

PRIVATE MATTERS

Public Stripping

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At a recent disability rights conference, a 30-year old woman with spina bifida described her medical experiences in a voice shaking with pain and anger. All through childhood and adolescence, Anne told us, the semi-annual orthopedic examinations her doctors required her to have took place in a large hospital room, with 20 or more doctors, residents and physical therapists looking on. After the hospital acquired videotaping equipment, the examinations were videotaped. During the sessions, Anne was permitted to wear only underpants.

When she was 12, she said, she tried to keep on her training bra. The head doctor, in order to explain something about her back to the residents, took it off without saying anything to her, but with noticeable irritation. A nurse quickly apologized — not to Anne but to the doctor.

Anne knew that when her sisters and classmates went to the doctor, they were seen by just one doctor, in a small, private room. No one ever explained to Anne why she had to be examined in front of a group. No one ever considered whether she found it embarrassing or upsetting to be viewed nearly naked by so many people. No one ever acknowledged to her that she was being used as a teaching tool. No one ever told her or her parents that she had any choice in the matter.

Anne grew up thinking that what she called “public

stripping," a crude phrase to describe a crude practice, was a periodic humiliation inflicted upon her because she was, as one young doctor called her, "significantly deformed and handicapped."

Anne's experiences are not unique. Privacy in medical examinations may be the norm for ordinary persons, but they're not the norm for disabled people — particularly not for disabled children. Doctors at hospitals and clinics which specialize in "pediatric handicapping conditions" such as spina bifida, cerebral palsy, muscular dystrophy, brittle bone disease and dwarfism have traditionally displayed their patients in front of colleagues, residents, therapists and other professionals. Although it may be slightly less extensive than a decade ago, the degrading practice continues today.

The individual is almost always examined without a hospital gown. Other procedures vary: she may be told to undress in the examining area; or he may be forced to disrobe with others in a hall.

My friend Joe, who has cerebral palsy, was repeatedly examined in an amphitheater where residents and medical students could line up to see and feel for themselves exactly how tight the muscles of a "spastic c.p." really were. Social workers, invited not for any clinical reason but just so they could feel "part of the team," looked on attentively.

The public strippings went on for Joe until he was 18, at which time he told his parents he'd never again go to any doctor for his disability. He never has.

It was only happenstance that I avoided public stripping myself. My first orthopedist, a consultant to a rehabilitation center, had both disabled and nondisabled patients, children and adults, whom he treated with equal respect and courtesy. He always examined patients in a private room, with only a parent present. Since the aim of the examination was solely to provide the patient with information, rather than to provide learning experience for other people, there was time when very little clothing removal was necessary,

My second orthopedist, associated with the esteemed Boston Children's Hospital, was a monster. He operated on me (as he did on almost all of his patients) with the result that my awkward but functional gait was turned into a snail-paced stagger. However, since Boston Children's Hospital, unlike some perhaps

more egalitarian hospitals, allowed the parents to "buy" the right for their child to be examined in private — and my parents could afford to do so — public stripping was the one indignity he was unable to inflict on me. Whenever I talk to someone who has had their privacy so incredibly violated, though, my stomach churns and I feel as though it has happened to me.

Doctors seem to find it hard to understand why anyone "suffering" from something so supposedly terrible as a "lifelong handicap" would be interested in anything so trivial as modesty and privacy. To them, the examination procedures they use on disabled children seem reasonable and efficient because they facilitate teaching and the exchange of medical knowledge. Why wouldn't "the handicapped" be eager to help in the development of cures and new treatments?

What the medical profession and perhaps the larger community does not comprehend is that disabled people who seek medical advice are like anyone else seeking such advice. By and large, we want to be *provided with* a medical service — not *render* one.

Examining a patient in front of and with the participation of an audience should be regarded as bad medical practice even when considered from a purely clinical viewpoint. A person may be so upset and intimidated that he/she will not disclose all the information the doctor would need to know in order to provide effective treatment. Indeed, it is virtually impossible for a patient to develop any rapport with a medical professional in such a situation. The actual results of the examination may be influenced as well; even at 4 years old, Joe was so uptight from the experience, he says, that he believes it was not possible for anyone to determine how tight his muscles were in a typical situation — or what should be done about it.

Public stripping also presents quality-of-life concerns. People who have been required to submit to the experience repeatedly say they have been traumatized by it. The trauma stems not only from being viewed naked or nearly naked by so many people, with videotaping or photography frequently included, but also from listening to oneself being discussed — often in quite derogatory medical terms — as though one were a defective machine.

Susan, who has a form of muscular dystrophy, was driven to hysteria and nightmares by hearing a large group of people,

oblivious to her views, dispassionately debate the multiple orthopedic surgeries she should have and the order in which she should have them.

Yet medical ethicists and others in the medical community who profess to be so concerned about "quality of life" when it comes to deciding whether it is worthwhile for a disabled person to live do not seem to be offended by public stripping.

Left unanswered is this question: If a person who's disabled can be subjected to medical examination procedures not designed for her benefit, can she not also be subjected to other things at the hands of doctors not to her direct benefit? Does a hospital's interest in giving practical experience to residents, for example, not play a role in recommendations for surgery?

Public stripping, of course, does not occur in isolation. Society's prejudices against disabled people are played out in medical settings in many virulent ways, ranging from indiscriminate surgery to unnecessary hospitalization to the denial of basic health care.

There are to be sure some health care professionals like my first orthopedist and my present physical therapist who will sincerely do their best for persons with disabilities who come to them for services. However, too often such individuals are found only by luck.

Both children and adults are victims of medical discrimination against disabled people. Children are the more vulnerable, though, since they lack the power to give and refuse consent. Moreover, parents who are slow to grasp the way the system works and who may be coping with their own prejudices may not always be able to act as effective advocates.

Unlike the women's movement, where health care concerns are high on the agenda, we in the disability movement spend very little time on medical issues. Our apathy in this area is amazing. We have not even begun to consider questions as basic as whether medical care given in segregated settings such as hospitals "for crippled children" can ever be equal. Not even deliberate medical murder galvanizes us into action.

As a movement, we seem to buy into the prevailing social myth that any problem a person has with the medical establishment is a personal problem — and probably the person's own fault.

However, equal access to medical care — that is, the right

to receive the same health care one would receive if one were not disabled — is as important and as vital to our interests as is equal access to transportation. Equal access to health care, like equal access to transportation, is a political issue.

Many health care issues will be difficult to resolve because they involve money and the readjustment of social priorities. We would be able to go far, though, in obtaining the right to privacy in medical examination by simply discussing the issue whenever and wherever we can. When publicly confronted with our views, doctors will find that public stripping is a practice impossible to defend.

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