Health Services</td>
<td>Managed in community +/- short IP admission +/- MH Act</td>
<td>Significant impairment and high risk of harm to self or others</td>
<td>-Major Depression</td>
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<tr>
<td>(3rd NMH Plan) 3%</td>
<td></td>
<td></td>
<td></td>
<td>-Bipolar Disorder</td>
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<td>-Schizophrenia</td>
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<td>-Acute Mental Disorder</td>
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<tr>
<td>Mental Health problem</td>
<td>Diagnosed from DSMV but seen as a developmental disorder Rx by</td>
<td>EBD is as severe as impairment from ID. The combination makes for</td>
<td>Severe impairment, risks to care esp in acute exacerbation</td>
<td>-ADHD/ODD/CD</td>
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<tr>
<td>(3rd NMH Plan) 20-40%</td>
<td>Paediatrics &amp; disability service, +/- specialist ID MH. (not a serious MI)</td>
<td>complexity and severity</td>
<td>Needs high expertise MD subspecialty collaboration of disability &amp; health</td>
<td>-ASD</td>
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<td>--Depressive symptoms</td>
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<td>-Anxiety Disorders, OCD,</td>
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<td>-Lability of mood,</td>
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<td>-Panic disorder,</td>
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<td>-Dissociation</td>
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<td></td>
<td>-Trauma based problems</td>
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<tr>
<td>Challenging Behaviour</td>
<td>Culturally Abnormal Behaviours Disability Services, ABA approach</td>
<td>the physical safety of the person /others</td>
<td>High impairment, intensity, frequency or duration big impact on QOL</td>
<td>-aggression/self harm</td>
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<tr>
<td>40-60%</td>
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<td></td>
<td>-behaviour disturbance</td>
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<td>-stereotypy</td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td>-habits, Pica</td>
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<tr>
<td>Mental Health &amp; Wellbeing</td>
<td>emotional &amp; social wellbeing. PPEI across family, school, community</td>
<td>Promote resilience to cope with the normal life stressors</td>
<td>Chronic moderate severe EDBD probs. Aim to achieve potential &amp; QOL</td>
<td>attention, restless,</td>
</tr>
<tr>
<td>(3rd NMH Plan) 100%</td>
<td>&amp; interagency</td>
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<td>behaviour, reciprocity,</td>
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<td>self esteem, autonomy,</td>
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<td>skills, part’n, employm’t</td>
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Mental Health Initiatives for ID

Initiatives funded and supported by ADHC

- MOU between Health/MH and ADHC 2007
- Fellowships in ID MH (7) since 2010
- Specialist MH Clinics in Large Residentials (approx 500 people in the state)
- Chair of Intellectual Disability Psychiatry and a Chair of Positive Behaviour Support (UNSW)
- Employing private ID Psychiatrists for their tertiary services

What else does ADHC do that is mental health intervention

- Monitoring and Review: Complex case reviews
- Workforce capability development, training and education
- Safeguarding: Policy leadership and guidelines (eg restrictive practice regulation)
- Practice Leadership in EB Practice in allied health disciplines, including outcome research
- Innovation through partnerships, research and service model development: treatment and clinical services eg Modified Trauma CBT, Play Therapy, Systems clinic, sexual awareness and protective behaviours
- Access to specialist tertiary consultation support: Regional Behaviour Intervention Teams, MDT assessment and intervention for PBS
- Emergency LT Respite, with skilled management of aggression minimisation
- Community Justice Program, Integrated Services Program

- Collaboration: Developmental Psychiatry Clinic and Partnership with Statewide Behaviour Intervention Service and NSW DE.
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)
- CAMHS Clin Psych (ID & ASD) funding
- ASD 2 day Workshops

1991

1995

- Funding ceased
- Conjoint paediatric clinic at CHW

Lesley Watson head of CT SBIS joined Conjoint Developmental Psychiatry Clinic

2000

2005

- Training Curriculum Partnership Project & textbook

2008

- CAMHS Clinical Psych #2 funding
- EBSST school based interventions

2009

2014

- CHW School-Link Funding; Free electronic Journal
- NSW DE joins DPC

2016

- DPC & P Evaluation by CDS
- Meet Jessica, MH Awareness raising for Special needs
- Publishing EBSST +online training with ACER.
- EBSST goes to China & Cultural validation study with TMHC
- Aspect clinic & EBSST partnership

Much is achieved sharing resources, with minimal funding
Developmental Psychiatry Team, Dept of Psych Med, CHW, SCHN (DPT) → Developmental Psychiatry Clinic (DPC) → Children’s Team, Statewide Behaviour Intervention Service (SBIS), NSW FACS → Collaboration outside of DPC → Developmental Psychiatry Partnership (DPP) →

- A unique resource in NSW of clinical expertise
- Collaborative research with funding and in kind donations
- NSW Department of Education (DE)
- 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
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 Psych, OT, Speech Thx, Special Ed, Pharmacy, Case Mx;
- Skill building approaches: support specialist skills of treating teams
- Specialised therapies eg EBSST, play therapy or trauma focused CBT

**Family and System Skills.** Different to mainstream
- incl skill enhancement; **cultural expertise**
- **The system issues;** (also separate special referral service).
- 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 OOHC.
- Legal: human rights/child protection eg service systems that are failing

**High level of interagency collaboration.**
- To influence each other’s service systems for the needs of the child & family
- Match service provision with clinical need vs business funding formulas.
Developmental Psychiatry Team

- DPC and partnership has expanded
  - to cases discussed but not seen in clinic
  - Cases seen with cross team representation, incl through CAPTOS.

- Tertiary Referral Services:
  - >100 cases of ID/ASD/yr
  - 2 tier 4 specialist ID Health Services,
  - public & private paediatricians & psychiatrists, some NGOs

- 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.
The DPC Evaluation: What Value Does the Clinic Add?

- Explore the value and effectiveness of the DPC to key referring agents with interviews of stakeholders and a sample of patients
- Examine the DPC - its purpose, activities, structure and governance
- Underpin these enquiries with an exploration of the literature specific to tertiary consultation models.
- Make recommendations regarding how the DPC could evolve to meet changing demands and priorities
- Funded by ADHC
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
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

Represents state of the art practice in the world
Likely to be highly cost effective in saving care costs
Major outcome:
Refining the model in view of NDIS
Conclusions: what will the NDIS bring?

- The Mental Health needs of young people with ID and ASD will be disadvantaged without increased access to both mainstream and sub-specialised services.
- Interagency partnership has achieved much on minimal funding.
- NDIS may bring an extra $6 Billion to disability, and may therefore work to provide support life-long.
- The withdrawal of State Disability Services will drastically reduce MH/PBS expertise and is a shift in the model of service to paediatrics and MH without any additional funding.
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 over 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, Enuresis, Neurological Disorder/Movement Disorder, incl progressive decline, Epilepsy, TB meningitis, Traumatic brain injury, Hemicranial Pyrexia, Blind/Deaf, Obesity, wt loss, Immuno-defic, Eosinophilic Oesophagitis, Dental caries

**Genetic Disorder or Behavioural Phenotype** eg VCFS, Kleinfelters, 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*
  - PreCGAS***, ASD***, SIB***, Agg**, ADHD*, NMeds*
- Lower IQ correlates with:
  - IQ***, Anx***, PreCGAS** (but not ADHD)
  - PreCGAS***, Dep***, Agg**, NMeds**
  - Dep***, Agg*, SIB*, DCD*,
  - PreCGAS**, ADHD**, Sensory**, IQ**, Dep*, NMeds**
  - SIB***, Anx***
  - Pre-CGAS***, IQ***, Dep***, Anx*, NMeds**,
  - PreCGAS***, ADHD**, Agg**, SIB**
  - IQ***, SIB***, NMeds***, ADHD***, ASD**, Agg**
  - Agg**
  - Anx*
  - -

*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, Choral 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\(^{nd}\) 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°, 2° & 3° treatments, drugs for different symptoms, or neurotransmitter theory.
3. 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
Psychiatric Disorder in ID: differences from the Literature

• 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
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; (ASPECT)
- 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%
  • Eneuresis, 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)
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 “clinical experience and consensus”
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

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

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

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

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.
Treatment Effectiveness in Intellectual & Developmental Disabilities

Levels of Evidence

- Systematic review
- RCT (Randomised Controlled Trial)
- Controlled Study
- Case Series
- Consensus
- Literature Review
- Expert Opinion
- Sales info

Levels of Evidence

- SI: Safety Intervention, incl room modification, CPI
- SPS: Specialised Parenting Skills
- BT: Behaviour Therapy; incl carer/staff training
- PMed: Psychotropic Medication
- SE: Special Education: skills to match needs
- CBT: Cognitive Beh Therapy
- DE: Developmental Enhancing Intervention
- EC: EBSST/Emotional Coaching
- SST: Social Skills Training
- FT: Family & Systems Therapy
- D: Diet
- AT: Alternative Therapy
- CA: Chelating agents, Oxygen Therapy
- SC: Stem Cell Therapy

Direction of effect in more severe disturbance:
- Rapid effect: days to weeks
- Intermediate Effect: weeks to months
- Slow long term effects: months to years

(The opposite generally applies for milder problems)

Confidence in effect
Likelihood & size for Emotional & Behaviour Disturbance

- High
- Low

- Not approved by DCP
Conclusion

• The mental health of children & adolescents is in a parlous state
• Vulnerable population
• Lack of research and research funding
• Complexity and relies of clinical consensus
• Lack of support for clinical specialty skills
• Rates of murder suicide and M/S ideation reminds us that they are at risk of slipping between the service structures

References in the Journal of MH for C&A with IDD. www.schoollink.chw.edu.au
What will the NDIS do for subspecialty expertise and the multidisciplinary services for complex mental health problems of young people with intellectual disability? Implications from the Centre for Disability Study’s review of the Developmental Psychiatry Clinic. Vol 6(1)
The Developmental Psychiatry Clinic: the assessment process. Vol 6(2)
Violence in children and adolescents with an intellectual disability and the importance of safety. Vol 7(1)