

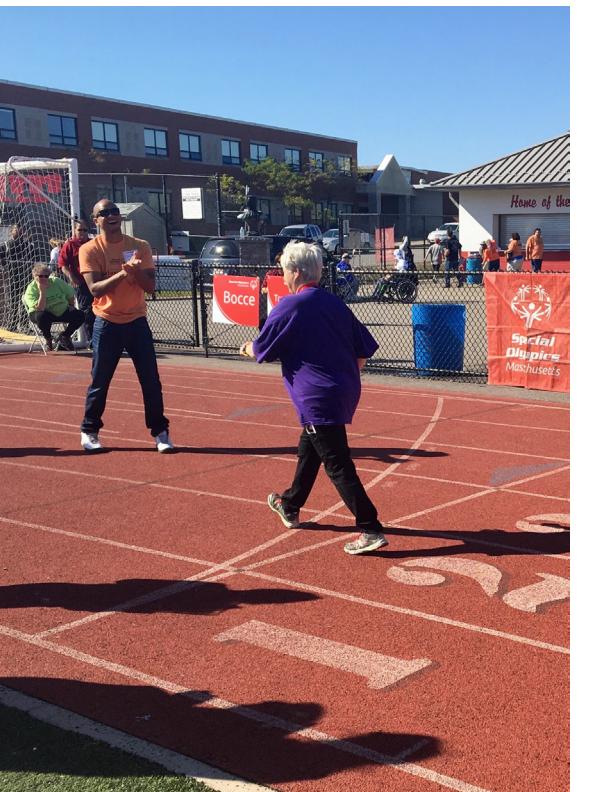
People with Developmental and Intellectual Disability: Community Living and Health Care Experiences

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INTELLECTUAL DISABILITY

- IQ less than or equal to 70
- Two functional needs
- Onset in the developmental phase

Ex: Down syndrome, Fragile X, hypoxia at birth



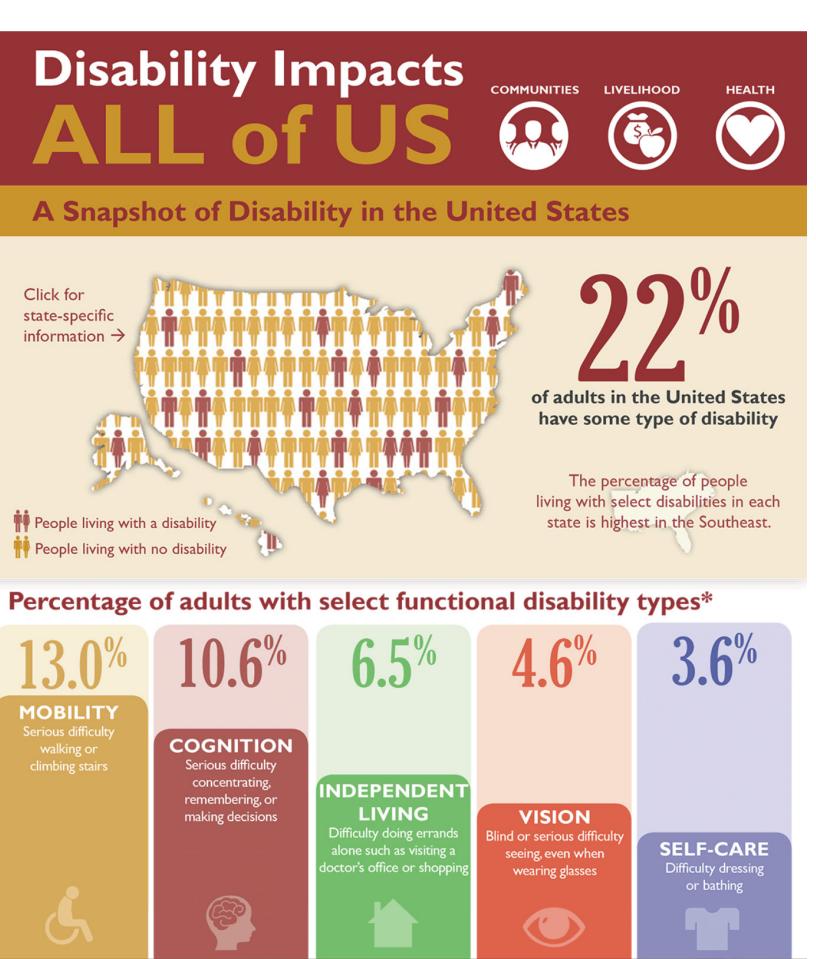
DEVELOPMENTAL DISABILITY

- Permanent cognitive and/or physical impairment
- Onset in development phase

Ex: Rhett syndrome, Fetal Alcohol Syndrome, Autism Spectrum Disorder

EPIDEMIOLOGY

- 2-3% of children are affected- that is 1 out of 33 newborns
- 1.0-1.5% (~4 mil. people) of intellectual/ developmental disability (ID) in the non-institutionalized U.S. population
- Health care costs for the 4.9% of the Medicaid population with ID account for 15.7% of total Medicaid expenditures
- Common causes include genetic mutations, chromosome abnormalities, toxic substance exposure in utero, infections during pregnancy, childbirth injury, traumatic brain injury, preterm birth



SERVICE LEARNING PROJECT

GOALS

Adjustment of existing health screening guidelines and medical factsheets for persons with intellectual disabilities

PROGRESS

Currently, existing forms are long, complicated, and challenging for families and caregivers to complete. As a result, the individuals, caregivers and families are not receiving the necessary services and resources.

OUTCOMES

- Routine Screening Guidelines: Age and gender appropriate suggested annual medical and preventative screenings
- Emergency Medical Information: Form containing basic information including, but not limited, the patient's emergency contacts, consent status, advanced directive information, medication lists, allergy, etc., which is meant to be utilized in emergency situation
- "All About Me": Form to be carried by the individual to inform others of likes/dislikes, potential communication barriers, social skills in order to support and ensure a positive experience for the person in social settings



FIELD EXPERIENCE

- Center for Autism and Neurodevelopmental Disorders (CANDO Clinic)
- Massachusetts DDS Worcester Assistive Technology Center
- Group Home Settings
- Hogan Developmental Center
- Wrentham Developmental Center
- Seven Hills Foundation
- The MENTOR Network
- Massachusetts Special Olympics
- Tewksbury Hospital
- UMass Division of Developmental and Behavioral Pediatrics



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LEARNING POINTS FOR HEALTHCARE PROVIDERS & NEXT STEPS

Healthcare providers must:

- Understand the challenges and barriers that patients with IDD face in accessing quality personalized care
- Recognize that individuals with IDD need individualized care
- Assessing and screening for abuse and trauma
- Improve interaction techniques: speaking directly to the individual and on his or her level
- Create individualized plans of care
- Modify office visits as needed, i.e. not requiring exam gowns
- Integrate interdisciplinary model of care in an effort to address the unique and dynamic needs of each individual
- Understand the importance of planning a seamless transition from pediatric to adult care
- Promote awareness amongst other healthcare providers and professionals about the local resources and services available to this population

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