

Michael Fuss

Audio transcript: On the development of the concept of independent living

Date: December 4, 1997

Interviewer: Sharon Bonney

Note: Transcripts have been lightly edited; therefore there may be slight discrepancies with audio clips.

Bonney:

Let me back up a second to how you got from being John's attendant to being a co-manager with him of PDSP [Physically Disabled Students' Program].

Fuss:

We've got to back up then. Over the years we talked more and more about the future, and as the program expanded up there what should be done. I think that John and Ed and a whole number of other people up there [at Cowell Hospital]—a lot of them, not all of them—really felt grateful for the opportunity, but also very constrained by the limitations.

Bonney:

Of living in the hospital.

Fuss:

Of living in the hospital and being under a medical model, and of being actively discouraged from attempting to live on their own. Nurses would come up from the floor down below, and it was helpful to have the nurses if somebody was in trouble at night. But also they'd come up and tell people to be quiet or they'd start ordering people around like they were sick. Well, these guys weren't sick [laughter]. They had disabilities of one kind or another. Most of them were quads—not all of them. They were healthy, late adolescent to early adult, mostly males—though we had two women eventually—who wanted to be like everybody else and explore their life, explore possibilities. Don't forget the time. This is the middle to late sixties, and everything was exploding, everything seemed to be possible, you could do anything you wanted, that was the whole idea. So we talked a lot. There was a certain recognition on the part of the hospital administration that something had to be done as the program got larger. So they hired a nurse—

Bonney:

Who was it?

Fuss:

Eleanor Smith. I became her assistant, which put me in a position where I helped interview and do ongoing training with attendants, because that had always been a problem: we'd get these people who wanted to work, but then they had to completely train them from the beginning. So I

did training with attendants. I was there for like three hours a day so that I was available for anyone to use without having to use their attendant money to hire somebody. So I was available. They put me in a position where I was really *there*. We talked, and a whole bunch of ideas started coming up about what to do. I think my experience in organizing—because I had started a number of programs and had been involved in a number of things in the past—and my connections to the organizations on the campus that were trying to change the world at that point brought a certain advocacy and a certain style and a certain direction, and a belief that something could happen.

How it all evolved was not simple—it was complex. So we started thinking about it, and the ideas for the Center for Independent Living and the idea first of more of a group home sort of thing run by the disabled themselves—by the quads in this case. Put people in apartments, with a place that they could come for wheelchair repair, and maybe a meal, advocacy with the Department of Vocational Rehabilitation. All that started developing.

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