



**White Paper Title:** Improving Access to Quality Healthcare and Prevention Programming for Individuals with Intellectual Disabilities through Education and Training of Health Influencers

**Authors:** Christine Bottrell Mirzaian, MD, MPH and Larry Yin, MD, MSPH

**Affiliation:** University of Southern California University Center for Excellence in Developmental Disabilities (UCEDD) at Children’s Hospital of Los Angeles

**Background:** Individuals with developmental disabilities (DD), including intellectual disabilities (ID), experience significant barriers to accessing healthcare, resulting in poorer health, higher rates of preventable mortality, co-morbidities, and chronic conditions, as recognized by the Surgeon General.<sup>1</sup> These disparities have been recognized on a national level, and became clear on a local level as well during quarterly review of morbidity and mortality reports from the San Gabriel Pomona Regional Center (SGPRC), one of seven regional centers in Los Angeles, California which provides services and supports children and adults with DD. Beginning in 1998, in his role as a medical consultant for SGPRC, Dr. Larry Yin led an effort that identified that many adult clients were dying at earlier ages from preventable disease. It was noted that adult clients were not receiving basic health screenings for cholesterol, hepatitis and diabetes as well as routine medical subspecialty care for their existing conditions. Cancer screenings such as mammograms, pap smears and colonoscopies were also not routinely performed. The group also found clients passing away from non-medical conditions such as accidental drowning, heat exhaustion and choking while eating.

**Action:** It was decided to develop healthcare guidelines, informed by major medical industries such as the US Preventive Services Task Force, the American College of Obstetrics and Gynecologists (ACOG), and the American Heart Association (AHA), that were summarized in a brochure to guide families and their physicians to conduct necessary health screenings in individuals with DD. This brochure was distributed to parents caring for adult children with DD, group home providers, independent living services (ILS) providers, regional center nurses, regional center social workers and to those living in intermediate care facilities (ICFs). Brochures were distributed both via email and printed. In addition, they were provided at annual Individualized Program Plan (IPP) meetings. The brochure was translated into multiple languages, and adopted by other regional centers in California. To address other public health concerns that might impact individuals with DD, notices were sent prior to key seasons on safety prevention messages. Some examples include water safety, heat safety, and the importance of annual flu immunization notices that are disseminated to families and service providers.

**Results:** Direct feedback from regional center clients and caregivers was received that an increase in health screenings occurred as a result of having the opportunity to share this brochure with their medical provider. Overall, there appeared to be a positive trend, whereas previously the regional center would hear from community providers statements such as “they can’t sit still for a mammogram,” or “why should they get a pap smear if they aren’t sexually active?,” over time the conversations changed to “should Mr. Smith, who is 80 years old, undergo radiation or chemotherapy for cancer?” The conversation changed from clients not being screened and dying at earlier ages, to being screened and surviving for many more years. Accidental drowning and heat related deaths declined substantially. Clients with a history of overstuffing food or who had a previous incident of choking were required to have a feeding assessment with recommendations to the caregiver regarding food size and texture or about the need for possible supervision during meal time.

Data based on mortality reports sent to the state of California was analyzed. The mean age of death of SGPRC clients increased by 18 years between 2001 and 2016. Given that many deaths were secondary to preventable conditions, such as cardiovascular disease and cancer, increasing awareness of the importance of conducting standard health screenings in adults with DD likely contributed to an overall reduction of mortality amongst regional center clients.

The process of reviewing morbidity and mortality data at the SGPRC then evolved into a statewide effort to track morbidity and mortality. Key to this effort were Edward Kutik and Keith Penman, Executive Director of the SGPRC, who supported efforts to create a statewide system to track morbidity and mortality of regional center clients based on the processes developed at SGPRC. The state of California now requires all regional centers to develop corrective plans to address unusual increases in mortality and morbidity.

**Lessons Learned:** This effort demonstrated that by raising awareness, individuals with DD could access mainstream healthcare screening standards that were previously overlooked or dismissed. The biggest lesson learned is that effecting change is a very slow process, one must be persistent. This work occurred over nearly 2 decades, but results were substantive. Most importantly, you must continue to work to advocate for clients’ rights: individuals with DD should have the same access to routine, preventive healthcare as individuals without DD.

**Next steps:** The brochure was updated with 2018 healthcare guidelines as provided by the US Preventive Health Task Force, and supported by literature specific to adults with ID.<sup>2</sup> Next steps include increasing distribution of this brochure by focusing on training programs that prepare medical providers to care for individuals with DD, such as family medicine residency programs, both through local and national efforts, in order to continue to raise awareness of the need to include individuals with DD in mainstream healthcare efforts. The group at SGPRC continues to develop new trainings and public health messages all focused on chronic conditions and preventable illness in individuals with DD.

## References

1. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation, 2001. Washington, DC: US Public Health Service
2. Wilkinson JE, Culpepper L, Cerreto M. Screening tests for adults with intellectual disabilities. *J Am Board Fam Medicine*. 2007;20(4):399-407