

HOW SELF-ADVOCATES AND FAMILIES CAN DEAL WITH HEALTH DISPARITIES AFFECTING PEOPLE WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

Families of children with special needs may not realize that there are disparities in health care, which include differences in access to health care, health care quality, and exposure to harmful conditions that impact health such as environmental factors and living conditions (*see information on social determinants of health at www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health and www.cdc.gov/socialdeterminants.) Access to quality healthcare can be unfairly limited based on age, gender, race/ethnicity, socio-economic status, and even disability.*

Because people of color and those with lower incomes are more likely to have disabilities, this lack of access to quality, culturally-appropriate healthcare is likely to result in poorer health outcomes, including increased morbidity and mortality among

people with disabilities. In fact, according to the National Alliance on Mental Illness, people with mental health conditions die on average 25 years earlier than their peers.¹ Despite these challenges, there are actions that parents and self-advocates can take to mitigate the potential for these negative health outcomes for their children with all kinds of disabilities.

WHEN DO DISPARITIES OCCUR?

There are many variables affecting health care access for people with disabilities. This can range from basic accessibility to differences in medical interventions.

ACCESSIBILITY

The first hurdle may be something as simple as getting into the doctor's office. Even when the outside of the facility is accessible, some of the inside features of the office may not be. For example, examination tables and diagnostic equipment may not be accessible to individuals with disabilities. Many people found that once Medicaid went to managed care, even in-network doctors often did not have accessible facilities.

TREATMENT

There may be a difference in the treatment of a secondary condition for a person with a disability. Some parents are still asked if they want sterilization procedures for their teen with special needs. One mother was asked if she wanted to give antibiotics to her toddler (who happened to have



Down syndrome) with pneumonia, a completely treatable condition. Families of typically developing children are not asked questions about whether or not they want their child to have potentially life-saving antibiotics when they have pneumonia!

ORGAN TRANSPLANTS

Disability is often seen by transplant specialists as contraindicated for organ transplants. The decision should be made based on the individual's medical condition and overall health, not if they have a disability, which would not affect or be affected by a transplant. There are two excellent resources addressing this issue. The Boggs Center has a booklet on preparing people with disabilities for transplant at <http://rwjms.umdnj.edu/boggscenter/news/documents/TransplantPamphletFINAL6-11.pdf>.

In addition the Autistic Self Advocacy Network (ASAN) has a report regarding transplant discrimination, particularly for those with intellectual/developmental disabilities, at https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf. Some states have since developed legislation to address this discrimination. ASAN also has a toolkit on transplants and disability including information on rights, guidance for clinicians, and tips for advocates at <https://autisticadvocacy.org/policy/toolkits/organs/>.

EMERGENCY PREPAREDNESS

It was demonstrated during both 9/11 and Hurricane Katrina that some people with disabilities were not being rescued. Many of them were either saved by friends, or their friends remained by their side waiting for rescue and perished with them. Some of the Centers for Independent Living now have initiatives on emergency preparedness and people with disabilities found at www.ncil.org. Family Voices also has a tip sheet on emergency preparedness for children with special health care needs at <http://familyvoices.org/wp-content/uploads/2018/06/EmergencyPreparednessResources.pdf>.

UNDERSERVED POPULATIONS

There are differences in several key areas which affect health outcomes. In addition to disability, certain racial/ethnic groups may lack any, or appropriate, health insurance, resulting in a later diagnosis. Besides making the condition harder to treat later, this adversely affects early intervention for children with disabilities, resulting in poorer outcomes. For example, African-American and Hispanic children with autism are diagnosed later.² The CDC (Centers for Disease Control and Prevention) recently recognized individuals with intellectual and developmental disabilities as a specific population subject to health disparities based on disability.³ The Arc National has a policy statement which includes "Integrating health disparities based on disabilities on the same basis as racial and ethnic disparities in research and program development."⁴ The Arc has also developed HealthMeet initiatives to address health disparities with information for families, providers, and self-advocates found at <https://www.thearc.org/healthmeet/whats-new>. It is also true that prevention/wellness initiatives help people with mental health issues as well as physical health issues.

The National Association of City and County Health Officials



EYE TO EYE: Examination tables and diagnostic equipment are often not accessible to individuals with disabilities. Some progress is being made.

(NACCHO) considers health care access for people with disabilities to be a public health issue and has developed a "Health and Disability" initiative found at <https://www.naccho.org/programs/community-health/disability>. NACCHO also offers a free online course for professionals regarding the inclusion of people with disabilities in public health programs at <https://www.pathlms.com/naccho/courses/5037>. For more information on NACCHO activities on including people with disabilities in public health, see <https://www.eparent.com/healthcare-2/including-people-disabilities-communities-public-health-initiatives-eliminate-health-disparities/>.

ADDRESSING HEALTH DISPARITIES FOR PEOPLE WITH DISABILITIES

According to the CDC, people with "any kind of disability experience three times the risk of heart disease, diabetes, stroke, and cancer as compared to the general population."⁵ Wellness and prevention is a key area for individuals with disabilities. Too often, medical visits solely address the main condition without consideration of general wellness such as lab tests for high cholesterol, diabetes, etc. The American Association on Health and Disability (AAHD) has a Health Promotion Resource Center which includes information on smoking cessation, physical activity, quality of life, emergency preparedness, and disability specific information at <https://www.aahd.us/resource-center/>.

If families or self-advocates think there has been health care discrimination based on disability, they can contact their state office on Protection & Advocacy at <https://acli.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> or file a complaint with the Office of Civil Rights at www.hhs.gov/ocr/complaints/index.html.

For additional information about health equity for children with special healthcare needs, check out the Catalyst Center resources at <http://cahpp.org/resources/?place=project&keyword=health-equity&sort=date-desc>.

For resources to enhance the capacity of diverse parents of CSHCN to advocate for quality healthcare services, check out resources from Family Voices and the National Center for Family Professional Partnerships at <http://familyvoices.org/ncfpp/resources-ncfpp/?sq=&f%5B%5D=best-practices>.

There are many issues affecting fair health care use for people with disabilities including physical access, stigma and stereotypes, and lack of preparation. For more information on health disparities and people with disabilities, see the blog from the SPAN Parent Advocacy Network, "Unfair Access to Healthcare Affects Our Families," at www.spanadvocacy.org/content/unfair-access-healthcare-affects-our-families-lauren-agoratus

Parents of children with special health care needs and self-advocates can lessen these barriers by knowing their rights, and being aware of wellness and prevention resources, which will improve health outcomes across their child's life span. •

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References

1. <https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers>
2. <https://www.cdc.gov/ncbddd/autism/addm-community-report/differences-in-children.html>
3. <https://www.cdc.gov/ncbddd/disabilityandhealth/features/unrecognizedpopulation.html>
4. <https://www.thearc.org/document.doc?id=3729>
5. <http://www.cdc.gov/vitalsigns/pdf/2014-05-vitalsigns.pdf>

COME ONE, COME ALL : RESOURCES FOR DEALING WITH HEALTHCARE DISPARITIES

GENERAL



AMERICAN ASSOCIATION ON HEALTH AND DISABILITY

Health Promotion Resource Center

www.aahd.us/resource-center



THE ARC: HEALTHMEET

www.thearc.org/healthmeet/whats-new



CATALYST CENTER

Inequities in Coverage and Financing of Care for Children with Special Health Care Needs

<http://cahpp.org/resources/?place=project&keyword=health-equity&sort=date-desc>



NATIONAL ASSOCIATION OF CITY AND COUNTY HEALTH OFFICIALS (NACCHO)

Health & Disability

www.naccho.org/programs/community-health/disability

Health & Disability 101: Online provider course for inclusion in public health

www.pathlms.com/naccho/courses/5037



SPAN PARENT ADVOCACY NETWORK

"Unfair Access to Healthcare Affects Our Families" blog

www.spanadvocacy.org/content/unfair-access-healthcare-affects-our-families-lauren-agoratus

DISCRIMINATION



PROTECTION & ADVOCACY

<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>



OFFICE OF CIVIL RIGHTS

www.hhs.gov/ocr/complaints/index.html

EMERGENCY PREPAREDNESS



NCIL

Centers for Independent Living: Lists all centers nationally

www.ncil.org



FAMILY VOICES

Emergency Preparedness for CYSCN (Children/Youth with Special Health Care Needs)

<http://familyvoices.org/wp-content/uploads/2018/06/EmergencyPreparednessResources.pdf>

See also: Best Practices in Cultural Competency

<http://familyvoices.org/ncfpp/resources-ncfpp/?sq=&f%5B%5D=best-practices>

TRANSPLANTS



AUTISTIC SELF ADVOCACY NETWORK (ASAN)

Organ Transplantation and People with IDD: report

https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf

Organ Transplantation and People with Disabilities: Toolkit

<https://autisticadvocacy.org/policy/toolkits/organs>



BOGGS CENTER

Transplants for Children with Disabilities

<http://rwjms.umdnj.edu/boggscenter/news/documents/TransplantPamphletFINAL6-11.pdf>