Chapter 10
Community Networks:
Infrastructure and Models for Therapeutic Support

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ABSTRACT

The authors present a socio-technical design that illustrates how a community network health intervention can mobilize human resources across social boundaries and enhance health and well-being for people on both sides of the boundary. They specifically address how to reduce the barriers to social engagement experienced by autistic individuals who want more supportive life opportunities. The authors focus on the social milieu of an American college town, on traditional town-gown boundaries, and on possibilities for integrating social resources within this context. Their design adopts community networking to not only connect autistic persons living within an existing social milieu (university undergraduates; local autistic children and their families), but also to integrate individuals across milieus. The key design idea is that facilitating cross-milieu interactions can initiate and sustain a virtuous cycle of being helped by helping others.

INTRODUCTION

Community networks are online communities that are coextensive with physical communities. They are infrastructures for exercising and developing civic life, including community nonprofit activities, and social networks, social support, and social capital throughout the community. They particularly enhance neighbor-to-neighbor interactions, relaxing the constraints of time and space, but strengthening community attachment and community engagement. In this chapter, we discuss the history of community networks in supporting community health from the Cleveland

Freenet in the early 1980s to the Blacksburg Electronic Village in the mid-1990s. These early efforts were landmarks, but were limited by then current networking technologies (telnet and the first-generation Web, respectively) and addressed community health quite broadly.

Building from these concepts and approaches, we propose a model that leverages Web 2.0 technologies and participatory design methods for developing community information systems and applications. One key contribution from Web 2.0 technologies is their richer support for social interaction and exchange. To illustrate the potential of the new model, we discuss a design example that benefits from the kinds of interaction these technologies afford—a developmental online community that we are building to support autistic young people and their families. We describe the participatory design methods we are using, emphasizing the more focus such methods bring to needs of patient, families, friends, and other community.

Our work on community networks leverages the complementary concepts of online community. As a broad concept, online communities seek to address the entire world through the Internet. They mitigate distance through networking software, increasing the possibility of critical mass for the discussion of particular conditions, but bring together people who are essentially anonymous. Community networks use networking software but to address particular locales. They leverage the physical proximity of members, increasing the possibility of more intimate and socially multifaceted support among people who either already know one another, or are only a link or two removed in the community social network.

In the first half of this chapter, we first present relevant background on the needs of autistic young people and argue that these needs might be addressed with Internet-based solutions. We briefly summarize the history of community networks and describe the concept of a developmental online community - a specialization of online community

that is aimed at developmental goals. In the second half of the paper we present a design example, showing how a developmental community for autistic individuals and their families might be supported by Web 2.0 network technologies.

BACKGROUND

Many researchers have been studying issues related to individuals in the autism spectrum. Much of this work has focused on the problems of reliably diagnosing the presence and level of the disorder. In this brief review, we direct attention to two strands of research most relevant to the work we propose to do: the current understanding of needs by autistic students and their families and Internet-based support opportunities afforded for autistic individuals and their families. We follow this with brief discussions of community networks and the concept of developmental communities – because this forms a base for the therapeutic intervention we are exploring

Needs of Autistic Individuals and their Families

There are many obstacles for Autism Spectrum Disorder (ASD) individuals to develop social skills and to acquire strategies that at once leverage their cognitive strengths (e.g., autistic children often have excellent math skills) and address their weaknesses (e.g., spatial memory and integration). Parents have difficulty accessing information that can help their children; there is often a lack of knowledge as to where and how to look for resources (Pain, 1999), an inability to comprehend information (Jackson et al, 2007), and confusion surrounding the availability of services (Mitchell & Sloper, 2002). The emotional support networks for parents of children with disabilities tend to differ from traditional family support networks (Kerr & McIntosh, 2000; Tsibidaki & Tsamparli, 2007), as these parents want to meet other par-

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