

Up with people

Dwarves meet identity politics

By David Berreby

Identity politics has been good for people with disabilities. For fending off prejudice, finding community and organizing politically to win things like universal wheelchair access and an accessible cash machine, the rhetoric of pride and rights makes sense. But insisting that deafness, for example, is an identity rather than a disability leads to political and cultural conflicts other communities don't face. After all, nobody tries to cure women of being female, and only a few cranks are still working on homosexuality. Genetics and medical technology are, however, gaining on disabilities. Is deafness an identity that needs protecting from doctors? Who gets to say so? To these contentious questions, another is now being added: Should dwarves be accepted or made taller? Is dwarfism a defect or a destiny?

About one birth in 10,000 in this country results in a baby with dwarfism, who will grow up with exceptionally short limbs (dwarves don't reach an adult height taller than 4'6"), though often with an average-size head and torso. A variety of medical complications can result from the condition, such as bowed legs, ear problems and spinal curvature. Most dwarves, however, are perfectly able to function normally with these conditions, and we have belatedly begun to overcome the stereotypes they once invoked. Little people, to use the correct term, were commonly shuffled off into entertainment (remember the munchkins? the endearing Australian sport of dwarf-tossing?), or relegated to a life of isolation. "Dropping out of school because they couldn't take the ridicule from the other kids, never learning to drive, living with their families and babysitting for their sister, that kind of life," says Ruth Ricker, a technical assistance specialist for the federal Department of Education's Office of Civil Rights in Boston.

Though most dwarves score no differently than other people on intelligence tests, some were shunted into institutions for the retarded.

A group of people, in other words, ripe for the benefits of solidarity. A dwarfed actor named Billy Barty saw that prospect and in 1957 founded the Little People of America, which has now grown into a nationwide organization of some 5,000 families. The LPA sponsors monthly meetings of its fifty chapters and a week-long national convention, publishes a newsletter and maintains an Internet bulletin board. The group helps dwarfed couples adopt babies (some average-height couples give up dwarfed children) and provides psychological and social counseling.

But the LPA is also a political and cultural organization, the NAACP or NOW of little people. "We work to change building codes, for instance," explains Angela Muir Van Etten, a lawyer and LPA activist in Rochester, New York. "We request ATMs, pay phones, elevator buttons that can be reached by little people." The annual convention includes dances, talent shows, athletic events -- the trappings not of a hospital but a community. The group's mission statement speaks of assistance and guidance for little people, but also of "peer support" and "personal example," and of networking to "enhance knowledge and support of short statured individuals."

LPA activists know the rhetoric of identity. "If there were a magic pill that would make me wake up tomorrow and be tall, I would not take it," says Robert Van Etten, an engineer who is married to Angela Muir Van Etten. "Height has made me what I am." They even have their heroes culled from history. "You know who was a dwarf, although we don't like to talk about it?" Barty told *The Los Angeles Times* in 1994. "Attila the Hun."

Some 80 percent of dwarves are born to parents who are of what the movement carefully calls "average" height. So membership in the LPA was a lifeline for many people who, like many deaf people and many gay people, were alone in their families. "I joined when I was 6. Knowing all these adults as role models my whole life certainly helped me," says Ricker, now, in her 30s, the president of the LPA.

Four decades of activism seem to have worked. "In the 1950s, most of our people were in entertainment," Ricker tells me. "A lot were not educated." Now, parents are less likely to send a dwarf child off to classes

for the retarded. Dwarves are far more likely to be lawyers, engineers and other white-collar sorts. And, if mainstream America isn't yet saying "little person" the way it knows to say "African American," dwarf-friendly plots have made it into the recent film *Living in Oblivion* and onto episodes of TV shows as distinct as "Baywatch" and "Seinfeld." "There's a lot of people in LPA who don't consider short stature a disability," Ricker declares.

But, she adds, only some 10 percent of the country's little people are in the organization, and there are many who still grow up in isolation, treated like freaks or morons. The Human Growth Foundation, an organization for families with children, cites studies showing that shorter people are literally not given as much space as others: people stand closer to them than they do to taller people. A study published in the *Journal of Pediatrics* in 1990 reported that men over six-feet earn starting salaries 12 percent higher than shorter men. A study by Linda Jackson and Kelly Ervin of Michigan State found that people rate tall men more attractive, accomplished, fit and masculine than short men. They rate tall women as being higher-class and more physically attractive than short women. These prejudices against short people are redoubled in the experience of dwarves, who are even shorter and who look different. "The reason little people have so many problems is not size," says Angela Muir Van Etten. "You can deal with the physical aspects. The hardest thing is people's attitudes. You can go out and get yourself an education and prepare yourself for the job market and find people who won't hire you."

So activism has given little people the same kinds of choices faced by members of other groups -- assimilation or insistence on one's difference. Do you militantly insist on difference and demand your place at the table ("we're queer, we're here, get used to it"), or do you stress the common ground ("hath not a Jew eyes? If you prick us, do we not bleed?")? But this choice -- once theoretical -- has suddenly become real. Advances in medical technology are giving us the option to make dwarves taller or to prevent them from being born at all.

First, in the 1980s, came a surreal-sounding surgical procedure that literally stretches dwarves' arms and legs. A surgeon cuts small incisions through skin and muscle to reach the bone, which he slices into two sections. Then he implants high-tension wires into the two sections of bone. These are connected to a "fixator": a frame, roughly resembling the

Eiffel Tower, that goes around the limb like a cast. The fixator pulls the two sections of bone apart -- with help from the patient, who has to turn screws on the apparatus every day to keep tugging the bone along. The body's natural healing mechanisms do the rest of the work, growing extra bone, muscle and skin as the tension continues. At the rate of about a millimeter a day, over a span of several months, the bone can be extended to as much as a foot longer than it would have been without "the human erector set," as some professional papers call it.

Developed in the 1950s and '60s by Gavril Abramovich Ilizarov, an orthopedist in the city of Kurgan, 1,000 miles east of Moscow, the technique came to Western Europe in the 1980s and was first tried in this country in 1987 by Dror Paley, now a Baltimore surgeon and an associate professor at the University of Maryland's medical school. There are a number of variations on the method, Paley says, but they all derive from Ilizarov. It has caught on fast, replacing much bloodier and less successful approaches like the Wagner Method, in which, Paley says, "you just cut through everything and crank it out at about two millimeters a day." Now, hundreds of the operations are performed every year. Paley himself -- now a co-director of the Maryland Center for Limb Lengthening and Reconstruction at the Kernan Hospital in Baltimore -- has performed some 1,500 since 1987.

The vast majority of the operations, though, reassemble shattered limbs or straighten bones deformed by infections, cancer surgery or birth defects. (A common use is to lengthen an injured leg so it will be as long as its counterpart.) Why, the LPA activists like to ask, should a little person put him or herself through it? After all, the Ilizarov technique is no day at the beach. The treatment takes months and is demanding in many ways, "especially," one journal abstract adds helpfully, "for the patient." Some people who've been through it say the lengthening bone merely aches; others say the pain is far worse than that. The patient can walk after a few days (the Ilizarov apparatus bounces along with each step like a trampoline), but the procedure requires physical therapy, and there can be complications, such as temporary palsies and other odd nerve behavior, infections from the wires, difficulty standing on the toes. The surgery is also expensive (\$80,000 to \$130,000 to lengthen a pair of legs, Paley says), though insurers often cover it. Most poignantly, as a way of making dwarves taller, it can only be performed on kids. After age 20 the bones aren't flexible enough to stand the stretching.

The LPA take on the surgery invokes the rhetoric honed in movements of the gay and the deaf: the image of a lone swan amid uncomprehending ducklings, unaware what others of his kind are about. After all, the child on whom Ilizarov surgery is to be done is likely surrounded by average-height parents, siblings and doctors. "Many of these decisions about leg lengthening are being taken by parents long before a child is of age to really know," says Angela Muir Van Etten. "We're not just talking about size, we're talking about identity. It's like saying, 'I wish I weren't born.'"

But not all LPA members want to play the identity card as thoroughly as the leadership does. They say being several inches taller makes a lot of things, from driving to reaching the second shelf to getting a job, a lot easier. And they point to signs that the surgery can help forestall some of the back problems dwarves often develop later in life. So the LPA confines itself to pointing out the drawbacks and recommending that dwarves who want the surgery have it done in the experimental program at the University of California at Los Angeles, which is run by David Rimoin, professor of pediatrics at UCLA and a member of the LPA medical advisory board. Rimoin said he was "totally opposed" to limb-lengthening surgery until he attended a conference on achondroplasia several years ago where he was impressed by how pleased and pain-free some European patients were. He takes only patients 12 years old or older and includes psychological counseling in his program ("a waste of time," says Paley, who stopped counseling years ago). Rimoin stresses that he considers the technique a medical experiment, whose long-term effects aren't known. "We can't say no member of the LPA has ever had it done," Ricker concedes. "Though certainly no second-generation person has had it done." Arguments over the procedure have broken out on the group's Internet bulletin board, she says, and what she then describes is the familiar identity-politics drama of someone discovering that the sturdy scaffolding the group provides can also feel like a cage: "There was a guy on the board who had had it done, and there were people infuriated at him that he had had it done. And he got mad, too. He basically said, 'Don't psychoanalyze me when you don't even know me.'"

After leg-lengthening surgery got established in the late '80s, the '90s brought medical advances that may have an even more profound impact on dwarves: the genes that cause the condition are being identified. In the summer of 1994, for example, a team headed by John Wasmuth, a

geneticist at the University of California at Irvine, found the gene that causes achondroplasia, which is responsible for more than half the incidence of dwarfed babies in the United States. Five or six other genes are responsible for another 30 percent of dwarfism, and they're eagerly being sought. Later that same year, for instance, another important dwarfism gene was found by a team from MIT and the University of Helsinki in Finland.

There was never any doubt that a fetal test for the achondroplasia gene would be developed, because a fetus conceived by two dwarf parents has a 25 percent chance of inheriting the mutated gene from both mother and father, which dooms the baby to an early death. (He or she has a 50 percent chance of inheriting one copy of the gene, resulting in dwarfism, and a 25 percent chance of not receiving the mutation from either parent.) But the prospect of an amniocentesis test for dwarfism raises the question: How deep do "average-height" Americans' laissez-faire attitudes about identity go?

Ricker points out that the question presents itself not as a simple yes-no switch, but as a continuum: there are some 200 genetic anomalies that can cause rarer forms of dwarfism, each with its own character. "For example, diastrophic dysplasia is another condition. This is typically more disabling orthopedically than achondroplasia. People who have it use crutches. They wear special shoes. But we don't see this as any big deal." But, as the joke goes, what mean we? An average-height doctor trying to give prospective parents an estimate of "quality of life" -- the kind of cost-benefit analysis beloved of HMOs -- might see it as a bigger deal. So might those parents themselves.

The prospect is considered remote by some geneticists, but it nagged at Wasmuth. In the journal *Cell*, in which he announced his team's discovery, he went out of his way to argue that only dwarf parents should be given the option of testing a fetus for the gene. Wasmuth, who died last year at 49, often spoke about the dangerous prospect of "personal selection" interfering with "natural selection," and to illustrate his point he said he knew of at least one dwarf couple who wanted amniocentesis so they could abort *unless* the fetus was dwarfed. "I don't know anybody that would do that," Ricker told me. "Or that would publicly say they would, anyway."

This little tale of role reversal, though, does underscore an irony of this identity-happy era: achondroplastic dwarves, having the same mutation, literally share a gene. In this respect, they are more genetically isolatable right now than any ethnic group or gay people. And their condition is far more amenable to surgical reversal. Once stereotyped as little more than freaks, dwarves are now on the edge of the dilemma of science and identity. How their culture finally determines the question could have ramifications far beyond their small world.