Champions for Inclusive Communities

Equality of Health for CYSHCN: Contributing Factors and Help for Families and Communities

This brief provides a short overview of the status of the literature and demographics with respect to our understanding of health disparities and access to care for children with special health care needs (CYSHCN) who are members of racial/ethnic minorities. Children and youth with special health care needs reflect the ethnic, economic, and educational health demographics of the U.S. as a whole. Though we can do little else than introduce you to the literature and several of the major issues regarding access to care for racial/ethnic/linguistic minority children, we also provide references for you to learn more for your family, your service provider, and your community.

The health disparities we describe involve a complex web of issues that interact with one another. Race/ethnic minorities: culture, socioeconomic status, insurance, poverty, language, usual source of care, access to care, relationship with health care professionals, and physical environment in which children grow up are all factors contributing to inequality in the health outcomes for children and youth. The disparities found within the CYSHCN population tend to mirror the general child population. What are the root causes and what can a community do to address the issues surrounding a child's right to grow up healthy?

What is ethnicity?

Federal policy categorizes both racial and ethnic groups for the purposes of analysis and policy decision making These groups include the categories of: White, Black, Asian, Hawaiian/Pacific Island, American Indian/Alaskan Native, and an ethnicity category of Latino/Hispanic (Office of Management and Budget [OMB], 1997). In this brief, the term "ethnicity" will include both race and ethnicity categories. The terms "ethnicity" and "ethnic health disparities" can easily be confused (Kaplan & Bennett, 2003). Though definitions of ethnicity and ethnic health disparities are defined in the health research literature (Dressler et al., 2005), it is important to remember that the ethnicity labels usually do not address inter- and intra-ethnic differences. Ethnicity is an "umbrella" term that becomes increasingly difficult to accurately define at the individual level as our culture continues to expand through immigration and self-definition and the fusion of cultural stereotypes.

What are health disparities?

The term "health disparities" is broadly defined as "observed clinically and statistically significant differences in health outcomes or health care use between socially distinct vulnerable and less vulnerable populations that are not explained by the effects of selection bias" (Kilbourne et al., 2006, p. 12). Health disparities are apparent in the data on health outcomes, socioeconomic status, access to health/insurance, and health care provider selection effects (Kilbourne et al.).

Factors contributing to health disparities for ethnic minority CYSHCN

Poverty

- Poverty is linked to underutilization of specialized health services, insurance, and access of health services.

Insurance and underinsurance

- Uninsured families are less likely to: be satisfied with the care they receive; feel like partners in decision-making; have less access to a medical home and community-based services; and, be less successful in their transition to adulthood (Oswald et al., 2007).

- Underinsured families of CYSHCN are also more likely to have difficulties with: unmet health needs, finances, access to specialty health care, and family members being required to reduce or stop work to provide care (Kogan et al., 2005).

Partnership in decision-making

- The extent to which families with CYSHCN feel that they are partners in decision making is associated with improved outcomes in missed school days, access to specialty care, care satisfaction, and unmet needs for child and family services. This partnership is hindered by the effects of poverty, lack of health insurance, the natal language of the family, and children with more limited functional abilities (Denboba et al., 2006).

Access to care

- Ethnic minority families have more difficulty in gaining access to; and, maintaining a usual source of care even after accounting for other factors (Escarce, 2007). A current model for providing access to care involves a medical home where both access and care coordination are addressed (Beal et al., 2007). Barriers to creating a medical home include language, insurance, and nonfamily centered care.

Culture and communication/language barriers

- Culture and language are very closely tied to our understanding of ethnicity. Each ethnic group manifests their needs through distinct methods of communication and conflict resolution. Thus, providers of services need to incorporate cultural and linguistic competence in their knowledge and skill base as it has been found to be a predictor of quality care of CYSHCN (Lieu et al., 2004). Parents of ethnic minorities use familiar cultural patterns of interaction to base decisions about their understanding of health care and the forms of intervention they are willing to use (Mandell & Novak, 2005). Parents of Hispanic children and Black children reported that health care providers never or rarely understood their child-rearing preferences.

Lessons learned

- Health disparities within the CYSHCN population tend to mirror those of the general child population, but more investigation is required.
- Information presented in the literature is primarily based on Black and/or Hispanic populations while "other" ethnicities are considerably less likely to be discussed (Flores et al., 1999).
- More specific targeting of socioeconomic determinants over a wider range of social factors is required so that a more complete picture of disparities can be explored.
- Having a culturally and linguistically competent medical home and partnership in decision making are good first steps in eliminating health disparities.

What does this mean for communities?

- Create opportunities by engaging ethnic minorities within a culturally safe environment to participate in community supports and services. Ask ethnic minority families how they would like to be involved in these structures.
- When planning for community needs, support the rights of the ethnic minority family to self-determine their needs.
- When creating or strengthening community programs, incorporate the self-determination rights of the ethnic minority in the implementation plan.
- When instigating a continuous quality improvement program of any community plan, include inter- and intra-ethnic differences in data collection methods.

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Resources that communities can use

- National Center for Cultural Competence – And the Journey Continues: Achieving Cultural and Linguistic Competence. http://www11.georgetown.edu/research/gucchd/nccc/resources/publicationstitle.html

- The Commonwealth Fund - Racial and Ethnic Disparities in U.S. Care: A Chart Book http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=672908

- Center for Health Care Strategies – Reducing Racial and Ethnic Disparities: A Quality Improvement Initiative in Medicaid Managed Care: Toolkit http://www.chcs.org/publications3960/publications_show.htm?doc_id=440684

- Office of Minority Health – A Community Approach to Address Health Disparities: Thrive Project Toolkit http://www.omhrc.gov/assets/pdf/checked/THRIVE_FinalProjectReport_093004.pdf

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NOTE: A full list of all articles reviewed is available from Champions for Inclusive Communities.