

# Lives of artists with disabilities documented in oral histories

When award-winning playwright and performance artist Neil Marcus was 8 years old, he was diagnosed with dystonia, a severe neurological disorder that set his life on a new path.

"I didn't know what it meant to be crippled," Marcus told interviewer Esther Ehrlich of the Regional Oral History Office at the University of California, Berkeley. "It took a lot of learning about society."

It's not easy to talk about being discouraged with one's disability, Marcus said, "because there's a lot of pressure to look good or to look hopeful."

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Marcus, who says that "life is a performance," is one of five performing artists and dancers with disabilities whose in-depth oral history interviews are available online as part of ROHO's Artists with Disabilities Oral History Project.

Funded in part with a \$30,000 grant from the National Endowment for the Arts, the project grew out of ROHO's Disability Rights and Independent Living Movement collection, which documents the social and political history of the disability rights movement, whose roots grew out of the civil rights movement of the 1960s.

Ehrlich said in the introduction to the online collection that those involved with the project "hoped to contribute to an understanding of the impact that the mainstream art scene has on those who, historically, have not been welcomed into it, as well as the role that artists with disabilities have had on artistic trends in the broader arts world."

On the Artists with Disabilities Web site, which can be accessed through <http://bancroft.berkeley.edu/ROHO/>, viewers can read transcripts and view excerpts of the artists' performances, enriching an understanding of what it means to be an artist with disabilities.

In addition to breaking new ground in documenting the lives and work of

artists with disabilities, the project breaks new ground in oral history interviewing techniques.

All of the interviews were videotaped in the narrators' homes, except for the interviews with Marcus. They were recorded at ROHO and relied on instant messaging between two computers set side by side as well as spoken questions and answers and frequent rest breaks to accommodate Marcus, who because of his disability, speaks slowly and unclearly.

Ehrlich described their initial interview session, the first of six that ultimately totaled 16 hours:

"I type a question. 'When and where were you born?' There is a long pause. Neil's body is curved forward. His finger hovers above the keyboard. He slowly steers his finger toward a key, strikes. Over and over, his finger hovers and strikes, hovers and strikes. I wait. 'I was born in 1954 in scarsdale ny.' I am astonished by how long it takes for Neil to answer my questions. He is working so hard, dripping sweat. What have I gotten us into? How will we possibly complete an interview of any substance if every word takes so long?"

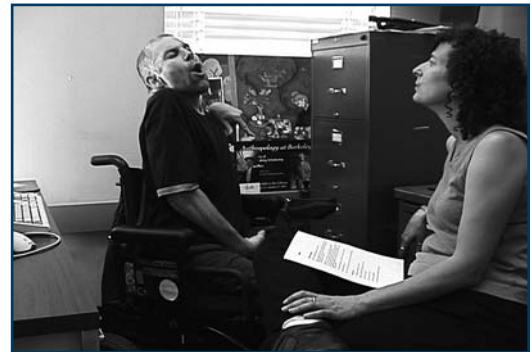
But they do.

As the transcript makes clear, Marcus and Ehrlich achieve a rhythm in questions and answers, sometimes instant messaging, sometimes speaking, sometimes with Ehrlich repeating Marcus' words for clarity for the transcriber.

Ehrlich said she learned to "aim for the heart of things" rather than use "precious time and energy" on typical, linear oral history questions like, "Where did you go to high school?" Instead, she said she entered Marcus' "world of pared-down language used powerfully, homing in, as Neil does, on what matters most."

In addition to Marcus' powerful interview, the collection includes detailed, dramatic interviews with:

- Poet, playwright and actor Lynn Manning, an aspiring visual artist



Esther Ehrlich interviews Neil Marcus. Courtesy ROHO.

who was shot by a stranger in a bar and blinded. He steered his creativity into writing and theater arts. Interviewing him included a visit to the judo class he teaches for blind and visually-impaired adults.

- Bill Shannon, an interdisciplinary performance and media artist who was diagnosed as a young boy with Legg Calve Perthes disease, a rare disorder affecting the growth of hip and leg bones. Using customized rocker-bottom crutches and a skateboard, Shannon's work is rooted in street dance but defies categorization.
- Judith Smith, artistic director of AXIS Dance Company, which she started after breaking her neck in a car accident. She pioneered physically-integrated dance, which involves collaboration of dancers with and without disabilities.
- Greg Walloch, a writer and performer born with cerebral palsy who incorporates his experiences as both a disabled man and gay man into his performances.

The site also pays tribute to Homer Avila, a dancer, choreographer and educator who lost his right leg and hip to bone cancer yet continued his dance career. Avila was involved in early project planning and was to be interviewed, but he died on April 27, 2004, two days after his last dance performance, before the interview could be recorded. ❖

#### Editor's Note:

Esther Ehrlich and Neil Marcus will be featured in a joint presentation at the Oral History Association's fall meeting in Oakland. Their plenary session, "Transforming Community," is scheduled for Oct. 25 from 10 a.m. until noon. Ehrlich is no longer with the Regional Oral History Office, but you can reach her at her new interviewing business, Story Lines, which creates videos and books for individuals, families and businesses. Her e-mail address is [ehrliche@sbcglobal.net](mailto:ehrliche@sbcglobal.net) and her telephone number is 510-847-0628.