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

Jeremy Turk

Institute of Psychiatry, King's College, University of London

Southwark Child & Adolescent Mental Health, Neurodevelopmental Service, Sunshine House, South London & Maudsley NHS Foundation Trust

Great Ormond Street Hospitals NHS Foundation Trust

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

Developmental Disorders

- Intellectual Disability
- Autistic Spectrum Disorders
- Attention Deficit Hyperactivity Disorders
- Specific Developmental Disorders
- Behavioural Phenotypes

St George's University of London

KING'S College LONDON University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

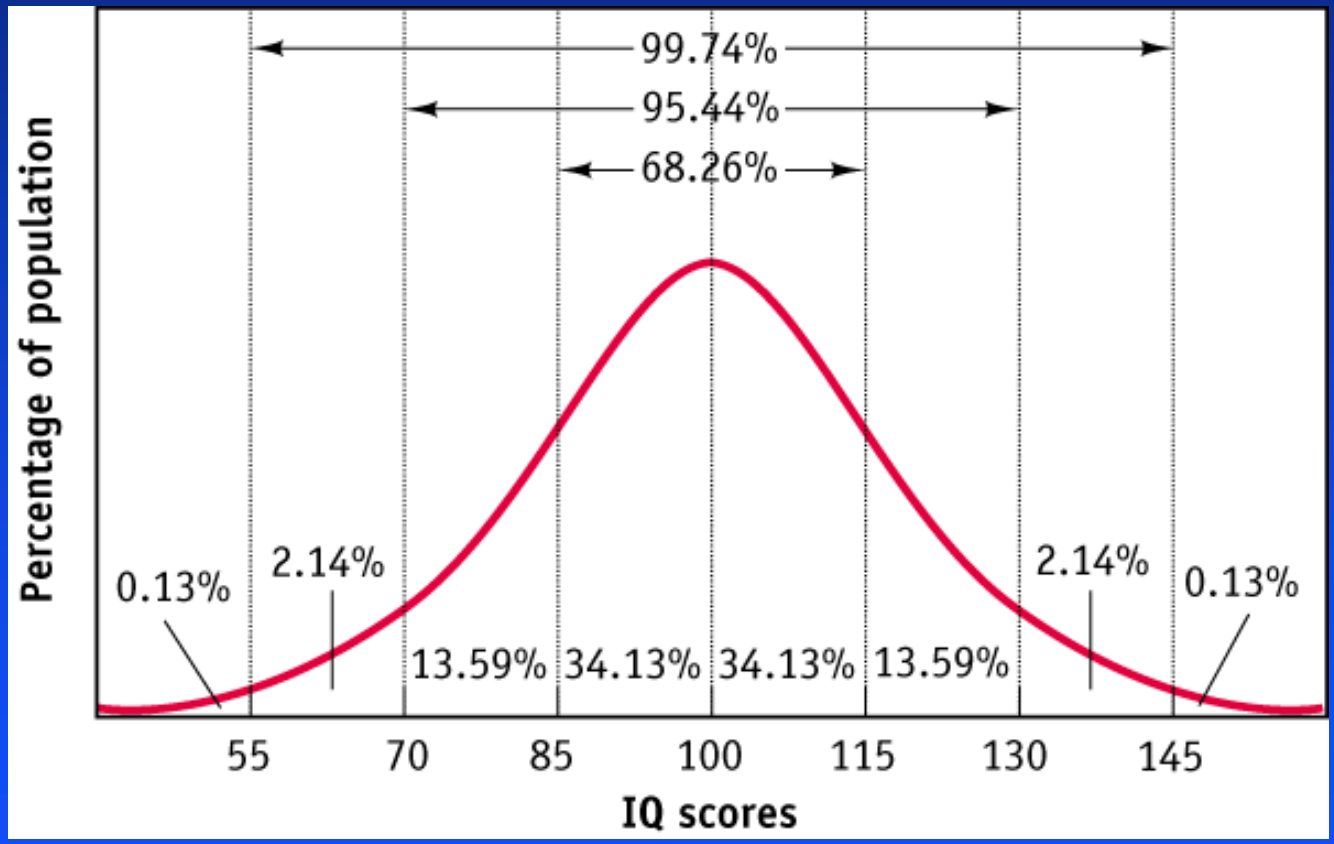
KING'S College LONDON University of London

South London and Maudsley NHS NHS Foundation Trust

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



St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

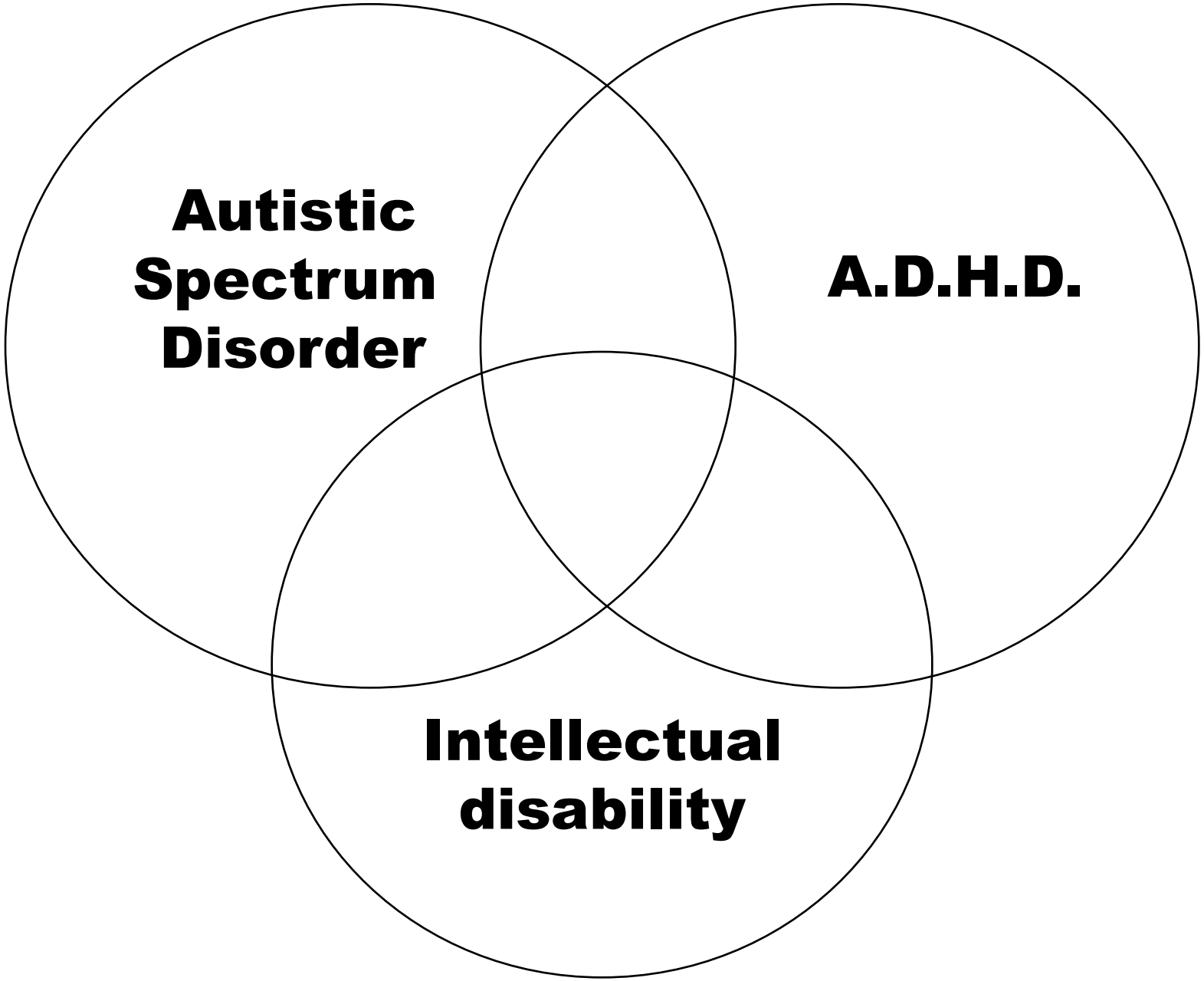
St George's University of London

KING'S College LONDON University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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%

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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 & obsessional 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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

Isle of Wight Study:

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

St George's University of London

KING'S College LONDON University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

Down Syndrome: current understanding

- intellectual disability
- characteristic personality & temperament
- relatively low rates of autistic spectrum disorders & attention deficit disorders in childhood
- depression
- Alzheimer disease

St George's University of London

KING'S College LONDON
University of London

South London and Maudsley NHS
NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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

St George's University of London

South West London and St George's NHS Mental Health NHS Trust

Clonidine *(Ingrassia & Turk, 2005)*

- α2A 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 µg daily in divided doses

St George's University of London

South West London and St George's NHS Mental Health NHS Trust

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

St George's University of London

South West London and St George's NHS Mental Health NHS Trust

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

St George's University of London

South West London and St George's NHS Mental Health NHS Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS
NHS Foundation Trust

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

St George's University of London

King's College London University of London

South London and Maudsley NHS NHS Foundation Trust

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