

Project tackles health care issues

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I recently met with Mandy Nichols, director of health care policy for the Arc of Massachusetts, formerly the Massachusetts Association for Retarded Citizens. She spoke about a new project she is overseeing to improve health care access for individuals with intellectual and developmental disabilities. As part of the initiative, the project also seeks to improve the quality of care and make resources attainable for everybody. Funding for the project is coming from the Boston Foundation and Community Foundation of Western Massachusetts.

The first step was to gather information from the community about health care and personal experiences in order to understand what changes are needed to make the necessary improvements. Arc sponsored 10 focus groups across the state, including Springfield, which was hosted by the Multi-Cultural Community Services. The focus groups consisted of self-advocates, parents, guardians and long-term support professionals.

One of the major findings of the focus groups was the issue of communication barriers. For example, people whose primary language is not English had difficulty communicating with health care providers. This also applies to non-vocal individuals or people who communicate through sign language.

Nichols said another significant issue was the difficulty of receiving quality health care due to what she described as "a complex maze of finding quality health care." The self-advocates brought up the issues of lack of direct communication as well as the assumption that they could not communicate for themselves or understand the issues.

Along with the focus groups, 26 interviews were conducted with medical personnel, state legislators and insurance providers. With 84 online surveys completed by those who could not attend the focus groups, the project team completed its research.

The team is in the final process of writing a report that will be shared through community meetings and the media. After gathering support and gaining key allies, the team will be ready to make suggestions and plans to resolve the issues uncovered by their research.

Nichols' research brought up many issues that people with disabilities deal with every day, including health care and other parts of their lives, such as dealing with stigmas, communication barriers and the lack of resources.

It will take a collaborative effort to change policies and to improve health care for all.

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