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Community, place, and information behavior: A grounded theory study of parents of children with Down Syndrome and government-sponsored information and services

Abstract: This poster will outline a dissertation study that explores relationships between place and place-based community, information behavior, access and practice.

Résumé : Cette affiche résume une étude doctorale sur les liens entre le lieu physique, les communautés rattachées à un lieu physique, les comportements informationnels, l'accès et la pratique.

There exists a dichotomy between recent information theory and practice regarding geography and physical, place-based communities. Much of recent information theory has assumed the death of locality espoused by economists in the mid to late 1990s (Cairncross, 1997). Meanwhile, much of daily life is organized by locality (Bauman, 1998). This poster will outline a dissertation study that explores relationships between place and place-based community, information behavior, access and practice.

This dissertation study seeks to address the inconsistency of availability and accessibility of government information, support and resources related to Down Syndrome in different place-based communities. The main purpose of this study is to examine the effect of place on the information behavior of parents of children with Down Syndrome as they seek and share information about Down Syndrome-related services. More specifically, this study uses grounded theory development to examine relationships between place-based communities, information behavior and government funded information sources. The study examines whether (and how) information access and behaviors vary between place-based communities, and how access to information can be improved.

The study examines the following questions:

1. Do the place-based communities in this study exhibit information behaviors at the community level? Do the information behaviors of the community as a whole demonstrate any identifiable trends of behavior at the community level? In what ways can these communities (as opposed to members of the community, or actors within the community) be said to “seek information”?
2. Who are the stakeholders in the place-based communities studied? How do the internal social structures of communities differ, and do these differences have any discernable effects on information practices, behavior or access within or between communities?
3. In stakeholders’ views, are some place-based communities “better” than others for Down Syndrome-related information and resources? If so, why?
4. What if any, relationships exist between these place-based communities and information behaviors exhibited by community members or by the communities?

5. If relationships do exist between these place-based communities and information behaviors, what are the implications of these relationships for improving government funded information services?
6. What if any, relationships exist between participants' information behaviors and individual demographic variables such as sex, race, income, or educational level?

This multi-method study involves a combination of interview, public participation mapping/social network visualization and a short questionnaire. A purposive sample of thirty participants will be selected from two communities in Florida – one in urban South Florida, and one in rural North Florida. Participants will answer questions about information practices related to raising their children with Down Syndrome, complete demographic surveys and create community and social network maps. A grounded theory approach will be taken toward interview data analysis.

Down Syndrome is the most commonly occurring chromosomal condition in the United States (National Down Syndrome Society, 2010). Understanding of funding, rights of children and parents of children with Down Syndrome and treatment options is important for parents, because those who do not understand these issues are at a disadvantage when engaging in decision making with health care providers, therapists, schools, and other government officials.

Understanding how place-based community affects parents' access to information (and how some communities are able to engage parents and seek and provide information more effectively than others) could help improve information accessibility. Any agency that provides public services can benefit from a better understanding of issues surrounding place and information behavior. There are also theoretical implications for improving understanding of the issues surrounding the effects of place-based community on information behavior and access. If, as Raber (2003) claims, human beings are essentially social, then understanding communities, and community behavior is as vital as understanding individual information behaviors.

References

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