

more quickly and more intensely than most of us. They learn from the beginning that our children have a claim on us even though they do not turn out to be what we expected. Normal children, of course, also always turn out to be quite different than we expected, but we are not made so intensely aware of the implications of that fact in those cases" (Hauerwas 1986)

Implicit in this paper is the belief that there is no universal ethic we can rightly apply to help us sort out the problems highlighted. I would argue that there is no such thing as "ethics," especially in the United States. Rather there are Amish ethics, Hopi ethics, Jewish ethics, Black pentecostal ethics, maybe even something that looks like modern American professional ethics. Consequently, decision making for our handicapped neighbors will reflect the unique characteristics of communities across this country. And well it should. Pivotal notions such as "autonomy" or "handicap" or "family" will be interpreted in thousands of different ways by thousands of different communities.

What might stand as a moral binder for us are the lives of the parents. "I think what we must do is let the witness of such parents guide our way, as they stand as a beacon to remind us what it means to be a parent no matter what our child may be like" (Hauerwas 1986) In letting these faithful parents stand as witnesses for us, we must surely learn what it means to be human.

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Kaleidoscope: 10 Years

A Review Essay by Mary Johnson

it's not the crutches we decry it's the need to move forward

Nikki Giovanni

Kaleidoscope, which calls itself an "international magazine of literature, fine arts, and disability" is celebrating its tenth anniversary. The fact that a literary magazine focusing on the disability experience has been publishing continuously for ten years should remind us that the experience of disability is not a barrier to creativity. Indeed, much of our art and literature has been born in the disability experience itself.

Why *Kaleidoscope*? Why 1980? In the first pages of this "look back" issue, we meet staff members who reminisce about the magazine's origins and its growth; they comment on mundane problems such as funding, staff roles, and office space. Yet I was looking for the answer to a more basic question: Why a literary magazine with disability as a theme?

In retrospect it seems that 1980 was a pivotal year in the disability movement, though few of us may have recognized it at the time. *Kaleidoscope* published its first issue. The Disability Rights Education and Defense Fund was founded. More than any other group nationwide, DREDF has championed disability rights legal action. DREDF staff successfully advocated Congressional passage of the 1990 "Americans with Disabilities Act," and in the early 1980s they organized the nationwide lobbying effort that saved the rules implementing Section 504 of the "Rehabilitation Act" and the "Education of All Handicapped Children Act." And in 1980 *The Disability Rag* published its first issue.

Now all three of us have reached the decade point. For *Kaleidoscope*, the passage of time signals a steady growth in literary work that focuses on the experience of disability as a valid springboard for creativity, rather than as mere

metaphor for something tragic, which is how disability has typically been treated.

In his essay "En-Abled Poetry," Joseph L. Baird discusses the change that has occurred:

Suffused as the subject of physical impairment has become (certainly in Western culture) with emotions of supersentimentality, self-pity, and sympathy, it is scarcely to be wondered at that such a theme has been branded as *verboden* by the canons of good taste. Yet one cannot help wondering whether this attitude does not speak to some deficiency in our own sensibilities. For the theme, in and of itself, is no less 'poetic' than the other frailties of the human condition...

Has the disability movement given us permission to write about disability "as though it mattered?" I can only guess. But, as Baird notes,

Almost totally unknown to the general public, a rather substantial body of poetry devoted to this theme has been quietly growing up over the past few years. Published in local anthologies, daily newspapers or magazines... these poems have gone largely unremarked. And yet in their simple, sparse delineation of tangled, complex feelings, and their penetrating glance at humanity from a startling, oblique angle, they have earned the attention of a far wider audience.

Although he doesn't mention it, Baird introduced a wider audience to this poetry in his anthology (co-edited with Deborah S. Workman), *Toward Solomon's Mountain: The Experience of Disability in Poetry* (Temple University Press, 1986), which showed that an "aesthetics of disability" is indeed emerging. This creative outburst, not only in poetry but also in fiction, theater, and dance, has stimulated *Kaleidoscope* and kept it publishing for ten years.

Kaleidoscope has published some of the finest writing born of the experience of disability. Poetry, fiction, and criticism have all been published in its pages, as have profiles of visual artists, musicians, and actors.

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This retrospective edition comprises writing and art that *Kaleidoscope* editors consider to be most representative of the work featured over the last decade. In it we find authors as diverse as essayist Nancy Mairs, award-winning fiction writer Anne Finger, and poet Nikki Giovanni.

Kaleidoscope was one of the first publications to discuss the effects of disability on creativity in the fine arts. An essay by James G. Ravin discusses the influence of cataracts and cataract surgery on the paintings of the impressionist painter Claude Monet. James N. Harris investigates the impact of scleroderma on painter Paul Klee:

As the scleroderma progressed, stiffening his arm and reducing his action, he began painting in wide, bold strokes, relying more and more on the ideogrammatic qualities of elemental lines and shapes. . . . And, just as Klee's brushstroke broadens and darkens, and his paintings acquire more resonance, so his entire technique is transformed.

Harris suggests that changes in Klee's style and materials testify, in writer Delmore Schwartz's epigraph, to "the witness of the body":

This "witness of the body" is a central theme that unifies disability art and culture. Someone once wrote that disability is an art. If that's true, it is nowhere better seen than in the disability culture mecca of the San Francisco Bay area. Disability culture? It's what psychologist Carol Gill contends is the "second wave, after fighting for our rights. The second wave is the emerging art movement." Bruce Curtis, who calls himself a "quadriplegic improvisational dancer," says that people like him who were once interested in social or political statements now see art as a way to make social, political, and personal statements. "Our disabilities are a way of interacting with the world," he says.

In the photograph (p. 104) of Santa Barbara **Access Theater** performers in a wheelchair *pas de deux*, *Kaleidoscope* graphically shows readers what the marriage of disability and art can be all about.

Over the past decade, artists in theatre, dance, painting, and music have triumphantly created a culture flowing from personal responses to their own disabling conditions. *Kaleidoscope* has chronicled this adventure, even though at times we see an uneven landscape.

Kaleidoscope was born with a commitment to publish fiction by disabled authors, and for ten years it has been doing so. The pieces selected for this an-

niversary edition range widely in tone and feeling. James Bellarosa's "A Problem of Plumbing" and Dallas Denny's "Just Another Year in Chronic IA" afford wry glimpses into the daily lives of two disabled people who seem less able to think about their disabilities than to plummet through life with them. Anne Finger's disability classic, "Like the Hully-Gully But Not So Slow," acutely yet with poignant hilarity shares the mixed-up feelings of preteen Kate in her leg braces confronting a family that's more than she wants to handle.

Because the voices of writers with disabilities need a place to be heard, *Kaleidoscope* has made it a point to publish their work. However, only now, in the emergence of a disability culture, can we find writing that deals with disability in a social and political context. Too many writers who use the personal experience of disability to craft fiction use it as a theme for personal catharsis. They don't examine their situation, or that of their peers, in any way other than how society (and their doctors) has taught them to see their lives: as a personal burden they accept and overcome, sometimes treating their disability with irony, sometimes with anger and bitterness, sometimes with humor, but always as a personal issue. In this anniversary edition of *Kaleidoscope* we can find fiction that sticks to the conventional path and some which, like Anne Finger's, begins to diverge.

But if disability is not yet written about from a social or political context as women and African-American authors have been doing in recent decades, there is an understanding that disability is a rich field, to be plowed deeply. As musician Ellen Hunnicutt puts it, her disability "gave me a glimpse into a mode of being I had not experienced before. It caused me to reassess my thinking in several important ways. . . . I must speak with total honesty," writes Hunnicutt. "During this period of my life, as I planned and plotted the music I could play, and wondered always if my condition would grow worse, *I was not unhappy!*"

Of her experience playing the piano while disabled, Hunnicutt writes, "I was manipulating my life, great chunks of experience and feeling, subconsciously, in the manner of Freud, of dreams, and of the structure of art itself. . . . My self-image changed subtly. I was no longer a depressive; I was a perfectly nice lady who happened to have disabled hands."

If one key theme emerges from sustained reading or viewing of works by artists who have experienced disability, it is that disability is rarely the problem. The

problem with disability is in the minds of the beholders.

Or, as poet Harold Bond puts it,
My affliction is
your hangup. It is yours more
than it ever could be mine.

Nancy Mairs is one writer who, while keeping disability personal, nevertheless shows its usefulness to her life as a writer:

Nearly ten years ago, I was told that I had a brain tumor, and this experience, I think, changed my relationship to adventure forever. I thought that I was going to die, that all my adventures were over. I did not, it turned out, have a brain tumor, but rather multiple sclerosis, which meant that, although they were not over, the nature of my adventures would have to change. Each morning that I wake up, that I get out of bed, is a fresh event, something that I might not have had. Each gesture that I make carries a weight of uncertainty, demands significant attention: buttoning my shirt, changing a light bulb, walking down stairs. I might not be able to do it this time. Inevitably, the minutiae of my life have had to assume dramatic proportions. If I could not love them, delight in them, they would likely drown me in rage and in self-pity, that tempting, obliterating sea.

Former *New York Times Book Review* editor Anatoly Broyard, who had cancer, says in his article "Good Books About Being Sick" (April 1, 1990 *New York Times Book Review*) that people who experience illness and disability need a literature of their own. "A critical illness is one of our momentous experiences, yet I haven't seen a single nonfiction book that does it justice," he laments. Even in fiction, he says, there are only a handful; among them he cites Thomas Mann's *The Magic Mountain*, most of Kafka, and Malcolm Lowry's *Under the Volcano*.

Kaleidoscope is making an effort to chronicle the first stirrings of "a literature of our own." In this attempt, we hear a voice emerging that, while focused on the intensely personal experience which for most of us has traditionally constituted the encounter with disability, seeks a timbre that will someday equal the finest writing produced by other oppressed groups who critique the human condition from their unique vantage points. For what better vantage point than disability?

As poet Nikki Giovanni puts it:
it's not the crutches we decry
it's the need to move forward