

Adults with Intellectual and Developmental Disabilities: Community Living and Health Care Experiences

Katherine Croke, Steven Em, Jessica Fournier, Stephany Gyasi, Kelsey Mantoni, Alexandra Bonardi, Emily Lauer

Population of Focus

Intellectual Disability is a disability characterized by significant limitations in:

- Intellectual functioning- generally defined by an IQ <70
- Adaptive behavior which includes conceptual skills, social skills and activities of daily living

Developmental Disability can include intellectual or physical disabilities or both that originate before the age of 18

Approximately **6.5 million** people in the United States are living with intellectual disabilities- that is over **2%** of the adult population.

Common Etiologies

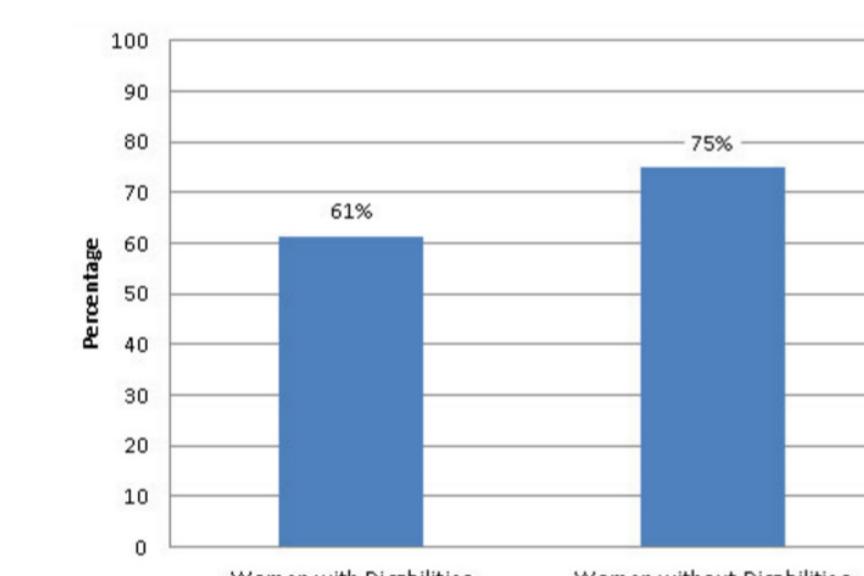
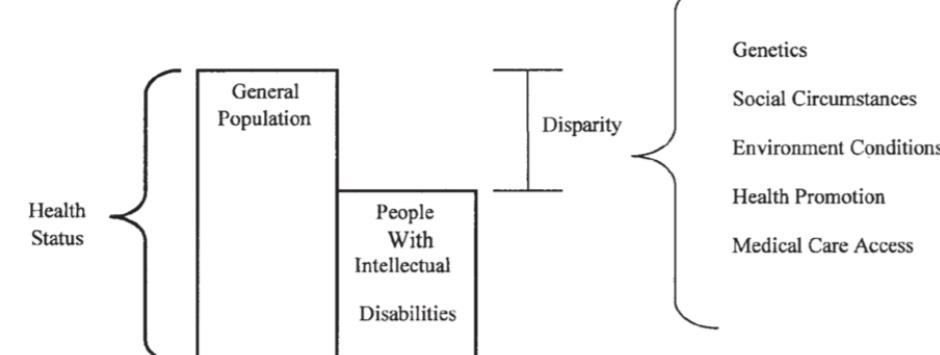
- Chromosomal abnormalities
- Infections
- Trauma (perinatal/postnatal)
- More than 75% of intellectual disabilities have an unexplained etiology
- Nutritional deficiencies
- Metabolic
- Toxic

Insufficient Census Data

- In 2008 the national census added six questions focused on people with disabilities, questions about disability status are required in ACA Section 4302
- Questions are not specific enough to identify the population with ID.

Health Disparities

- People with intellectual disabilities experience health disparities in mortality, and quality of life
- People with disabilities receive fewer routine preventative screenings than those without disabilities



Past, Present, and Future of I/DD

Prior to the 1980's, the majority of people with disabilities were living in large state institutions. People were institutionalized as young as six weeks of age and often never left. The conditions at many of these institutions were deplorable and the residents were denied essentially all basic human rights like privacy, property, education, and respect.

Several new laws and court cases culminating with the Americans with Disability Act (1991), and the Olmstead Act (1999) led to the wide-scale closure of institutions and a new focus on community life as the preferred goal for adults with intellectual disabilities.

Present Supports:

- Adult Family Care: provides supports for individuals living with their family in the community
 - Day Programs:
 - Adult Day Health- includes therapeutic, social, and recreational activities on-site and in the community, provides nursing care
 - Adult Day Habilitation- provides training including functional life skills, health maintenance, motor skills, communication for individuals with significant medical needs
 - Community Based Day Support (CBDS)- focuses on vocational training and work opportunities in the community
 - Residential Programs:
 - Independent Living Supports- individuals who can live alone in the community but may need extra support for daily living
 - Group Homes
 - Medically or Behaviorally Intensive Homes

Seven Hills Foundation
Making Dreams a Reality



Improving the future for individuals with ID:

- Social and community inclusion
 - Building friendships (Creating our Common Wealth)
 - Educating the community about people with ID
- Increasing work opportunities
- Providing quality health care and improving accessibility
- Continued vigilance and protection from abuse
 - Disabled Person's Protection Committee
- Promoting self-advocacy



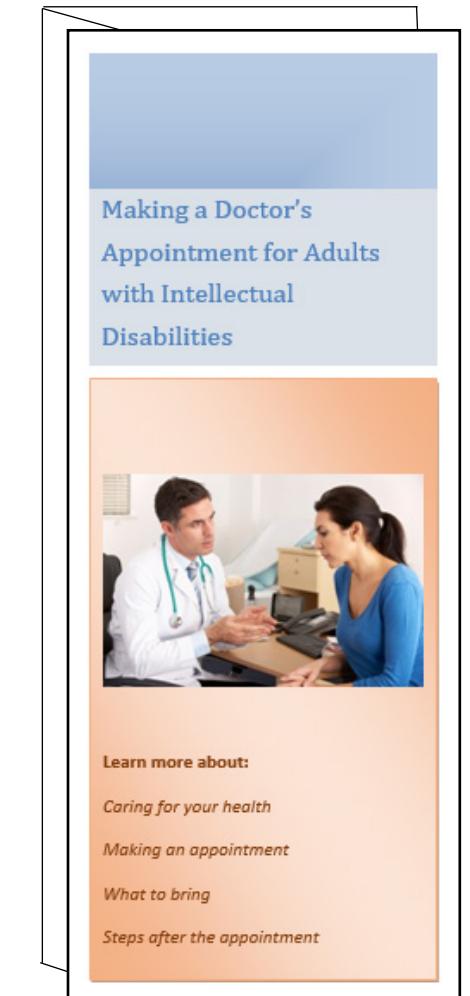
Service Learning Project

Our service learning project was to create a pamphlet focused on an audience of people with intellectual disabilities with the goal of motivating this population to take the lead in their own health care.

The pamphlet was broken down into what a patient can do:

- Prior to an appointment
- During an appointment
- After an appointment

as well as space to write down important names and numbers and resources for more information on disability services in the area and nationally.



Learn more about:
Caring for your health
Making an appointment
What to bring
Steps after the appointment

Acknowledgements

We would like to thank all of the people who helped us immerse ourselves in the population of adults with intellectual and developmental disabilities during this clerkship including our preceptors Alixe Bonardi and Emily Lauer, the members of Creating our Common Wealth, Maribeth Fisher and the staff and participants at Seven Hills, Nancy Altiero and the Disabled Persons Protection Commission, the Cardinal Cushing Center, Susan Wolf-Fordham and the EK Shriver Center, Dr. Monika Mitra, Dr. Robert Baldor, Dr. Julie Moran, and all of the people with intellectual and developmental disabilities who shared their stories with us. And a HUGE thanks to our mentor and inspiration, fourth year Rick Leslie.

References

- <http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.VhffLo2FOM8>
- http://www.specialolympics.org/Sections/Who_We_Are/What_Is_Intellectual_Disability.aspx
- <http://www.aapd.com/what-powers-us/disability-rights/?referrer=https://www.google.com/>
- <http://onlinelibrary.wiley.com/doi/10.1002/mrdd.20098/epdf>
- <http://www.cdc.gov/ncbddd/disabilityandhealth/breast-cancer-screening.html>
- <https://www.ncd.gov/publications/2012/Sept192012>