Children & young People with 
Intellectual Disability & Mental Health Challenges: Recent Developments

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What are developmental disorders?

- Early onset
- Long-term
- Frequently multiple
- Interferences in normally fluent skill acquisitions
- Necessary for maximisation of potential and quality of life
- Producing adverse physical & psychological functional consequences
- & multiple social adversities & social disadvantage
Developmental Disorders

- Intellectual Disability
- Autistic Spectrum Disorders
- Attention Deficit Hyperactivity Disorders
- Specific Developmental Disorders
- Behavioural Phenotypes
Intellectual Disabilities & Autism Spectrum Conditions:

- are developmental disabilities

- are not psychiatric disorders

- But they predispose individuals to mental health problems for a variety of biological, psychological, educational and social reasons
Causes of developmental disorders can be

- Infective e.g. rubella
- Toxic e.g. fetal alcohol
- Psychosocial e.g. deprivation, abuse & neglect
- Unknown cause
- Often genetic
Multifactorial Inheritance: intelligence
Intellectual Disability

- General level of intellectual functioning
  - Within the lowest 2-3% of the population
  - IQ less than approximately 70
- Significant impairments in adaptive behaviours and life skills
  - Self-care
  - Self-occupancy
  - Self-sufficiency
  - Self-determination
  - Safety
DSM-5 Intellectual Disability

- Impairments of general mental abilities that impact adaptive functioning & determine how well everyday tasks are coped with: 3 domains

- **Conceptual** domain: language, reading, writing, maths, reasoning, knowledge, memory

- **Social** domain: empathy, social judgement, interpersonal communication skills, making & retaining friendships

- **Practical** domain: personal care, job responsibilities, money, recreation, organising school & work tasks

- Diagnosis based on severity of deficits in adaptive functioning
Diagnosable Psychiatric Disorder with Significant Functional Impairment in Young People

- General population 7%
- Physical Impairment 11%
- Impaired brain functioning 33%
- “Severe learning difficulties” 50%
- Deprivation & disadvantage doubles the percentages
Autistic Spectrum Disorder

A.D.H.D.

Intellectual disability
**Autism Core & Other Diagnostic Criteria:**

- Impairments in **reciprocal social interaction**
- Impairments in **language & communication**
  - Receptive & expressive
  - Verbal & non-verbal
- Repetitive & stereotypic behaviours & interests
  - Gross motor
  - Abnormal sensory experiences
  - Abnormal obsessional interests
  - Insistence on routine & sameness
- Lack of **imaginary & symbolic skills**
- Multiple **sensory sensitivities**: fascinations, aversions
- Gross & fine motor coordination difficulties
DSM-5 Autism Spectrum Disorder

- Single diagnostic term
- Communication deficits
  - Receptive & expressive
  - Verbal & non-verbal
- Social impairments
- Obsessional interests, behaviours, routines & insistence on sameness
- Features from early childhood even if not recognised until later
Psychiatric Comorbidities

- 70% of individuals who have an autism spectrum condition also have a psychiatric disorder
- Children: social anxiety, ADHD, ODD
- Adolescents: mood disorders
- Females:
  - Shyness, social anxiety, social withdrawal, social immaturity, socially impressionable & vulnerable
  - Appetite & sleep disturbance
  - Language & communication anomalies
  - Obsessionality
Association Between Intellectual Disability & Autism

- 70% of children with ASD have a non verbal IQ below 70
- 50% of children with ASD have a non verbal IQ below 50
- Only 5% of children with ASD have an IQ above 100 (high functioning autism)
- Degree of intellectual disability related to likelihood of having ASD & severity of autistic features
- Up to 50% of individuals with “severe learning difficulties” have an autistic spectrum disorder
Prevalence: how common?

Intellectual Disability
- Mild: 2-3%
- Moderate-to-profound: 0.5%

ADHD/HKD:
- DSM: 3-5%
- ICD (ADHD combined type): 0.5-1%

Autistic Spectrum Disorders: 1-2%
Self-injury may be a presenting feature of

- **Lesch-Nyhan syndrome**
  - Knuckle gnawing, hand biting, lip biting
- **Cornelia de Lange syndrome**
  - Lip biting, head banging
- **Fragile X syndrome**
  - Hand biting over base of thumb in response to ↑ arousal
- **Prader-Willi syndrome**
  - Skin picking & scratching, impulsive tantrums, over-eating
- **Smith-Magenis syndrome**
  - Head banging, nail pulling
Rationale for Service:

- Emotional & behavioural difficulties are greatest challenges for carers

- Severity & frequency of above related to:
  - Degree of intellectual impairment
  - Prognosis
  - Quality of life
  - Dependency
  - Familial disharmony & fragmentation
How do Mental Health Problems Present in Children with Intellectual Disability?

- Just the same as in children with more average intellectual functioning (beware “diagnostic overshadowing”)
- Diagnosis complicated by frequent communication difficulties & having to adjust for mental age
- Social, communicatory, ritualistic & obsessionial impairments
- Overactivity, attentional deficits
- Aggression
- Self-injurious behaviour
- Cyclical mood & behaviour changes
Contributors to psychological difficulties in children & young people with developmental disabilities

- Severity of intellectual disability
- Social factors
  - Abuse, neglect & stigmatisation
  - Schooling issues
  - Poverty
  - Parental psychiatric disorder
  - Transgenerational social disadvantage
  - Bereavement
  - Life events, daily hassles, PTSD
  - Migration
- Cause of developmental disability
- Presence of autistic spectrum disorder
Isle of Wight Study:

- Michael Rutter, Philip Graham & Bill Yule
- A neuropsychiatric study of childhood
- First scientific survey of natures, associations & frequencies of mental health challenges in children & young people
- Two determining factors in likelihood & complexity of mental health challenges
  - Level of intellectual ability
  - Psychosocial environment
BUT...cause is important

**Behavioural Phenotype: Definition**

aspects of an individual’s psychiatric, psychological, cognitive, emotional & behavioural functioning which can be attributed to an underlying, discrete, usually biological (including genetic) abnormality which has occurred early in development
Down Syndrome: current understanding

- intellectual disability
- characteristic personality & temperament
- relatively low rates of autistic spectrum disorders & attention deficit disorders in childhood
- depression
- Alzheimer disease
Fragile X Syndrome: Intellectual functioning

- usually mild to moderate intellectual disability
- verbal/performance discrepancy
- characteristic developmental trajectory
Fragile X Syndrome: Social impairments (Turk & Graham, 1997)

- social anxiety
- aversion to eye contact
- self-injury, usually hand biting in response to anxiety or excitement
- delayed imitative and symbolic play
- stereotyped & repetitive behaviours
Fragile X Syndrome & Autism: (Cornish, Turk & Levitas: 2007)

- 4-6% of people with autism have fragile X syndrome

- a substantial minority of people with fragile X syndrome have autism (29%)

- many more people with fragile X syndrome have a characteristic profile of communicatory and stereotypic “autistic-like” behaviours
Distinguishing Behaviours:

- delayed echolalia
- repetitive speech
- hand flapping
- gaze aversion
- good understanding of facial expression
  - *(Turk & Cornish, 1998)*
- Theory of mind as expected for general levels of ability *(Garner, Callias & Turk 1999)*
- friendly and sociable but may be shy
Fetal Alcohol Spectrum Disorder (Alcohol Related Neurodevelopmental Disorder)

- Most common major toxin to which fetus is exposed
- Pre & post-natal growth deficiency
- IQ in Mild Intellectual Disability/borderline IQ range
- Fine motor & visuospatial problems, tremulousness
- Executive function, numeracy & abstraction problems
- Expressive & receptive language difficulties
- Irritability in infancy, anxiety states
- Problems perceiving social cues
- Autism Spectrum Conditions
- Potentially catastrophic ADHD: any of the 3 types
- Very unstable family environments
Cerebral Palsy

- Psychiatric disorder in 40%
- No gender predominance for boys
- Hemiplegia:
  - 25% conduct/emotional disorder
  - 10% hyperkinetic disorder
  - 3% autistic disorder
- Best predictor = low IQ
- Disorders manifest identically to those of psychosocial origin
Social Aetiologies

(Emerson 2006)

- Mental health is socially determined
- Socio-economic position strongly associated with:
  - Child mortality
  - Adverse birth outcomes
  - Child physical health
  - Child mental health
  - Educational attainment
  - Life experiences & opportunities
- Poverty associated with mental disorder
Helping with intellectual disabilities & autistic features #1

- The right educational setting & input; advocacy role of clinician
- Social & language skills groups
- Cognitive-behavioural approaches
  - social functioning
  - perspective & turn taking
  - stop & think
  - anger management
  - emotion recognition
  - obsessions & rituals
Helping with intellectual disabilities 
& autistic features #2

- Speech & language therapy
  - social use of language
  - semantic & pragmatic aspects
- Occupational therapy: motor coordination & sensory issues
- Occasional judicious use of low-dose medication
- Social welfare, advocacy & activism
Evidence-based psychological therapies

- Functional analysis, analogue ratings & behaviour modification for challenging behaviours
- Cognitive-behavioural psychotherapies for depression
- “Webster-Stratton” & other group approaches for conduct disorders
- Behavioural programmes for sleep disorders
- Systemic family therapy for pre-adolescent eating disorders & psychosomatic disorders
Evidence-based pharmacological therapies

- Psychostimulants, tricyclics & clonidine for hyperactivity & attentional deficits
- "SSRI's" for depression, anxiety & obsessive-compulsive features
- Anticonvulsants for cyclical (& not so cyclical) mood & behaviour disorders
- Melatonin for sleep induction problems
- Clonidine for sleep maintenance problems
- Atypical antipsychotics for early onset psychosis
- ? Atypical antipsychotics for social impairments
Clonidine *(Ingrassia & Turk, 2005)*

- $\alpha_2A$ noradrenergic receptor agonist
- Good for anxiety, overactivity, impulsiveness, inattentiveness & other features of ADHD
- Mildly sedating, mildly hypnotic, facilitates sleep
- Good for tics & Tourette’s
- No effect on appetite
- Can reduce blood pressure
- 25-300 $\mu$g daily in divided doses
Melatonin (Turk, 2003; Turk, 2010)

- Pineal indole
- Diurnal secretion variation in response to light levels
- Beneficial, short-term, rapid-onset & safe treatment for intractable sleep disturbance
- Therapeutic dose not predicted by:
  - severity of sleep disturbance
  - severity of intellectual disability
  - presence/absence of autism
- Habituation common but not universal
- Psychological, behavioural, educational, family & social interventions essential
- No obvious short-term adverse effects; long-term safety unclear
Carbamazepine, Sodium Valproate & Lamotrigine *(Turk, 2012)*

- Anticonvulsants
- Well established, generally well tolerated
- Usually non-sedating, usually no effect on appetite
- Mood stabilisers for serious cyclical mood disorders
- Can be a good mood & behaviour stabilisers in cyclical & not-so-cyclical challenging behaviours in children & young people
- Initial anecdotal reports of enhanced social & language functioning, sleep & attentional skills
MEDICATION USE FOR YOUNG PEOPLE WITH & WITHOUT INTELLECTUAL DISABILITY WHO HAVE ADHD

(Osunsanmi & Turk, 2014)

- ADHD more common in those with intellectual disability than in those with average cognitive functioning; but more difficult to diagnose
- Combination of intellectual disability and ADHD → ↑ likelihood of residential education
- Non-stimulant medication more commonly used than stimulants in younger children with ADHD & intellectual disability
- Other medications more often co-prescribed in this group, e.g. sleep enhances, mood and behaviour stabilisers, antipsychotics
- Adverse medication effects more common on those with intellectual disability – but lower doses often beneficial
Evidence-based educational interventions

- Structured & focussed programmes for autism spectrum disorders e.g. TEACCH
- Applied Behavioural Analysis approaches
- Developmentally based skill acquisition programmes
- ADHD
  - Stop, think, do, reflect
  - 1, 2, 3 magic
  - Traffic light systems
Positive Prognostic Features

- Level of intellectual functioning
- Presence of social awareness
- Presence of meaningful language
- Presence of attentional skills
- Warm, nurturing & structured family environment
- Developmentally appropriate, focussed & structured schooling
- Progress to date
Assessment Scale Comparisons (Ezer & Turk, 2013)

- Children’s Global Assessment Scale (CGAS)
- Developmental Behaviour Checklist (DBC)
- Quality of Life Questionnaire (KINDL-R)
Eating Disorders & Autism Spectrum Conditions
(Huke, Turk, Saeideh, Kent & Morgan 2013, 2014)

- 22 adult females recruited from specialist services
- Features of ASC and disordered eating measured
- Premature termination of treatment (PTT) was recorded to explore whether ASD traits had impact on early discharge
- Healthy control group (HC) was recruited to investigate ASD traits between clinical and non-clinical samples
Eating Disorders & Autism Spectrum Conditions

(Huke, Turk, Saeideh, Kent & Morgan 2013, 2014)

- Statistically significant positive relationship between disordered eating severity and ASC traits
- No significant effect was found between ASC features and treatment completion
- All participants with high features of ASC completed treatment as planned compared to 56% of those with low ASC traits: enhanced treatment adherence in ASC
- Adverse effect of ASC on disordered eating severity.
Eating Disorders & Autism Spectrum Conditions

(Huke, Turk, Saeideh, Kent & Morgan 2013, 2014),

- Autism spectrum conditions over-represented in female eating disorder populations

- ASC traits associated with
  - enhanced therapeutic programme compliance
  - Reduced treatment drop-out
  - Worse prognosis
Childhood Onset Neuropsychiatric Disorders (CONDs) in Adult Eating Disorder Patients (Wentz, Lacey, Waller, Rastam, Turk & Gillberg 2005)

- 30 females from specialist hospital clinic with longstanding eating disorders
- Examined on measures tapping in to COND & personality disorders
  - 53% had at least one COND diagnosis
  - 23% had an ASC
  - 17% had an ADHD
  - 27% had a tic disorder
- Suggests COND may be common in females with severe & longstanding eating disorders
Mental Health Problems in Children & Young People with Developmental Disabilities

- Are common
- Are frequently severe, multiple & challenging
- Often present in different ways from usual e.g. aggression, self-injury, chaotic disruptive & destructive hyperactivity, repetitive stereotypic behaviours, obsessions, passive resistance
- Create substantial morbidity for family
- Have substantial economic cost
- Are treatable