
People with Developmental Disabilities Focusing on Their Own Health Care

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People with developmental disabilities have often been denied the opportunity to participate in their own health care decision-making. This paper describes how a group of adults with developmental disabilities began to correct this inequity. With support, seven individuals with cognitive limitations learned how to make choices and decisions about their own health, and then created a training program that enabled them to advocate for others like themselves on health care decision making.

As people grow older, they experience more medical problems. This increased need for health care becomes complicated as people are faced with changes in the health care system — with the increased use of technology, with the emergence of managed care, and with the need for advance directives. Making medical decisions is often confusing and difficult. Having a cognitive impairment increases the relative complexity of making these health care decisions. Complexity and decision-making needs, which may be ill-matched to individuals' capacity to respond to those needs, brings into question the role that individuals with developmental disabilities should have in their own health care. Using a project by the University of Missouri-Kansas City as a base, this paper will examine that role. When should the individual be the one to make decisions to seek medical attention? How can individuals with developmental disabilities make decisions about life-sustaining procedures? What role should they play in determining the type of treatment they receive?

In 1992, researchers at the University of Missouri-Kansas City (UMKC) Institute for Human Development/UAP saw a need to work with adult individuals with developmental disabilities to learn what they thought about decision making in their own health care. A focus group was formed, consisting of seven individuals with cognitive impairments who agreed to participate in

focused discussions about health care choices and decision making.

Focus Groups

Focus groups are an important research tool for applied social scientists (Stewart and Shamdasani 1990). They may serve a variety of purposes, but most frequently they are used early in a research program where little is known about the phenomenon of interest. Bellenger, Bernhardt, and Goldstucker (1976), along with Higgenbotham and Cox (1979), provide detailed discussions and examples of the use of focus groups. Common uses are listed in Table 1 on the next page.

The focus group discussions held at the UMKC Institute for Human Development/UAP supplied a surprisingly large amount of usable data. The participants were good at giving background information on opportunities, or lack thereof, to participate in decisions regarding their own health. They provided useful information during the production of the training materials, which were part of the project. They were also able to

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help prioritize and orient the work toward critical issues. This gave insight into the needs and concerns of individuals with developmental disabilities as they shared their ideas and experiences about participating in their own health care decision making.

An unexpected outcome of the focus group's efforts was the emergence of an advocacy group. Participants organized to advocate for themselves regarding health care choices and decisions and learned what it was like to make choices and informed decisions about their own health. The group determined they wanted to share this independence with others like themselves.

Topics of Discussion in the Medical Decision-Making Focus Group

Several categories of concern — for example, how to maintain good health, when to seek medical advice, how to interact with a physician — emerged during the early sessions of the Medical Decision-Making Focus Group, which it came to be called. These individuals are interested in maintaining their own health through exercise, proper diet, and other means, and want to know how to accomplish this. For example one person said she wanted to “keep good health” in retirement; another said, “you have to watch your

health. Old people just sit around and their health goes bad.” Weight control issues were mentioned as a concern by multiple focus group participants.

Historically, persons with developmental disabilities have not had a voice in decisions concerning their health care. Such questions as “How do you know if you are sick?” and “When do you call the doctor?” were regarded by focus group members as highly significant and meaningful. Discussions focused on the fact that most of the time it is a parent or residential supervisor who makes these decisions. Individuals related both good and bad experiences with physicians: sometimes people felt the doctor was helpful and informed them of procedures; at other times, these older adults felt that they had no control over events.

At times discussion shifted from health maintenance concerns and physician-related issues to more complex ideas such as advance directives, treatment consent, and managed care. Advance directives are seen by some to be an abstract concept; the notion that individuals with developmental disabilities cannot comprehend such a concept is commonly accepted. However, the Medical Decision-Making Focus Group shattered this notion. After a brief discussion about what

Table 1.
Common Uses of Focus Groups

- Obtain general background information about a topic of interest
- Generate research hypotheses that can be subjected to further research and testing using qualitative or quantitative approaches
- Stimulate new ideas and concepts
- Anticipate the potential for problems with a new program, service, or product
- Generate impressions of products, programs, services, institutions, or other objects of interest
- Learn how respondents talk about the phenomenon of interest. This, in turn, may facilitate the design of questionnaires, survey instruments, or other research tools that might be employed in more quantitative research
- Interpret previous quantitative results

an advance directive is, the group began to give examples of relatives and people they knew that had advance directives about feeding tubes and respirators. When discussing cancer, one member commented that if became critically or terminally ill, he "didn't want to suffer."

There were also several discussions on when and how to give treatment consent. Some members said that they had never been requested to give consent, nor had they ever given permission for treatment. Most often the consent to perform a procedure was assumed by the physician or obtained from a person providing support to that individual.

Concerns were also raised about managed care. The most common fear was the possibility that physicians not previously known to them would be substituted for their regular doctors and that they would not have the privilege of choosing their doctors. "I have had my doctor for many years," a focus member stated. "He knows me and knows what is wrong with me before I even tell him." This member did not want to change doctors; most other members agreed with him.

Following are other topics discussed. Each begins with questions and is followed by several responses.

On Growing Older

Question: *What's different about being older, compared to being younger?*

Responses:

- "Can't do as much stuff. Tendency to slow down a little bit. And your health is sometimes not as good either."
- "You get a bad heart and blood pressure and stuff, and you can't eat no more food; you have to diet and stuff."
- "My hair was black, and now it's gray."

On experiences with Medical Professionals

Question: *Do you ask your doctor questions?*

Responses:

- "No."
- "I ask him why my back hurts and why my

chest hurts, but he doesn't understand me."

Question: *What do you want to know from your doctor?*

Responses:

- "My doctor is crabby. I don't like him. I'd like him to tell me how I'm doing."
- "I want to know why people die. Why did my mother die? Am I going to die?"
- "Why my knees hurt."

Question: *When is a doctor not a good doctor?*

Responses:

- "He scheduled too many people at one time, and then he don't talk to you."
- "He gave me medicine and shots, and I didn't know what for. He acted like I couldn't hear."
- "Someone who just won't take time."
- "I didn't understand what they wanted and they bawled me out."

Question: *What makes a good doctor?*

- "Sits down and talks to you."
- "They know what to do if you tell him something's hurting."
- "He always takes time for us. He don't care how many's up there waiting; healways talks to us."

On Patients Rights

Question: *Why is it important to be told why you are at the doctor's office or at the hospital?*

Responses:

- "You want to know what is wrong, then you want to know what they are going to do next."
- "I want to have any worries about my health explained to me in ways I can understand"

How the Focus Group Became a Self-Advocacy Group

People who have an opportunity to participate in group process eventually learn to talk for themselves, listen to others, make decisions, solve problems, and feel good about who they are (Cunio et al. 1970). For members of our focus group, the experience of meeting and discussing regularly

lead to a shared history of achievement and a new collective identity. They learned to talk for themselves when in a medical situation and began to make their own decisions. The process generated a feeling of self-worth and independence. In essence, they became a group of self-advocates on health care issues.

According to Medgyesi (1992), groups offer an opportunity to develop self-confidence and leadership skills when in a supportive environment. In fact, focus group developed as the study indicated. As individuals became comfortable with one another and with the idea of discussing health care issues, their self-confidence and leadership skills began to grow. During a discussion on advance directives, one of the members commented about signing her own papers at the hospital: "They think I can't sign my own papers, but I can. I have the right to sign if I want to!" In the past, she had been offered few opportunities to make simple choices about what clothes to wear or what she could eat. Now she demonstrates that she can speak out for herself and identify clearly what her rights are regarding hospital admission papers.

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As the focus group began to develop self-advocacy skills, discussion turned toward methods of advocating for themselves and for others. The group was eager for knowledge about making choices and about possible situations in which they could make good decisions regarding their health care.

Obviously, advocacy for individuals with de-

velopmental disabilities is long overdue. People with cognitive impairments have long been denied the opportunity to assert their rights. With the help of the UMKC Institute for Human Development/UAP, Midwest Bioethics Center, the Medical Decision-Making Task Force, and Heartland Productions, the focus group created an advocacy tool for people with developmental disabilities, a video program called, "Healthcare Choices, Healthcare Decisions," that provides information about rights of persons with developmental disabilities while in a health care situation.

On the video the members of the focus group talk about rights in three different health care settings. In one, a task force member interacts with a dentist. In another, a member exemplifies what rights a person with a developmental disability has when at the pharmacy. In the third setting, a doctor's office, one of the members demonstrates a "good" visit to the doctor. The program uses language and illustrations that aid people with developmental disabilities in understanding choices in health care and assists them in making decisions about their own health care.

The establishment of the focus group and the creation of the advocacy tools have enhanced the self-image of task force members. The experience reinforced the fact that everyone has self-worth and something important to offer, especially as regards participating in health care decisions.

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