

# 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

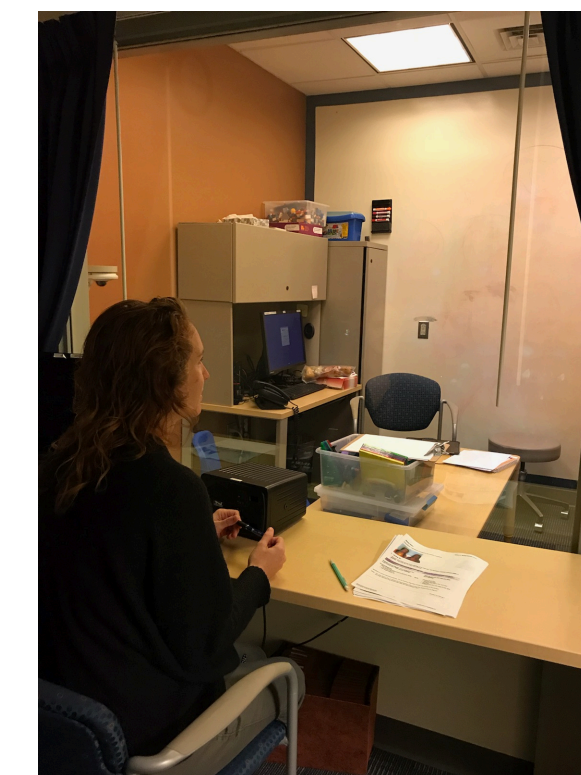
Adjustment of existing health screening guidelines and medical factsheets for persons with intellectual disabilities

### 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 mean 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

## 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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