

Racial Disparity in Health Outcomes Among People with Down Syndrome Fact Sheet: Information to Better Support Families

- Research shows that although people with Down syndrome are living longer, there remains a disparity in health outcomes and life expectancies among African Americans with Down syndrome.
- A 2001 Center for Diseases Control (CDC) study found that African American infants with Down syndrome have a lower chance of surviving beyond the first year of life compared with white infants with Down syndrome. The study also revealed a stark racial disparity in the median life spans of people with Down syndrome. The study, based on an analysis of 34,000 cases from 1968 to 1997, indicated that the median age at death for Caucasians with Down syndrome was 49 years, while it was 25 years for African Americans.
- Recent information shows that this gap has lessened from original studies. A study of data from 1991-2009 (in Tennessee) shows that Caucasians with DS live on average to age 52, while African Americans with DS live on average to the age of 48. Whereas the earlier study (1968-1997) included infant mortality rates; this most recent study does not. Thus, the findings from Tennessee suggest a narrowing of the health disparity gap in mortality for individuals with Down syndrome that have survived through early childhood.
- These findings are congruent with health disparities among African Americans at large, as this community experiences higher rates of obesity, breast cancer, diabetes, asthma, infant mortality, and heart disease.
- Possible contributing factors for disparities are:
 - Socio-economic status
 - Parental education regarding health care
 - Systematic discrimination and inequities within the health care and social services systems
 - Community supports
 - Rate and treatment of comorbidities
 - Unequal quality of and access to health care
 - Use of health care
 - Day-to-day stress

Steps for Healthcare Systems/Providers and Parents/Caregivers can take to improve disparities and achieve equity for those with intellectual disabilities:

Healthcare Systems and Providers:**

- ✓ Race/ethnicity should be routinely collected on ALL individuals (by practices, health systems, etc.), so disparities can be identified, monitored and targeted as part of improving quality of care
- ✓ Racial/ethnic disparities must be framed and addressed as Quality of Care issues
- ✓ Aim to attain highest level of cultural competence
- ✓ Pursue workforce diversity
- ✓ Leverage innovative, evidence-based interventions
- ✓ Ensure and advocate for ALL individuals to have access to needed subspecialty care
- ✓ Ensure the individual in your care has health insurance and medical/dental homes
- ✓ Connect individuals with community supports, parent mentors***

Parents/Caregivers:

- ✓ Advocate for equitable care; refer to American Academy of Pediatrics health guidelines when discussing questions or concerns
- ✓ Commit to giving feedback on appointments and care, answer surveys and communicate the quality of care you have received, holding your provider accountable
- ✓ Connect with community supports
- ✓ Educate fellow community members on healthy practices

The DSAGC Healthcare Advisory Board will continue to monitor this issue and advocate for meaningful change within the healthcare system. Over the past two years, the DSAGC has expanded its outreach program to encompass medical, employment, school, and community outreach as well as government advocacy. The outreach coordinator visits area hospitals and medical centers to share information regarding Down syndrome, a sensitive diagnosis, ways to support all individuals, families and parents, and community inclusion as a whole. The DSAGC also participates in health and disability outreach fairs/expos. Along with this outreach, the DSAGC will continue connecting parents to resources and assistance through our program coordinators' support, community groups, and our monthly 21 Series which will include at least one health-topic per year to help families to better advocate for the health of their loved one with Down syndrome. If you are interested in helping with our outreach efforts, please contact our Volunteer and Communications Coordinator, Krissy Vinson, at 513-761-5400 or krissyv@dsagc.com

*** These suggestions provided by Glenn Flores, MD - Connecticut Children's Medical Center*

****The DSAGC is encouraged by the concept of Parent Mentors developed out of Connecticut Children's Medical Center (Glenn Flores, MD) to help families who are experiencing inequities in medical care. This program, led by healthcare systems, supported in part by community partners, has shown in other markets to help improve child outcomes, empower parents, enhance healthcare access, increase quality of care. CCHMC would need to be the driver of this sort of a program as it has possible implications for other disability populations beyond just Down syndrome. In addition, they have the expertise to manage this sort of a program and could have access to some federal grant money to implement a program like the one created in Connecticut here in Cincinnati. If CCHMC wants to explore or implement this sort of a program, the DSAGC would be enthusiastic collaborators with them. Parent Mentors would be a special category of paid community health workers in which parents who have children with particular health conditions/risks leverage their relevant experience, along with additional training, to assist, counsel, and support other parents of children with same health conditions/risks.*



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