

Caring for Adults with Intellectual Disabilities

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DEFINING INTELLECTUAL DISABILITIES:

Three major criteria:

1. Significant limitations in intellectual functioning (IQ below or around 70)
2. Significant limitations in adaptive behavior (conceptual skills, social skills, and practical skills)
3. Onset before age 18

The prevalence of ID is 1-2% in the general population, but with considerable variability in estimated of prevalence.

EPIDEMIOLOGY

Individuals with ID experience more health problems than their peers without ID. Often these health problems go unnoticed due to many factors such as: communication abilities, masking of symptoms, lack of training of health care professionals specific to caring for individuals with ID, and absence of generic screening programs.

Most common physical health problems of individuals with ID:

- Epilepsy, mobility problems, and sensory problems

Most common secondary health problems of individuals with ID:

- Obesity, fractures, poor oral health, constipation, gastro-esophageal reflux disease

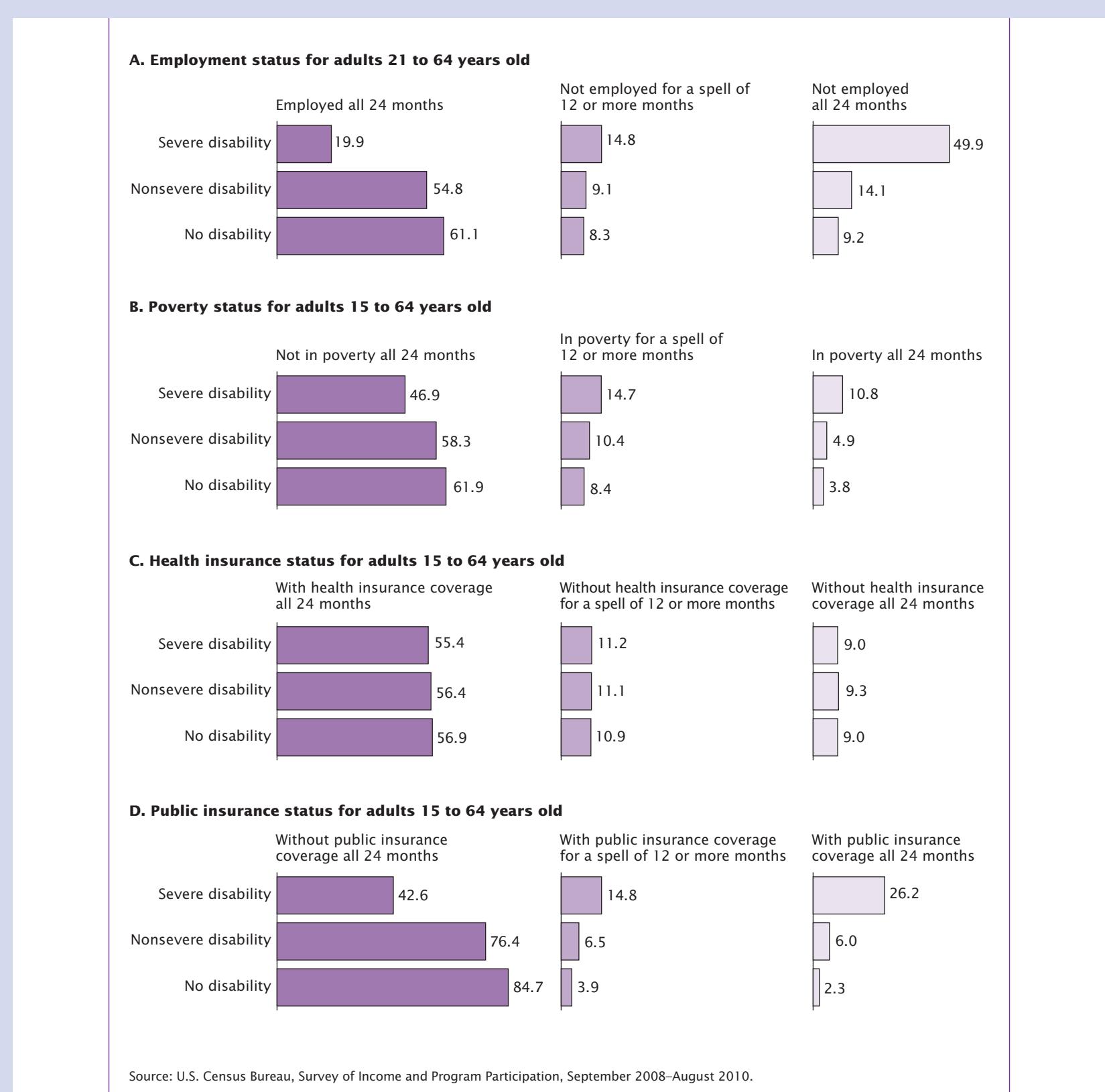


Figure 1. Information from 2010 census regarding employment, poverty, and health insurance status for adults with intellectual disabilities

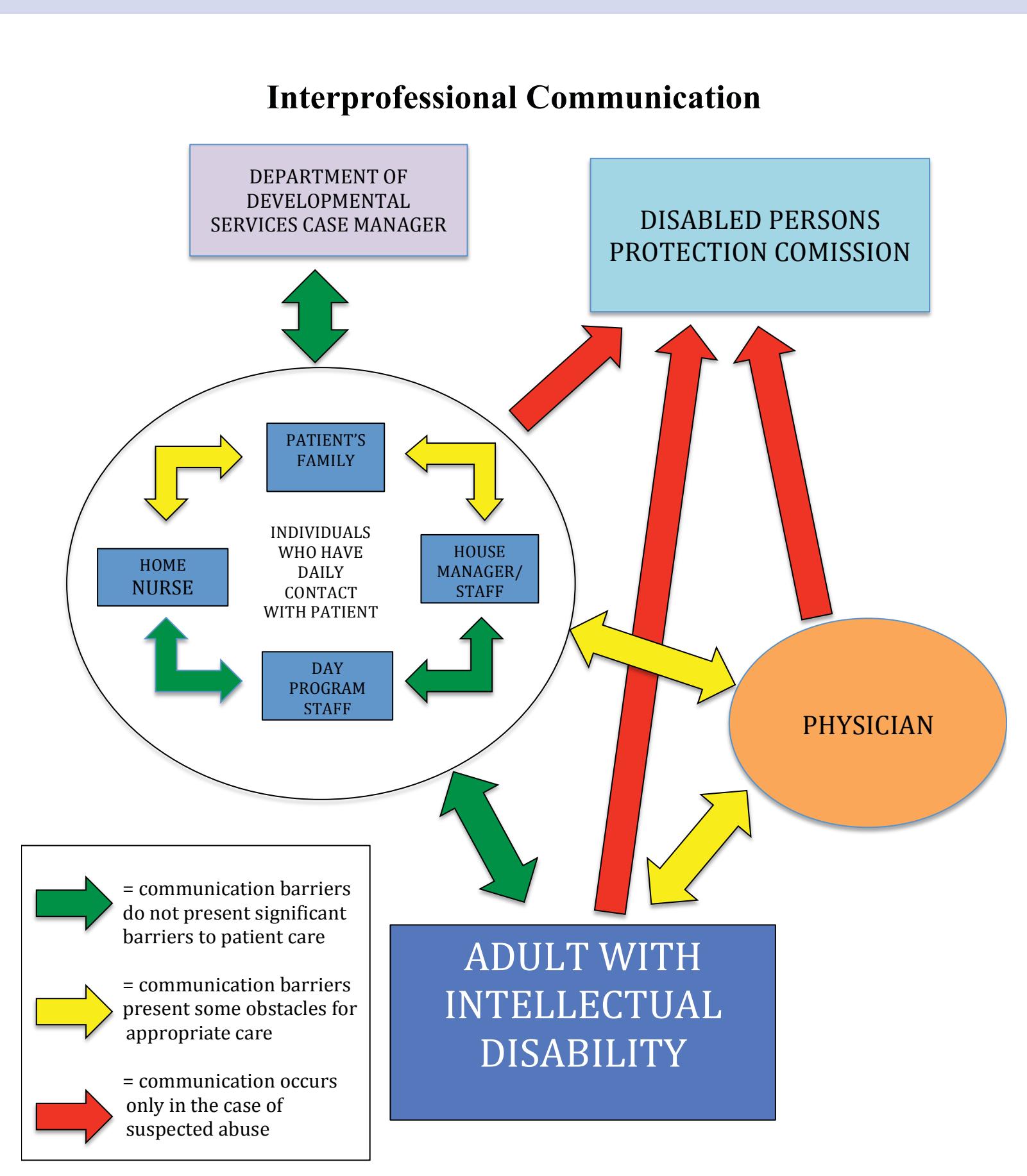


Figure 2. Many different professional entities are involved in providing medical care to adults with intellectual disabilities. The persons who care for the individual on a daily basis include home managers and staff, home nurses, day program workers or job coaches, and the family of the patient. In order to provide excellent care for their patients, it is necessary that physicians have open communication with all of these people. This presents a problem, as these lines of communication are not always present. For example, the physician only gets to obtain pertinent medical history from whoever accompanies the patients to their appointments. The information obtained is usually not adequate to provide clinicians with the entire picture of a patient's health. The Department of Developmental Services provides oversight for these caregiving fields, while the Disabled Persons Protection Commission handles allegations of abuse for adults with intellectual disabilities between the ages of 18 and 59 years old.

POPULATION HEALTH CLERKSHIP: SERVICE PROJECT

Healthy Athletes is a program that offers routine health screening in seven key health areas to participants in Special Olympics. The Healthy Athletes FUNfitness program offers screening in strength, balance, flexibility and aerobic fitness.

On October 19th we volunteered at the Senior Sports Classic, a Special Olympics event for athletes over the age of 45, together with an interdisciplinary team of physical therapists and nurses.

We interviewed Special Olympics athletes to identify any health problems that might prevent them from completing fitness testing. Information we collected can be tracked by Healthy Athletes, which manages the world's largest data base on the health issues for individuals with intellectual disabilities.



IMPORTANT LESSONS FOR PHYSICIANS

- Focus on abilities, not disabilities
- Greet the person first and ask for permission to discuss with the accompanying person
- Talk respectfully, do not shout, do not treat patient as child when they are an adult
- Ask how the patient communicates, especially for answering yes and no
- Challenging behaviors are not automatically psychiatric issues, assess for other ailments first
- Make sure to take time with the patient

REFERENCES

- AAIDD - Resources for Intellectual and Developmental Disability Professionals. (n.d.). AAIDD - Resources for Intellectual and Developmental Disability Professionals. Retrieved October 28, 2013, from <http://www.aaidd.org>
- Brault, M. (2012). Americans With Disabilities: 2010 . us census, U.S. Department of Commerce Economics and Statistics Administration , 70-131.
- Krahn, G., & Fox, M. (2013). Health Disparities of Adults with Intellectual Disabilities: What do we know? What do we do?. *J Appl Res Intellect Disabil*, doi: 10.1111/jar.1206, PubMed PMID: 23913632.
- van Schrojenstein Lantman-de Valk, H. M., & Walsh, P. N. (2008). Managing Health Problems In People With Intellectual Disabilities. *BMJ*, 337(deco8 1), a2507-a2507.

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