

## Canaries in the Coal Mine: People with DD in the Health System

People with developmental disabilities face similar obstacles as everyone else in accessing quality health care yet, they also face challenges that, although not unique, disproportionately impact their health care. As institutions close and people live longer, the community health care system has not developed the capacity to serve this population.

- Most people with developmental disabilities depend on MediCal for their health care. The number of doctors who accept MediCal keeps declining given low reimbursements and high paperwork. Specialist are difficult to find or non-existent for certain specialties. The difficulty or unwillingness to refer people with disabilities to specialists often results in the primary doctor dispensing all kinds of special medications.
- Access is a significant obstacle to adequate health care. Limited physical access including lack of ramps, wide doors, adjustable exam tables and other equipment impact people who use wheelchairs and others. In addition, often people with disabilities require a longer appointment and/or the presence of a third party to assist with communication. Behavior and communication issues may lead to misdiagnosis
- 65% of adults diagnosed with intellectual disabilities live at home and are cared for by aging parents. Adults with developmental disabilities cared for by parents are less likely to receive routine or preventive care. The health of care givers correlates with the health of consumers.
- Research shows that people with intellectual disabilities are 4 to 6 times at higher risk of dying from preventable causes than the general population.
- About 50% of people with intellectual disabilities are seriously overweight, compared to 1/3 of the general population. The use of atypical antipsychotic drugs, which is common for people with developmental disabilities, may cause significant weight gain. Additionally, opportunities for physical activity may be limited, resulting in a sedentary lifestyle. There is a higher incidence of diabetes.
- People with developmental disabilities are at risk for delay in diagnosis and treatment. For example: Fractures, dislocations, tumors, cancers, medication toxicities, ulcers, strokes, arteriosclerotic heart disease, ulcers, etc. Consumers' medical complaints are often attributed to their disabilities instead of diagnosing separate medical problems. Significant healthcare disparities have been found in utilization of all preventive cancer screening in people with intellectual disabilities
- People with developmental disabilities have the highest incidence of dental problems and often suffer unnecessary pain, infection, and disfigurement. They often rely upon caregivers and family members for preventive care and have poor access to ongoing dental treatment.
- While the incidence of depression and other mental health conditions is higher than in the general population, access to mental health services for people with developmental disabilities is a serious challenge. [In addition, chemical restraints are sometimes used as a means for behavior intervention.]
- A coordinated health service delivery model which addresses the issues of people with complex medical needs will work best for everyone. The needs of vulnerable populations highlight the more general failings of the system. Any Health Care reform proposal must take into consideration issues of access for people with developmental and other disabilities and must set standards that respond to the needs of this population. If it works for people with developmental disabilities, it will work for everyone.