PCP Handout

Caring for Persons with Intellectual Disability

Intellectual disability is a term used when there are limits to a person's ability to learn or process information at the expected level and function for age and daily life. While a significant proportion of those with ID may not have an identified etiology, the diagnosis warrants further evaluation, across genetic conditions (such as Fragile X) and metabolic disorders. By definition, ID should manifest prior to age 18, and can be caused by brain malformation, injury, infection, toxin or other problems within the brain. Estimated prevalence is 2.5-3.5% of adult population.

System	Information	Follow-up
Cognition	▪ By definition full scale IQ under 70-75 ▪ Eligible for SSI if adaptive function is limited ▪ Variable in ability to identify and explain illness or health symptoms ▪ May not disclose or present with the diagnosis	▪ Collect neuropsych (eg. IQ) prior results from school or health system ▪ Assess self-reporting ability, adapt to more comprehensive approach in review of systems ▪ Assess caregivers understanding of abilities
Nutrition	▪ Under and over nutrition, selective diet with increased risk of avitaminoses	▪ Obtain weight, BMI, dietary review ▪ Consider MVI use, check 25 –OH vit D or iron if dietary, sleep or menstrual issues
Cardio-vascular	▪ May struggle with typical history questions eg. palpitations, syncope, chest pain, swelling	▪ Routine screening BP and lipids ▪ Use exercise tolerance and activity history to estimate cardiopulmonary status
Pulmonary	▪ Higher aspiration risk related to eating behaviors and/or oropharynx hypotonia	▪ For individuals with hypotonia and dysarthria, increase suspicion for choking behaviors
GI	▪ Constipation and heartburn both common ▪ Risks of feeding too fast, cramming, inadequate chewing, rumination, pica	▪ Teach a long-term bowel program, including how to titrate treatments ▪ Assess any swallowing symptoms, throat clearing, preference of cup/straw, etc., pill swallowing
GU	▪ Overflow incontinence ▪ Underhydration, chronically or when ill	▪ Routine timed voiding reminders can prevent urinary accidents, for those insensitive to cues of full bladder ▪ Consider surveillance of fluid intake and urine concentration to help estimate hydrational state
Endocrine	▪ Puberty education gaps, need accommodations ▪ Menstrual issues with hygiene, emotions, cramping, contraception, cyclical flaring of condition such as seizures, migraines.	▪ Provide educational supports—hygiene reminders. ▪ Consider menstrual suppression options ▪ Consider rights to dignity in adult life, i.e. appropriate sexual education, freedom from victimization
Skin	▪ Higher rates of skin issues, eg. picking at insect bites, rashes, etc. ▪ Higher rate of difficulty or forgetting nail care	▪ Support routine skin care, distraction from picking, how to use lotion ▪ Surveillance re: general hygiene needs and nail care
Neurology	▪ Higher risk for seizures ▪ Higher risk for sleep disorders ▪ Loss of function with aging has a broad differential diagnosis	▪ Seek hx of abnormal neurological movements, spells ▪ Verify restorative nature of sleep Perform complete assessment when considering dementia diagnosis to rule out other possibilities.
Psych	▪ Increased rates of depression, anxiety ▪ Behavioral challenges can be treated too hastily with psychoactive meds, while due to occult physical issues, social/environmental issues, etc.	▪ Rely less on typical instruments, consider adapted PHQ9 / GAD7 for IDD, use clinical interview ▪ Screen for metabolic, physical, environmental issues prior to initiating psych meds.
Other	▪ All patients with ID do not require guardianship ▪ Caregiver training/respite needs ▪ Higher risks for abuse/neglect/victimization and/or social isolation ▪ Higher risk dental caries and poor teeth hygiene, occult vision or hearing issues	▪ Evaluate for appropriate decision making supports. ▪ Balance need for independence and supports, use services, eg. Medicaid BDS waivers, vocational rehab ▪ Screen for bullying, harassment, withholding of needed supports, community participation, etc. ▪ Verify engagement in routine dental, eye, audiology.

Reference: Sullivan WF, et al. Primary care of adults with IDD: 2018 Canadian consensus guidelines. *Can Fam Physician*. 2018 Apr;64(4):254-279.

Summary by CYACC: April 2025

Center for Youth and Adults with Conditions of Childhood (CYACC)