What is an intellectual and developmental disability?

- Intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18.

- American Association on Intellectual and Developmental Disabilities
- Developmental disability is a broader term that encompasses disabilities with onset before age 22 that may be purely physical in nature, such as cerebral palsy
- Intellectual and developmental disability (IDD) is now the preferred medical term for the group of disabilities previously diagnosed as mental retardation

Common Causes of Intellectual Disability

- Genetic Factors
- Prematurity & Prenatal Issues
- Birth Trauma & Injuries
- Environmental Factors

Us until the movement to deinstitutionalization of adults with IDD in the 1970’s and 1980’s, many individuals spent their entire lives in institutions, interacting minimally with the general population.

Cardinal Cushing Center

- Provides community-based supports for individuals with a broad spectrum of disabilities
- Staffs and runs over 120 group residential homes in Massachusetts and Rhode Island for adults with IDD
- Offers education and day programs along with an employment program to help individuals work in the community

CDDER

- Center for Developmental Disabilities Evaluation and Research
- Research on vulnerable patient populations to improve the services and supports provided to adults with IDD
- Provides evaluation and training to service agencies to help them better support and serve adults with IDD

MassMATCH

- REquipment Center
- Promotes the use of assistive technology services to empower people with disabilities to live more independent lives
- Recycling center for assistive mobility devices, such as wheelchairs

Seven Hills

- Provides community-based supports for individuals with a broad spectrum of disabilities
- Staffs and runs over 120 group residential homes in Massachusetts and Rhode Island for adults with IDD
- Offers education and day programs along with an employment program to help individuals work in the community

Cardinal Cushing Centers

All ages. All abilities. All together.

Service Learning Project

Every two years, CCDER collaborates with the Department of Developmental Services (DDS) to update the preventative health screening recommendations for adults with IDD.

These guidelines are crucial for this population because of the immense hurdles faced by adults with IDD in navigating an increasingly complex healthcare system. At least 30% of adults with IDD have unique health issues requiring additional screening.

Advice for Clinicians

- Focus on the PERSON, not the disability
- Communicate directly with the patient even if they are nonverbal
- Commonly under-recognized health problems in this population:
  - GI: dysphagia, constipation, GERD
  - Vision: cataracts, glaucoma, retinal detachment
  - MND: osteoporosis, degenerative joint disease
  - Neuropathies: compressive neuropathies from contractures or long-term use of assistive devices for mobility
  - Down syndrome: screen specifically for hearing and ocular problems, hypothyroidism, seizure disorders

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Medical Education Tips

- After concluding this clerkship, we believe our medical education is lacking in its inclusion of adults with disability in the curriculum.
- We think it would be beneficial to 1st year medical students to have a discussion about adults with IDD during DC51