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Intellectual Disability: Information for Psychiatry Residents

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Summary: Intellectual disability is a chronic developmental condition (previously known as mental retardation in the DSM-IV) which impacts a person's adaptive functioning in conceptual, social and practical domains. Individuals with ID are at higher risk of presenting to psychiatrists with mental health and behavioural difficulties. Identifying individuals with ID as well as their severity is important, as they require different levels of support to reach their full potential.

Case

You are asked to see a 10-yo with intellectual disability (ID) due to problems with aggression at home and school. His aggression includes swearing, kicking others. Triggers include sensory issues, as well as teachers trying to ask him to follow the school routine. Unfortunately, his aggression is so severe that he is at risk of being suspended from school, which will cause extreme hardship to his mother, as she will then be at risk of losing her job.
What are you going to do?

What is Intellectual Disability?

Intellectual disability (ID) is a chronic developmental disorder, with onset in the developmental period (i.e. before age 18), with impairment of general mental abilities which impacts adaptive functioning in three domains:

1. Conceptual domain, which includes skills such as:
    - Language
    - Reading
    - Writing
    - Math
    - Reasoning
    - Knowledge
    - Memory
2. Social domain, which are social and interpersonal skills such as:
    - Empathy
    - Social judgment
    - Communication skills
    - Ability to make and retain friendships
3. Practical domain, the ability to self-manage in areas such as:
    - Personal care, health and safety

    - Ability to function at school or work
    - Manage money and finances
    - Recreation and leisure

Impairment of mental abilities is defined as significantly below, i.e. 2 standard deviations below the population, which means an IQ score of 70 or below.

Terms

There is variation in terms across the Western world:

- Australia:
    - Intellectual disability
- North America:
    - With the DSM-5, the term is now Intellectual disability (or intellectual developmental disorder).
    - With the DSM-IV, the previously used term was mental retardation.
- UK:
    - *Learning* disabilities.

Developmental disability

- Refers to various developmental disabilities, which includes intellectual disability as well as autism spectrum disorders and other developmental disorders.

Red Flags

Infants with language delays

- No words by 12-months
- No 2-word phrases by age 2
- Parents concerned the child is deaf

Toddler with motor delays

- Delays in self-feeding, toileting, dressing
- Troubles with comprehension

Clinical Presentation

Borderline intellectual functioning

- If symptoms are not identified while in school, they may even remain unidentified as adults.

Mild ID

- Delays may not be noted in preschool years, but rather in school age.

Severe or profound ID

- Significant delays in motor, language and social milestones may be noted earlier on such as within first 2-years of life

Individuals with intellectual disability (ID) may have difficulty in numerous domains:

• Speech	Delayed language and difficulties speaking and expressing themselves

• Perception	Difficulties with perceiving the environment, contributed to by sensory and processing issues.
• Cognition	Impaired ability to understand and problem-solve.
• Concentration	Impaired concentration
• Emotions	May have problems with emotion development, as well as emotional control.
• Coordination	May have problems with poor coordination; stereotyped movements.
• Behaviours	May have aggression. Many factors such as lack of communication skills, ability to problem-solve, sensory issues may contribute to disruptive and aggressive behaviors.
• Social and interpersonal	Tend to be gullible and naive, as they have troubles identifying risky situations due to their limitations in everyday reasoning and social judgment. Higher risk of being taken advantage by others which includes: • Childhood abuse and trauma; • Bullying in school; • More serious exploitation in adulthood.

Presentation to Psychiatry

As a psychiatrist, you may encounter individuals with ID in various ways:

- The diagnosis has already been made and they have been referred to you for mental health issues (e.g. depression, anxiety) and/or behavioural issues.
- You are seeing a child/youth or adult for mental health issues, and you suspect they may have ID.

Epidemiology

Prevalence of intellectual disability

- 1% of the population

Gender

- Males > females (due to sex-linked genetic factors; male vulnerability to brain insult)
    - Mild ID M:F = 1.6 : 1
    - Severe ID M:F = 1.2 : 1

Etiology

There are many different causes of intellectual disability which include:

- Known causes 60% (Curry, 1997)
- Idiopathic (no specific known cause) 40% (Curry, 1997)

Known Causes

Prenatal (before birth)

Chromosomal disorders	Down’s Syndrome Fragile X syndrome Prader Willi syndrome Klinefelter’s syndrome

Single gene disorders	Inborn errors of metabolism Phenylketonuria Hypothyroidism Tay-Sachs
Other genetic conditions	Cornelia de Lange
Adverse environmental influences	Maternal infections such as rubella, syphilis, toxoplasmosis, cytomegalovirus, HIV Exposure to alcohol, drugs, toxins Maternal disease (e.g. diabetes)

Perinatal (around the time of birth)

Third Trimester	Complications of pregnancy Diseases in mother (e.g. diabetes) Placental disease
Labour (during delivery)	Labor/delivery-related events leading to neonatal encephalopathy Complications of prematurity: ischemia, hypoxia, intra cerebral hemorrhage
Neonatal (first four weeks of life)	Septicemia, jaundice, hypoglycemia

Postnatal causes

Infections	Infections (such as meningitis, whooping cough or measles)
Trauma	Head injury
Toxins	Heavy metals such as **lead**, mercury
Nutritional	Prolonged malnutrition
Abuse and trauma	Severe and chronic social deprivation

Screening

Screen a child’s development at regular intervals (American Academy of Pediatrics), such as by using parental surveys:

- Parents' Evaluation of Developmental Status (PEDS),
- Ages and Stages Questionnaires (ASQ)
- Child Development Inventories (CDI).

Diagnostic Measures

Psychologists may use common psychological tests such as:

- Bayley Scales of Infant Development-III,
- Stanford-Binet Intelligence Scale,
- Wechsler Intelligence Scale for Children-IV,
- Wechsler Preschool and Primary Scale of Intelligence-Revised,

- Vineland Adaptive Behavior Scales-Second Edition (Vineland-II)
    - The “Vineland” is designed to measure adaptive behavior of individuals from birth to age 90.
    - Contains 5 domains
        - Communication
            - Receptive: How the individual listens and pays attention and what he or she

understands.
- Expressive: What the individual says, how he or she uses words and sentences to gather and provide information.
- Written: What the individual understands about how letters make words, and what he or she reads and writes.

- Daily Living Skills
  - Personal: How the individual eats, dresses, and practices personal hygiene.
  - Domestic: What household tasks the individual performs.
  - Community: How the individual uses time, money, the telephone, the computer, and job skills.
- Socialization
  - Interpersonal Relationships: How the individual interacts with others.
  - Play and Leisure Time: How the individual plays and uses leisure time.
  - Coping skills: How the individual demonstrates responsibility and sensitivity to others.
- Motor Skills
  - Gross Motor: How the individual uses arms and legs for movement and coordin
  - Fine Motor: How the individual uses hands and fingers to manipulate objects.
- Maladaptive Behaviour (optional)
  - Any internalizing, Externalizing and other types of undesirable behavior that may interfere with the individual's adaptive functioning.

- Adaptive Behavior Composite: A composite of the communication, daily living skills, socialization, and motor skills domains.

Assessment / History of the Person with known (or suspected) ID

Ensure your physical space is safe, such as being mindful of sensory needs:

- Reduce visual overstimulation, e.g. keep waiting rooms tidy, try to avoid harsh fluorescent lighting; dim lights if possible; allow patient to wear baseball cap, hoodies, etc.
- Reduce auditory overstimulation, e.g. don't have background radio in the waiting room.
- Consider booking individuals with ID during quieter periods, e.g. first or last appointment of the morning/afternoon.

Communication recommendations (Kelly, 2011; Sullivan, 2018):

- Is it an older youth or adult with ID?
  - Explain to caregivers that you will address patients directly (as opposed to simply turning to their caregivers) AND that you also want caregivers' input as well.
- Is it a child with ID?
  - Address caregivers primarily, in the same way as you would with other children AND ask the child for input when appropriate (e.g. asking about their thoughts/feelings, sensory issues, triggers and stresses) as well as meeting alone (when screening for neglect / abuse).
- Engage the patient, e.g. around a preferred item that has been brought to the appointment; their clothing; ask about interests.
- Communication aids used by those with ID may include
  - Signing (such as American Sign Language)
  - Picture exchange communication systems (such as on tablet device)

A comprehensive assessment would include the following:

- Concerns
  - What are the main issues that are stressful, difficult, or troubling?
  - Any behaviours that are challenging for caregivers? (aka behaviours that challenge (BTC))?

- Goals

    - What are the patient’s best hopes from the visit? (if patient is able to articulate, such as with those with mild ID)
    - What are the caregiver's best hopes from the visit?

- Current services and supports
- Any stressful life events?
    - E.g. abuse, neglect, bullying, exclusion.
- Medication history
    - Review medications regularly (eg, every 3 mo), including the indication, when started / stopped, effectiveness, and any side effects (Sullivan, 2018)
- Caregiver needs (Sullivan, 2018)
    - Ask caregivers about how they are coping, and if they have any particular needs.

- Psychiatric review of symptoms including
    - Neurovegetative symptoms, e.g. sleep, energy, concentration, appetite.
    - Screening for abuse/trauma: Meet alone with the individual with IDD to screen for abuse, exploitation or neglect (Sullivan, 2018)

- School / Workplace history
    - What schools were attended in the past? Were these mainstream, or in a specific program?
    - With adults: What work/ employment in the past?

- Pregnancy history

- Birth history

- Developmental history
    - Language development
    - Sensory processing
    - Motor skills
    - Socialization
        - Any troubles with social skills
- Family medical history
    - Genetic conditions?
    - Mother
        - Infections during pregnancy?
        - Any possibility of prenatal exposure to toxins?
        - Any consanguinity?
        - Fetal loss
    - Premature?

Physical Examination

As a psychiatrist, either perform, or ensure that there is a primary care provider who can provide physical examinations as necessary.

General observations	Child’s ability to communicate, social skills, eye contact, compliance, attention span, impulsivity, and style of play. Dysmorphic facies? Consider flat, broad face of Down syndrome. Obesity? Consider suggest Prader Willi Any signs of abuse? E.g. unexplained injuries, bruises; choke marks around the neck; human bite marks, cigarette burns, unusual fractures

Height	Short stature? • May suggest genetic disorder (e.g. Turner syndrome in females), fetal alcohol syndrome, or hypothyroidism. Tall stature? • May suggest fragile X syndrome (FraX), or overgrowth syndrome associated with ID.
Weight	Monitor regularly, including body mass index, waist circumference (Sullivan, 2018)
Head and Neck	Assess vision (e.g. Snellen eye chart) Assess hearing (e.g. whisper test) (Sullivan, 2018)
Head circumference	Microcephaly? • Correlates highly with cognitive deficits. Macrocephaly? • Associated with hydrocephalus; some inborn errors of metabolism]
Cardiac	Any murmurs?
Respiratory	Any wheezing (i.e. suggestive of asthma) Any respiratory infections?
Abdomen	Any hard lumpy abdomen suggesting constipation
Neurologic	Any problems with gait/ coordination? Tics / tremors? Muscle tone: Low tone (i.e. Hypotonia) or spasticity? Any neurologic deficits? Strength and coordination Deep tendon reflexes Persistent primitive reflexes? Ataxia Abnormal movements such as dystonia or athetosis?
Dermatologic	Hyperpigmented and hypopigmented macules? • May suggest café-au-lait macules (associated with neurofibromatosis type 1) • Ash-leaf spots (associated with tuberous sclerosis), fibromas
MSK	Any discomfort with limb movement, suggesting injuries or joint issues Any pressure sores? Any injuries from self-injurious behaviours?

Mental Status Examination (MSE)

Appearance	Including hygiene, grooming, clothing and overall health status Any signs of abuse/neglect?
Behaviour	Including stereotyped behaviours, involuntary movements, self-injury
Mood / affect	Any change in patient’s mood/affect from their usual baseline mood?
Speech	Level of speech, lack of speech, level of understanding, screaming or shouting
Cognition	If formal testing for cognition and IQ has not been performed, try to estimate level of intellectual disability

Estimating Intellectual Disability Based on Level of Function

Mild ID	Can usually hold conversation with interviewer Can usually achieve independence with self-care, activities of daily living Troubles with academics, but capable of independent work

Moderate ID	Usually need assistance with interview from caregiver Usually need supervision with self-care May have basic reading, writing or counting skills Can do tasks with supervision and engage in activities
Severe ID	Limited ability to communicate, requiring caregiver Needs supervision with self-care Commonly has physical issues such as epilepsy
Profound ID	Severely limited ability to communicate, requiring caregiver May have physical issues such as problems with mobility, seizure disorder, incontinence

Spectrum of Intellectual Function

Intellectual Disability	←	Borderline intellectual functioning	→	Normal IQ
1% of the population		7% of the population		Majority of the population
IQ 50-55 to 70 (or below)		IQ 71-85		
		Still face significant challenges compared to those with “normal” IQ. May perform daily activities and work without assistance but are more vulnerable to stressful life events and mental health concerns.		

DSM-5 Intellectual Disabilities

DSM-5 Intellectual Disabilities are the following:

1. Intellectual disability (aka intellectual developmental disorder)

- Previously known as mental retardation in DSM-IV

2. Global developmental delay (GDD)

- The term GDD is used when a person is < 5 years of age and has significant deficits in learning and function, however reliable (IQ testing) assessment is not possible
- GDD requires reassessment after a period of time (DSM-5)
- A child with GDD will not necessarily test in the ID range when older.

3. Unspecified intellectual disability (ID)

- The term “Unspecified ID” is used when a person is > 5 years age, and reliable assessment is not possible.

DSM-5 Intellectual Disability (Intellectual Developmental Disorder)

DSM-5 Criteria for ID

A. Deficits in intellectual function

- Deficits (reasoning, problem- solving, planning, abstract thinking etc) confirmed by clinical assessment and individual standardized testing (IQ: 70 ± 5).

B. Deficits in adaptive function

- The person's intellectual deficits lead to deficits in adaptive function, i.e the person is unable to meet socio-cultural standards for activities in daily life (at home, school, work, community) without ongoing support.

C. Age of onset is during the developmental period.

Note:

- A diagnosis of ID is not made only on basis of IQ score (i.e. IQ ≤ 70) -- it requires troubles with adaptive functioning as well.

Specifiers

- Severity for ID
  - Mild IQ 50-55 to 70
  - Moderate IQ 35-40 to 50-55
  - Severe IQ 20-25 to 35-40
  - Profound IQ < 20-25

Severity	Intellectual Function	Adaptive Function
Mild 85% of those with ID	IQ 50-70 Slower than typical in all developmental areas No unusual physical characteristics Able to learn practical life skills Attains reading and math skills up to grade levels 3-6	Able to blend in socially Functions in daily life
Moderate 10% those with ID	IQ 35-49 Noticeable developmental delays (i.e. speech, motor skills) May have physical signs of impairment (i.e. thick tongue) Can communicate in basic, simple ways Able to learn basic health and safety skills	Can complete self-care activities Can travel alone to nearby, familiar places People with moderate intellectual disability have fair communication skills, but cannot typically communicate on complex levels. May have difficulty in social situations and problems with social cues and judgment. Can care for themselves, but might need more instruction and support than the typical person. Many can live in independent situations, but some need the support of a group home.
Severe 3-4% of those with ID	IQ 20 to 34 Considerable delays in development Understands speech, but little ability to communicate Able to learn daily routines May learn very simple self-care Can only communicate on the most basic levels.	Needs direct supervision in social situations Cannot perform all self-care activities independently and need daily supervision and support. Most in this category cannot successfully live an independent life and will need to live in a group home setting.

Profound 1-2% of those with ID	IQ less than 20 Significant developmental delays in all areas Obvious physical and congenital abnormalities Extremely limited communication ability. May respond to physical and social activities	Requires close supervision; require 24/7 support and care. Requires attendant to help in self-care activities Not capable of independent living Depend on others for all aspects of day-to-day life Frequently have other physical limitations as well.

Differential Diagnosis of Intellectual Disability: DSM-5 Differential

• Communication disorders	Individuals who have troubles communicating may appear to have ID upon first meeting However, those with communication disorders alone do not show deficits in intellectual and adaptive behavior. Other individuals may have both ID plus communication disorder(s)
• Specific learning disorder (SLD)	Individuals with specific learning disorder will have problems in one area of learning, but normal learning in others. Do not show deficits in intellectual and adaptive behavior. Can co-occur with ID
• Autism spectrum disorder (ASD)	Are there troubles with social communication? E.g. is communication two way, or is it one way (i.e. impairment with reciprocal communication)? Are there restricted interests or activities?

Differential Diagnosis of Intellectual Disability: Medical Causes

Consider the following in those with otherwise unexplained developmental delay or intellectual disability:

Is there maternal history of alcohol consumption during pregnancy? Facial dysmorphisms? Neuropsychiatric problems such as problems with learning, language, ADHD symptoms, sensory issues?	Consider fetal alcohol spectrum disorder (FASD) For more information
Any of the following physical signs? • Decreased or poor muscle tone • Short neck, with excess skin at the back of the neck • Flattened facial profile and nose • Small head, ears, and mouth • Upward slanting eyes, often with a skin fold that comes out from the upper eyelid and covers the inner corner of the eye • White spots on the colored part of the eye (called Brushfield spots) • Wide, short hands with short fingers • A single, deep, crease across the palm of the hand • A deep groove between the first and second toes Any of the following cognitive or behavioural signs? • Troubles with attention, behaviour, learning, delayed language or speech?	Consider Down Syndrome For more information
Any of the following physical features? • Large head circumference, long face, prominent forehead, large ears, and prominent jaw. Any of the following medical issues? • Seizures (seen in 25% of those with Fragile X) Any of the following psychiatric symptoms? • Intellectual disability • Hyperactivity / ADHD, • Autistic behaviours, • Sensory problems, • Anxiety / social anxiety • Speech delays, or perseverative speech?	Consider Fragile X, the most common single-gene cause of hereditary mental retardation. For more information

Any of the following behaviours? • Extreme food seeking behaviours (Hyperphagia), Any of the following physical features? • Obesity, • Hypotonia • Small hands/feet • Short stature,scoliosis • Microorchidism (i.e. small testes in males) • Fair hair/light skin • Almond shaped eyes • Sleep apnea Any of the following psychiatric symptoms? • Obsessions and compulsions • Cognitive rigidity, i.e. stubborn, inflexible, needing sameness • Behavior problems: aggression, temper tantrums, emotional lability, daytime sleepiness	Consider Prader Willi
Any of the following? • Lower social activity, poor social coping skills, increased immaturity, • Hyperactivity/impulsivity • Higher anxiety, shyness, depression, lower self-esteem Any of the following physical features? • Short stature, • Webbed neck, • Cardiac abnormalities, • Thyroid disease, • Hearing loss. (heterogeneous) Any of the following cognitive features? • Generall normal intellectual function; • Verbal skills better than nonverbal skills; • Visuospatial deficits	Consider Turner Syndrome

Comorbidity

People with ID are at a higher risk of having numerous conditions (Oeseburg et al., 2011) such as:

Medical isssues

- Epilepsy (22%)
- Cerebral palsy (20%)
  - Alzheimer’s disease (particularly in those with Down Syndrome)

Psychiatric (and neuropsychiatric) conditions

• Anxiety disorder (17%)	Any problems with worrying too much?
• ADHD (9-18%)	Any problems paying attention? Any troubles acting before thinking?
• Autistic disorder (10%)	Any problems seeing things from other's perspectives?
• Depressive and bipolar disorders	Any problems with depressed mood?
• Anxiety disorders	Any problems with anxiety?
• Developmental coordination disorder (DCD)	Are there problems with fine motor skills? Gross motor skills?
• Sensory processing problems	Usually present with ASD, but can also co-occur with ADHD, learning disabilities, FASD and other conditions Can occur with multiple conditions Are there sensitivities to sensory input, e.g. auditory, tactile, olfactory, visual? Or abnormal responses to sensory input?

Investigations

Has a psychoeducational assessment been done, with full-scale IQ? • If not, then refer to psychology for psychoeducational assessment.		Psychoeducational Assessment
Does child have unexplained MR/DD, even in the ab-sence of dysmorphic facial features, other clinical features or positive family history." (Shaffer, 2005)		Psychoeducational assessment Refer to genetics (Shaffer, 2005)
Is there a possibility of metabolic condition?		Refer to pediatrics who can consider metabolic screening
Any structural differences noted, e.g. microcephaly, macrocephaly? Any neurologic symptoms (e.g. spasticity, ataxia, dystonia, seizures, loss of motor skills, abnormal reflexes)		Refer to neurology Consider neuroimaging
Is there possible seizure disorder?		Refer for EEG
Are there any medical issues suspected? (E.g. hypothyroidism)		Do testing as indicated

Management / Treatment

Psychoeducation

- When providing education to the individual with ID about conditions or other issues, use appropriate resources targeted for those with ID such as
    - Easy Health (from the UK) has a wide range of handouts on various topics including healthy living, as well as anxiety, depression, and autism. http://www.easyhealth.org.uk.

Education

- Attending school is essential for individuals with ID to learn academics as well as life skills; most school boards have specialized programs for those with ID.
- Recommendation
    - Liaise with the school.
    - Ensure that the student with ID has an IEP in place, as well as appropriate support, such as educational assistant (EA), or specialized classroom.
    - Those with mild ID tend to be integrated in the mainstream school setting, whereas those with severe ID will likely be in a specialized classroom.

Occupational therapy (OT) and physiotherapy (PT)

- Are there ongoing sensory / motor / self-regulation issues?
    - Occupational therapy (OT) can help, as well as with day-to-day function at home and school, such as life skills.
    - Physiotherapists (PT) can help with motor issues such as low muscle tone, problems with coordination.

Speech language therapy (SLP)

- Are there difficulties with communication?
    - SLP may help improve the ability to communicate (Wilkinson, 2007).

Service Navigation

- Ensure that the family is connected to community organizations that support those with intellectual disabilities (and their families), such as a case worker.

Healthy activities for a sense of connection, belonging and purpose

- Persons with ID may benefit from the usual activities for others such as sports and recreational activities; spiritual-based activities, etc.
- Persons with more severe ID may need more specific services geared to those with ID.

Family Support

- What are the family's needs?
    - Information / knowledge about the diagnosis, or related issues
    - Emotional support
    - Help with practical issues, e.g. finances
    - Peer support with other families?

Sleep Challenges

Are there problems with sleep?

- Start with sleep hygiene and behavioural strategies including limiting screen time 1-2 hrs before bedtime

Are there still problems with sleep?

- Consider melatonin, which has been specifically studied in people with autism and shown considerable benefit (Cortese, Wang, Angriman, Masi & Bruni, 2020)
- Note:
    - Off-label use of antipsychotics for sleep issues is common but unfortunately not evidence-based
    - The American Academy of Child & Adolescent Psychiatry (Findling, Drury, Jensen, Rapoport, & AACAP Committee on Quality Issues, 2011) recommends AGAINST the usage of antipsychotics for sleep.

Behaviours that Challenge (BTC)

Behaviours that challenge (BTC) (aka challenging behaviour) include:

- Self-injurious behaviour
- Anger, aggression, irritability
- Property destruction
- Pica

Assessment

- Understand what is beneath the challenging behaviour, as there may be many different causes for the behaviour such as:
    - Health related reasons, e.g. pain; constipation.
    - The person is sensory overloaded (e.g. too much sound)
    - The person is reacting to stressful life circumstances such as a loss or change (e.g. change in caregiver)
    - The person is aggressive because they do not yet have the skills to express their feelings or wishes in a more appropriate way, e.g. not yet able to express that they are frustrated, sad, angry, anxious.
    - Mental health related reason, e.g. depression, anxiety, adjustment problems

Management of challenging behaviour (CB)

- Address the underlying cause (rather than simply using positive/negative reinforcement strategy for the

behaviour)
    - Example
        - If the person is aggressive because they are constipated, it will be more effective deal with their constipation (as opposed to punish them for being aggressive).
- Consider referral to behaviorist if available
    - Behaviorists uses multiple interventions including
        - Functional assessment
        - Antecedent-behaviour-consequence (ABC) charts

- Are there challenging behaviours that persist despite exhausting non-medication strategies? Is the severity sufficient to warrant medication trial? (e.g. person at risk of losing their placement or housing, etc.)
    - Options
        - Second generation antipsychotics for problem behaviours (Snyder, 2002)
            - Note a lack of evidence for medications in ID, and thus, much evidence is extrapolated from studies in those with ASD.
            - Start low and go slow -- people with ID generally have more comorbid medical issues, and may be more sensitive to side effects
            - Antipsychotic medications appear to be effective in the short-term, though they carry significant side effects (McQuire C et al., 2015).
        - Is there comorbid ADHD?
            - Consider stimulant medication for ADHD
                - Evidence for the use of methylphenidate first-line for ADHD with comorbid ID -- note lower effect size than in children with ADHD and average intelligence (Arnold, 2013).
                - First-line
                    - Methylphenidate, given that
                        - More evidence for methylphenidate (than amphetamine) for ADHD in the context of ASD (Mahajan et al., 2012; Rodrigues et al. [in press]) and ID (Arnold, 2013)
                        - Methylphenidate is better tolerated (than amphetamine) in children and adolescents (Cortese et al., 2018)
                - Watch for paradoxical effects such as worsening behaviours, irritability and insomnia (DeFlllipis & Wagner, 2016)
        - Is there self-injurious behaviour?
            - Consider Naltrexone (Revia)
        - Are there mood/anxiety issues?
            - Consider SSRIs

Antipsychotic Medication Table for Adolescents and Adults

Medication	Dosage	Comments
Aripiprazole* (Abilify™)	Start 5-10 mg daily Target 5-30 mg daily	Felt to have less side effects (less metabolic effects, less prolactinemia) than other medications Some evidence suggests equivalent to Risperidone in irritability/aggression for autism (Lamberti et al., 2016)
Risperidone (Risperdal ™) • Tablets • Liquid	Start at 0.25-0.5 mg daily Target 1-4 mg daily	Risperidone dosage of 1-2 mg/daily shown to be most beneficial for irritability / aggression in children with autism (Lamberti et al., 2016).

Olanzapine (Zyprexa™) Olanzapine (Zydis ™) (rapid dissolve)	Start 2.5-5 mg daily Increase 2.5-5 mg daily in weekly intervals up to target dosage Initial therapeutic target 10 mg daily Max 20 mg daily	Compared to Risperidone, lower risk of motor side effects and elevated prolactin but higher risk of sedation and weight gain
Quetiapine IR (Seroquel™)	Adolescents/Adults Immediate-release tablet (IR): Day 1: 25 mg twice daily Day 2: 50 mg twice daily Day 3: 100 mg twice daily Day 4: 150 mg twice daily Day 5: 200 mg twice daily target dosage Usual dosage range: 200 to 400 mg twice daily Maximum daily dose: 800 mg/day.	Studies show no additional benefit was seen with 400 mg twice daily vs 200 mg twice daily.
Quetiapine XL (Seroquel XL)	Day 1: 50 mg once daily Day 2: 100 mg once daily Day 3: 200 mg daily Day 4: 300 mg daily Day 5: 400 mg once daily Usual dosage range: 400-800 mg once daily Max daily dose: 800 mg/day.	
Ziprasidone (Geodon™)	Adolescents/Adults Start 20 mg daily Target 20-160 mg daily	

NOTE:

- CAMESA Monitoring Guidelines recommend:
    - Height, weight, waist circumference, blood pressure
    - Bloodwork: fasting plasma glucose, insulin, total cholesterol, LDL, HDL, triglycerides, prolactin.
- Ideally, values are monitored at baseline, three months, six months, and every six months thereafter (Pringsheim, Panagiotopoulos, Davidson, Ho & CAMESA guideline group, 2011).

Capacity and Consent in Emerging Adults with Intellectual Disability

With children/youth with intellectual disabilities, ensure that informed consent is obtained for any interventions especially medications.

- Discuss risks, benefits, and alternative treatments with parents (and ideally, the child/youth is providing assent).

As children become youth and emerging adults however, they may make increasingly assert their autonomy and also decisions that their parents disagree with, e.g. a youth with intellectual disability who wants to stop taking necessary medications; who wants to date an older boyfriend and move out with him, etc.

For more information about capacity and consent in emerging adults with developmental disabilities

- Capacity and Consent As Your Child/Youth with Developmental Disabilities Becomes an Adult: Information for Parents
  https://docs.google.com/docume...

Outcome / Prognosis of Intellectual Disability

High mortality rates

- Individuals with severe/profound ID have higher mortality rates because of complications associated with physical disease.
- Accidental injury rates may be increased due to lack of awareness of risk/danger.
- There is increased risk for suicide, presumably because life is more challenging and difficult for them.

Victimization by others

- Gullibility and lack of awareness of risk may result in exploitation by others, victimization, fraud, unintentional criminal involvement, false confessions, risk for physical/sexual abuse.

Outcomes vary, depending on the severity of the intellectual disability. One estimate is the following:

	Mild	Moderate	Severe	Profound
IQ	50-55 to 70	35-40 to 50-55	20-25 to 35-40	<20 or 25
Age at death (years)	50s	50s	40s	About 20
% of population with ID	89%	7%	3%	1%
Academic level achieved by adulthood	Gr. 6	Gr. 2	Below Gr. 1	Below Gr. 1
Placement / residence	May be able to live in community with supports	Likely needs sheltered placement	Requires highly structured, supervised setting	Requires highly structured, supervised setting

Clinical Practice Guidelines

Shaffer L: American College of Medical Genetics guideline on the cytogenetic evaluation of the individual with developmental delay or mental retardation,
Nov/Dec 2005, Genetics in Medicine 7(9):650-654.
https://www.acmg.net/PDFLibrary/Developmental-Delay-Cytogenetic-Evaluation.pdf

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NOTE - these Practice Parameters are out of date, but are provided for historical information.
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Authors

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