

# Commentary

## Don't Make Decisions About Us, Without Us

Robert Berke, Ann Morse Abdella, and Laurie K. Adams

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Chautauqua County, known as the “western gateway” to New York State, is a rural county located in the southwest corner of the state. Bordered by Pennsylvania to the south and by Lake Erie to the northwest, Chautauqua County has a population of approximately 137,267. The population is distributed across two cities (Jamestown and Dunkirk), 27 towns, and 15 villages. The racial makeup of the county is 94 percent White, 2.2 percent African American, 0.4 percent Native American and Alaska Native, and 0.4 percent Asian; 4.2 percent are persons of Latino or Hispanic ethnicity. The median household income is \$33,458, and 13.8 percent of the population lives below the poverty level. About 24.5 percent of the population of this county is youth.<sup>1</sup>

The county is proud of its history and works hard to preserve it. There are six beautiful lakes, with close to 50 miles of shoreline to Lake Erie. The bodies of water in Chautauqua County are significantly related to the history of the county. The county has the most farms in New York State, producing more than 15,000 acres of grapes, and eight wineries. The Chautauqua Institution, founded in 1874, attracts more than 142,000 visitors annually who participate in summer educational and cultural programs. Recreational opportunities include public trails for hiking and biking, boating and canoeing on the lakes, and skiing. There are 24 active historical organizations and museums that enhance history courses in the schools and also educate the county's population related to Chautauqua County.<sup>2</sup>

Like any other community, Chautauqua County has had its share of public health challenges. Alarming high teen pregnancy rates in the early 1980s and again in the early 1990s caused the Chautauqua County Health Department (CCHD) to invest considerable resources to address the problem. As a result, the CCHD was successful in dropping the teen pregnancy rates, and won

awards at the state and national levels for exemplary modeling of cooperative efforts between schools and county government in addressing this public health issue.

To advance its public health goals by further engaging the community in public health initiatives, in 1997 the CCHD responded to a competitive solicitation issued at the very beginning of the national *Turning Point* initiative. *Turning Point*, a joint program of The Robert Wood Johnson Foundation and the WK Kellogg Foundation, was established “to transform and strengthen the public health system in the United States by making it more community-based and collaborative.”<sup>3</sup> The CCHD viewed *Turning Point's* community-based and collaborative approach as an opportunity to further Chautauqua's public health goals.

However, an unexpected crisis occurred in October 1997.<sup>4</sup> Following more than 5 months of an intensive public health investigation, it was confirmed that 15 adolescent and young adult women had tested human immunodeficiency virus– (HIV) positive as a result of contact with one man, and as many as 134 teenaged girls and young women were potentially exposed to HIV infection through sexual contact.<sup>5</sup> The incident received national press attention<sup>6–10</sup> and shook the community's pride.

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Community-wide self-reflection focused on why events occurred as they did. Because youth demonstrated both a dramatic increase in HIV infection rates and previously unrecognized high levels of sexual activity, the community was forced to acknowledge that some of its young people had unmet needs. For unknown reasons, youth were not being affected in the way intended by community programming. However, the county was uniquely positioned to respond to this crisis, because of its size and progressive public health commitment.

Recognizing the need to develop both short-term and long-term objectives, a community conference was held in December 1997. Despite short notice and stormy weather, the conference was well attended by approximately 160 participants, including high school students, parents, teachers, principals, faith leaders, business leaders, foundation representatives, minority representatives, representatives from county and state agencies, and representatives from the Centers for Disease Control and Prevention and nonprofit agencies. The format of the conference was a dialog between the conference participants and community-based agencies. Of 69 participants who provided feedback, 65 (94%) found the conference to be valuable and 60 (87%) indicated that they would be willing to be a part of programming that fulfilled long-term objectives. Short-term objectives were accomplished by collecting input and solutions at the conference regarding the current public health issue; a short-term response team evaluated the input and selected key improvement areas, which were developed and implemented. The long-term objectives embraced a new paradigm for integrating public services to ensure the community's well-being.<sup>11</sup>

Coincidentally, Chautauqua County received notification that its *Turning Point* proposal was successful and that funding from The Robert Wood Johnson Foundation and the WK Kellogg Foundation would be forthcoming. In recognition of local circumstances, the CCHD and *Turning Point* representatives agreed that the project concept would be revised to focus entirely on youth engagement in the community.<sup>12</sup> Guided by the slogan, "Don't Make Decisions About Us, Without Us," Chautauqua County's teens connected nationally with peers to share their experiences and insights. Chautauqua County was a focal point for national adult and youth discussions regarding empowerment and transition to new models of engaging youth in meaningful ways.

Through funding from the New York State Department of Health (NYSDOH) and *Turning Point*, a *Kidsultants* program was developed to engage youth from each of the county's school districts. On the basis of a standard business approach of using expert advice

when developing product lines, *Kidsultants* taught community leaders the value of accepting teens as active, paid participants in policy making. The CCHD's coalition of schools and community-based agencies had a history of collaborative efforts in the development of teen pregnancy prevention programming in the community, allowing for a culture of trust and mutual respect that is essential in youth engagement. A facilitator coordinated activities that crossed school district boundaries. In addition, an individual served as a neighborhood organizer to identify and develop community asset mapping that laid the groundwork for meaningful dialogue at the community level, with teens as active participants.

Early successes with the *Kidsultants* model created a high level of interest among local businesses and agencies for youth to provide consultation services. Services included teen focus groups to critique the merits of future initiatives of the county's tobacco control coalition, advice regarding the marketing of new local telephone company products to young people, and youth-only summits to address youth-related issues in the county.

Continued commitment by the NYSDOH to assist the CCHD to establish criteria for policy and youth-based initiatives created opportunities for youth to be involved in decision making and policy change. In New York State's *Reality Check* program, Chautauqua's youth, community leaders, and health advocates developed initiatives to target audiences with tobacco prevention messages, with an emphasis on education about the tobacco industry's marketing practices.<sup>13</sup> This movement created a statewide campaign for policy change, driven by youth who were actively involved in decision making.

Despite the redirection of some efforts and funding related to youth into corporate models or mandated activities, youth continue to have a decision-making role in the development and implementation of youth-related activities. Eight years after the beginning of efforts such as *Kidsultants* and *Reality Check*, Chautauqua County continues to invest in youth development efforts.

## ● Looking Ahead

Public health policy is traditionally guided by data-driven models available to adult decision makers. Business, on the other hand, uses a market-driven approach, on the basis of perceptions of targeted consumers and the advice of consultants to help guide the product to market, prior to launching any new initiatives. Following the crisis generated by the HIV-cluster, the CCHD reoriented local public health practices and

incorporated business techniques to draw target audiences into the development of local health policy. As a result, public health policy in Chautauqua County is now made with input from those it is intended to affect, even though political realities make this a challenging process.

The training and inclusion of teen *Kidsultants* in conjunction with efforts to prepare adults to accept and work with youth at the community level is a model with merit. However, there must be a long-term and broad-based commitment if this approach is to inform and affect local policy. Involved teens need to be trained to acquire the requisite knowledge, skills, and attitudes to be active partners in the decision- and policy-making process. Adult community leaders also need to acquire new skills and attitudes, enabling them to interact with youth in these processes. As teenagers involved in these activities grow into adults, their successors will need to be trained in an ongoing fashion. If youth are treated with respect and are valued, they should be more respectful and welcoming to youth themselves when they are adults, on the basis of their firsthand experiences.

Youth represent an essential resource to inform and improve community health. In response to an unexpected public health crisis, Chautauqua County learned a valuable lesson about the groundwork necessary to develop, implement, and then sustain health policies and programs to reach and react to the advice target communities.

The CCHD continues to work with community-based programs and initiatives that collaborate with youth. Youth involved in these initiatives are then assimilated into our communities as adults who desire to be involved in policy changes.

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