

I: Bodies and Images

All of us develop images of our bodies and attempt to understand and accept our physical selves. In Western culture particularly, with its emphasis on and proscriptions for attractiveness, body understanding and acceptance is problematic for women. How much more problematic and important acceptance is for disabled women is the focus of this section. The chapters discuss disabled women's experience of their bodies as well as their attempts to reconcile their senses of themselves with cultural models of acceptable bodies and stereotypes of disability.

We need not cite the numerous examples of academic works that link disability to psychological disorders to make the points that disabled people are regarded as impaired people, and that disabled women are regarded as damaged and asexual.¹ The remarkable resurgence of concern with health, fitness, and physical beauty in the 1970s and 1980s has prompted feminists to reiterate or reframe questions about the cultural meaning of femininity and beauty.² Lakoff and Scherr (1984), for example, discuss appearance as the last taboo and great divide among women. Even in the women's movement, women avoid acknowledging their attractiveness or feelings of competitiveness about appearance; they do not admit to themselves or to others that appearance matters in this culture. The feminist discussions of self-image or competitiveness among women are not related to disabled women. How do women with disabilities come to terms with bodies that depart from cultural norms of acceptability and attractiveness? The silence in the literature seems to imply that the implications are obvious.

Like some recently published accounts of disabled women's lives,³ the following chapters contradict much of the prevailing wisdom by testifying to women's capacity to integrate experiences that are conventionally associated with drastic and adverse psychological consequences. Gelya Frank presents an anthropological reconstruction of Diane DeVries' life experience, DeVries, a woman with congenital absence of arms and legs, challenges preconceived notions about identity and appearance. Beth Meyerowitz, Shell Chaiken, and Laura Clark explore the meaning of breast cancer to women who were socialized as

non-disabled women and who experience this body-altering disability in adulthood. The section closes with Deborah Kent's childhood and adult responses to literary portrayals of disabled women within the framework of her own search for identity. She contrasts negative and devalued stereotypes with depictions of disabled women forging positive self-images and leading rich lives. Because no one develops a sense of self apart from others, these chapters open the discussion of relationships that occupies the following section.

Notes

1. For classics of psychoanalysis on body image with bearing on the mental health of people with disabilities, see S. Freud, "Some Character-Types Met With in Psycho-analytic Work," *Standard Edition of the Complete Psychological Works* (1916), vol. 14 (London: Hogarth, 1953-1974); E. Jacobson, "The 'Exceptions': An Elaboration of Freud's Character Study," *Psychoanalytic Study of the Child* 14 (1959), pp. 135-54; A. Lussier, "The Physical Handicap and the Body Ego," *International Journal of Psycho-Analysis* 61 (1980), pp. 179-85; W. Niederland, "Narcissistic Ego Impairment in Patients with Early Physical Malformations," *Psychoanalytic Study of the Child* 20 (1965), pp. 518-34. For a critique of psychoanalytic writing on people with disabilities, see A. Asch and H. Rousso, "Therapists with Disabilities: Theoretical and Clinical Issues," *Psychiatry* 48, no. 1 (1985), pp. 1-12. For a discussion of the implications for life chances of physical appearance for women and men, see E. Berscheid and J. Walster, "Physical Attractiveness," in L. Berkowitz, ed., *Advances in Experimental Social Psychology*, vol. 3, (New York: Academic Press, 1974); R. K. Unger, M. Hilderbrand, T. Madar, "Physical Attractiveness and Assumptions about Social Deviance: Some Sex-by-Sex Comparisons," *Personality and Social Psychology Bulletin* 8, no. 2 (June 1982), pp. 293-301.

2. For feminist discussions of the role of beauty in women's lives, see L. C. Poguebin, "Of Beauty," *Ms* [December 1983], pp. 73-78, 109; S. Brownmiller, *Femininity* (New York: Simon and Schuster, 1984); R. T. Lakoff and R. L. Scherr, *Face Value: The Politics of Beauty* (Boston: Routledge and Kegan Paul, 1984).

3. Writings of and interviews with British, U.S., and Canadian women with disabilities can be found in J. Campling, *Images of Ourselves: Disabled Women Talking* (Boston: Routledge and Kegan Paul, 1981); S. Browne, D. Connors, and N. Stern, *With the Power of Each Breath* (Pittsburgh: Cleis Press, 1985); and G. F. Matthews, *Voices from the Shadows: Women with Disabilities Speak Out* (Toronto: Women's Educational Press, 1983), respectively.

1. On Embodiment: A Case Study of Congenital Limb Deficiency in American Culture

GELYA FRANK

The use of the body for most people has a culturally prescribed, developmental, and finally habitual character. The individual with physical disabilities, however, must learn to integrate identity and function anew—to accept a variant body image and to learn to use the body automatically and unself-consciously in culturally acceptable ways. The purpose of this paper is to describe and interpret the manner in which Diane DeVries, an American woman, now in her thirties and born with quadrilateral limb deficiencies, views her body and uses it to accomplish everyday activities. The rubric will be “embodiment,” a concept taken from the phenomenological movement in philosophy (Spiegelberg 1976). A goal of phenomenological investigations has been to identify and describe the essential forms of human experience, beginning with the body as a locus for sensation, perception, and interaction (Merleau-Ponty 1962; Sartre 1957; Schilder 1950). In a recent article I drew on the life history of Diane DeVries to develop a theory of the phenomenon of empathy (Frank 1985). But here my purpose is applied, hence my reference to the phenomenon of embodiment as a “rubric” to **frame** a discourse on the experience of disability in American culture.

Experiences of the world presuppose an embodied consciousness habituated to the biological endowments of the species; these in turn constitute the way that the environment is perceived and experienced (Von Uexküll 1957). It is distinctive of human beings that they inhabit cultural worlds, each a selection and elaboration of elements with the

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capacities of our species (Hallowell 1956). The parameters of a world-view are time and space as defined by the culture (Kearney 1984). In Henry's [1971] ethnography of American families with schizophrenic children, attention to these highly abstract parameters helped make even the most mundane behaviors comprehensible: a father's usual failure to provide a flashlight on hikes while exhorting his frightened sons to keep their pace in the dark, an absent mother's sudden attention and display of physical affection when her infant strays close to traffic could be seen to promote patterns of dysfunctional behavior in the children given the cultural constitution of their environment. The concept of "embodiment" might well cover a broad range of traditional anthropological topics such as the effect on personality of weaning and toilet-training practices, the coding of voice and gesture for communication, and the ritual elaboration of life cycle events as expressions of the social body or the body politic (Scheper-Hughes and Lock 1987). A phenomenological treatment of such topics, as in the work by Henry, would emphasize the experience of the individual as the sensory and productive unit of the species. This paper addresses the embodiment of one individual, Diane DeVries, a woman with disabilities, in order to mark its features as an American case for this and future discourse.

To what other concepts might the rubric of embodiment stand in contrast? In the United States, the embodiment of persons with disabilities has been the target of research in social psychology on "adjustment" to physical handicap and illness (Barker 1977).¹ The approach holds that persons with disabilities experience inner conflicts because of a loss of body function or appearance that is culturally valued [Wright 1983].² The negative emotions accompanying loss and stigma may be managed through unconscious psychological defenses such as denial or through such conscious attitudes as the favorable reevaluation of one's intact features and capabilities relative to those impaired. Management of inner conflicts leads to active engagement in social life, a sense of achievement, and satisfaction. While this theory does explain the adjustment of Diane DeVries to her disabilities, it glosses over some areas of her experience, such as the cultural problem of interpreting when adjustment was indeed taking place. Diane rejected the use of prostheses for upper extremity function. Using Wright's terminology, it could be said that this represented an adjustment to the lack of arms and legs since Diane stressed instead her "asset values"—e.g., her womanly figure and her ability to write better with her stumps when unencumbered by artificial arms. At the time, however, Diane's rejection of prostheses was judged by clinicians to reflect poor adjustment and to auger a life of dependence. Looking back over Diane's life history, an

active and essentially normal pattern for her age, gender, and class is revealed (Frank 1984), which suggests that Diane did “adjust” to her disability as a participant in American culture. The embodiment of Diane DeVries—her view of her body and use of it—came into conflict, then, with the special culture of rehabilitation³ as represented by her clinical team.

There are other dimensions of experience that the more inclusive rubric of “embodiment” may illuminate better than the concept of “adjustment.” In addition to managing internal conflict and social interactions, a person with disabilities may face a heightened ambiguity⁴ in living a conventional American life. For example, the interdependence with others in daily tasks of dressing and toileting can engender an intimacy and identification that defies cultural definitions of the boundaries of the physical self. Consider Diane’s expression of participation in the embodied experiences of her younger sister:

It’s true that there is a Diane within this Diane who can dance which enabled me to teach my younger sister Debbs, but there’s another reason I could coach her so well. It’s hard to explain. Ever since Deb could walk she was taking care of me. I saw her body move from childhood’s awkwardness to adult gracefulness and strength. But not only did I see this, I felt her movements. In a sense, part of her body (the part I lacked on the exterior) was mine too. So, since I knew how her body moved, I could coach her in dancing.⁵

The problem of ambiguity further arises in forming a realistic body image on which function can be based. Diane grappled with the implications of being diagnosed as someone who does or doesn’t have legs. Through adolescence and early adulthood she believed, in disagreement with her clinical team, that she could walk with prostheses if an appropriate pair were fabricated. In 1981, Diane expressed a vision in which she was “restored” arms and legs:

“There’s a woman minister in the church. She’s highly anointed and has the gift of healing, and she’s been promised a miracle,” Diane told me. “I had a vision that God promised to restore my arms and legs. That minister was standing at the foot of my bed.” “That’s great!” I said. Perhaps wickedly, I added, “Did you ask Him when?” Diane laughed, and replied most reasonably, “In His own eternal time.”

Such an image represents a reservoir of latent powers, powers that belong to Diane by birthright. With her Christian faith, Diane still believes that she may one day walk. From the standpoint of embodiment, it would be an error to dismiss such experiences of the body as irrelevant to Diane’s functioning or as evidence of faulty adjustment.

There is an intactness to Diane’s descriptions of her body. She is

native to it; she knows it from the inside. Persons with disabilities like Diane are presently living out a dialectical problem in defining themselves as "disabled." By accepting this label, they are attempting to deal with their variance in straightforward ways that include accepting tax-supported services for independent living, engaging in collective action to extend legal protection for their rights, and even publicizing their lives in studies such as this one to promote understanding and social responsibility. At the same time, they are insisting upon their intactness and wholeness as individuals facing essentially the same challenges as other members of society—work, sexuality, family, play, and so on. Ultimately, they wish to be seen as "persons," not as "patients." For them, it is "being-in-the-world" that is important, as indicated by the response of the mother of a ten-year-old girl born without arms and legs to an article I had sent her on the life history of Diane DeVries:

I found it a little difficult to write a response to your paper because it was so very academic and it is so *different* to be living it day to day with someone like Diane or our Robin—we take for granted so much!!, presuming I guess that other people know what limb-deficient people *can* do. The adjustments we make in helping Robin are constants in our lives and therefore "normal"—forexample toileting and dressing. And we have tried to have Robin see herself as "normal"—and have found that her peers accept her as such in so many (or most) ways. Lots of day to day and living experiences of Diane are similar to Robin's, and adaptations are commonly made by Robin to get things the things she gets into and out of are wonderful. The enclosed article was done by the city editor of our local newspaper after several people had suggested Robin as a subject—he spent quite a lot of time on it and we think it's pretty nice. The hardest part is "being under the microscope" again, but we felt it might help educate a few people . . . there is no guarantee that anyone will not become handicapped at some time in their life, and everyone deserves as much freedom as possible. Maybe your **work** and our reality **will** help in this direction.⁶

If medicine aims at being not only curative but restorative, its goal must be to relate back to the world of the patient. We must therefore have conceptual structures—languages—that let us mediate our understanding across settings, from the clinic, to the academy, to the community. It is proposed that the very highly abstract concept of "embodiment" can give us a vantage to see the experiences of persons with disabilities across the boundaries of those settings. Finally, there is the temporal dimension. As the historical context in which persons with disabilities live is ever-changing, the cultural meaning of disability changes. People once regarded in Western cultures as "freaks" (Fielder 1978) or "paupers and beggars" (Stone 1984) are now defined as "persons with disabilities." Concrete descriptions will always be necessary to

comprehend the fit between theories of their embodied life and their lived experiences.

CLARITY AND AMBIGUITY IN LIVING AS A "CONGENITAL AMPUTEE"

Diane Fields DeVries was born on March 20, 1950, in a small town north of Dallas, Texas. She was the first child of Kenneth and Irene Fields, each 20 years old, white, nominally Christian, and the product of working-class homes. Another child, Debbie, was born two years later, after the family had moved to southern California. After several years, two more children—a boy and girl—were added to the family. Diane's father worked as a carpenter. At age 5, Diane was referred to the new Child Amputee Prosthetics Project (CAPP), at the University of California at Los Angeles, where she began a program of wearing artificial arms and legs. She was given a three-wheeled cart for ease of mobility. As a result of growth in her stumps, she underwent numerous surgeries during childhood to remove painful bone spurs. She also suffered from attacks of constipation, heat prostration, rhinitis, and asthma.

Until junior high school, Diane attended the Benjamin F. Tucker School for Handicapped Children and spent summers at the Los Angeles County Crippled Children's Society Camp. Beginning about the time of puberty, she lived for intermittent periods at Rancho Los Amigos Hospital, a Los Angeles County rehabilitation facility. There she gave up using her artificial arms, replaced the three-wheeled cart with an electric wheelchair, and eventually began wearing a pair of nonfunctional cosmetic legs, which she later abandoned. Diane attended a "normal" high school in Long Beach, and her first active sexual encounter occurred at graduation. The following years were marked by independent living in an apartment with her own attendant, the social use of "pills and weed," sexual experimentation, and frequent changes of residence. In 1969, Diane began living with Jim DeVries. In the turbulent years that followed, Diane and Jim split up. Diane bounced in and out of convalescent homes, her father was diagnosed with cancer, and her parents were divorced. Diane returned to Rancho, where she experienced an important love affair with a man with quadriplegia. Concurrent with the breakup of that relationship and the death of her father, Diane was motivated to leave Rancho and begin studies at UCLA. It was there, in 1976, that our collaboration began on her life history.

In 1977, Diane transferred to the University of California at Berkeley, partly to be at the pulse of the Independent Living Movement. Diane and Jim were married there. It was a year marked by Jim's

struggle with alcoholism and a tense adjustment to the responsibilities of married life. The couple returned to Los Angeles, filed for divorce, and Diane moved to a convalescent home. There, in 1980, she was "saved" at a Christian church and "healed" of asthma. In 1981, Diane **was** seriously injured in a car accident. Jim returned and was introduced by Diane to the church, where he **was** baptized by immersion and "delivered" of alcohol. Subsequently, Diane and Jim attended Bible college and their life, until recently, has been centered almost entirely around the church community. Despite rather frequent changes in residence and a minimal level of financial security, this has been a period of stability and peace for them. Their recent disenchantment with the "hypocrisy" of their church in integrating the disabled into full participation, and with other practices, has led them to break away. While Diane remains committed to a self-consciously Christian life, she has decided to return to **UCLA** to finish her undergraduate degree in sociology. Currently, she works on a part-time basis as a peer counselor at a transitional living center for persons with mainly traumatic disabilities. She presently plans to make a career in social work after graduation.

The events just recounted summarize and up-date the life history of Diane DeVries (Frank 1984). The synopsis is intended to provide background to questions of embodiment raised by Diane's having been born a "quadruple amputee," missing both legs almost completely and having above-elbow stumps of about equal length. At birth, Diane weighed 5 pounds 3 ounces and measured 17 inches. Labor lasted 48 to 60 hours and culminated in a breech presentation. Diane's mother remembered having a case of the "flu," which lasted three days near the end of the second trimester of pregnancy but was not severe enough nor early enough during the pregnancy to account for Diane's having been born without limbs. The lack of a known etiology leaves an open field for interpretation. Diane has taken the point of view that "it was just something that happened." This **was** Diane's father's response to her childhood inquiries. Diane argues strongly against any association of her limb deficiencies with thalidomide: not only are her "amputations" symmetrical and neat, but there are no other malformations. Compared to people having complex disabilities, Diane feels "*really* lucky."

- D: When Mom was pregnant with me, they had no idea that anything was wrong, because I kicked and the whole bit, you know. And they couldn't take X rays. It was too far past that to take X rays. So they had no idea. The doctor, when I was delivered, the doctor fainted.

G: Literally?

D: Literally. The **nurse** had to finish it. He was just out, you know. So they

got me out. And I guess they probably took some test to find out, but they never did.

G: Did your mother take any drugs while she was pregnant?

D: No. Well, see, I asked after, you know, when they were divorced. That's when I started asking a lot of questions, and first I asked *her*. And she kinda, every time I asked her she gets real quiet and looks away and doesn't *say* too much. You know, Yes, or No, and that's about it. So I finally got ahold of my Dad, and I tried to get him, and he says, 'All I **can** tell you is what I know. I know that when I saw your mother, she wasn't taking anything. And there's never been anything else like this in the rest of the family, going back.'" So, he doesn't know. *He* believes, my Dad believes, it's just something that happened. And I do, too. I don't believe she took pills. That's not like her.

C: No, but around the time you were born or a little bit later, there was a thing with thalidomide.

D: That was later. Yeah.

G: That was later.

D: That was about '56 or something.

G: Right.

D: But, uh, Dad believed and I do, too, that it was just something that happened. Because that's the only thing that's wrong with me, is just that I don't have no arms and legs. And they're nice and neat, too. I didn't have any weird fingers hanging off or any feet, you know. A lot of them have that.

G: Yeah, you were lucky

D: Yeah, I think I'm *really* lucky, 'cause I've seen kids like that, and I just, I couldn't stand it. At least I can dress how I want and look how I want, and I've been pretty lucky. So . . . but that was it. There was no other defects. Like my lungs weren't crooked, or my heart wasn't, you know, **up** in the wrong place or something. You know. So probably it was just something that happened, I would think.

From childhood Diane DeVries' attitude toward her body when healthy and free of devices has been remarkably positive. This sense of her body has persisted despite surgeries beginning at age 7 for painful neuromas and cysts at the ends of her stumps, attacks of asthma perhaps at first self-induced but later involuntary, and discomfort from heat due to her high ratio of body volume to skin area. While Diane was always aware of the differences between herself and others, they might often be taken for granted

G How old were you when you first realized that you looked different from most other people?

D I realized that right away.

G So you always had that awareness

D Oh yeah. It never hit me one day

G You never had a special awareness that outside your family people were looking at you differently?

D. I always knew it. It was always there because my body was so different

- G: How did you feel about that differentness? **How** did you understand it?
- D: I just knew I was different. Certain things could happen during the day to make me sad or mad, 'cause I could go . . . weeks without it bothering me at all, because nothing happened. But something *could* happen, like once when I was a little lud. I was in the wagon and we were in this trailer park, and some kid came up to me with a knife. He said, "Aw, you ain't got no arms, you am't got no legs, and now you're not gonna have no head." He held me right here, by the neck, and had a little knife. It was one of those bratty kids that did weird things. So that day, I really. . . . You know, certain times, certain **things** happened. Otherwise, I didn't notice it.

If Diane has moments of alienation from herself or feelings of regret about her body, she has not conveyed them to me. A more relevant focus for an individual like Diane may be to protect herself from the attitude so easily taken by the non-disabled that her body is flawed and unacceptable. In an interview, for example, I sensed a defensiveness in Diane's response to questions meant to elicit a global assessment about her body. "Do you feel like you're crippled?" I asked her. "Do you feel handicapped?" Diane answered, "Yeah. Lately." Her back had been giving her trouble. There **was** pain when she **moved** and difficulty in moving gracefully. She felt lucky that her arms were still strong enough to pull her up as she transfers from place to place. Taking her unexpected response as a cue, I asked Diane not to assess her body as a whole but to tell me how she feels about the parts she has.

- G: What's your strongest point?
- D: My arms.
- G: Your weakest?
- D: You mean physically? It's a toss-up between my back and my hips. Now it's my back. But that's iucking up my hips, too. My lungs are probably weaker than my back.
- G: What parts do you feel affectionate towards?
- D: My arms. I love them. My boobs. That's about it.
- G: What parts make you feel the reverse?
- D: My back. My lungs. My chest cavity. I hate them.
- G: How about your face?
- D: I don't know. I don't **like** my mouth. That area. I've always wished I could change that. My teeth and everything. It's weird.
- G: What's wrong with them?
- D: My lips—the top one—which is it? I haven't even looked at myself for days. Anyway, one of my lips is bigger. The bottom one goes in. I don't like it. If I could, I'd . . . {gestures}⁸
- G: Have your chin pushed down!
- D: **Make** it even. When I was young I never smiled. I hated my picture taken anyway. But when I had to have it, I never smiled, because I thought I looked dumb smiling. I got over it, but I don't remember at

- what age. I let it all out. Started showing ~~my~~ teeth because I wanted to laugh and smile.
- G: What about the rest of your face?
- D: It's all right except the acne. That's because I'm Aries and I worry. The rest is all right.
- G: How do you like your eyes? Your nose?
- D: They're not extraordinary, but I like them.
- G: What kind of ears do you have?
- D: My left ear sticks out. I've got my Dad's left ear. The right one's normal. It just goes back. So I always keep my hair cut over my ears, 'cause I don't like this left ear to stick out. They look all right.
- G: What does your back look like!
- D: . . . I don't know. I mean, I haven't seen my back in so long. Um. I know it's starting to look like. . . I noticed one day in the other apartment . . . I was getting out of the bathroom and I went over to the bed. The mirror was there standing against the wall. I looked at myself—hadn't done it in a while, didn't have no clothes on—and I could see that it was "going" . . .

Diane traced an "S" in the air with her stump to indicate scoliosis. Like us all, then, Diane scrutinizes her body and evaluates it according to normative standards of appearance and function. Expecting her to praise or damn her body as a whole is to force an alien perspective. Judging her body on its own terms, neither more nor less, she appears to judge well.

There are fundamental ambiguities concerning Diane DeVries' body, however, that she has had to live with and resolve. Paramount is the question of whether Diane does or doesn't have legs. The term "congenital amputee" is a misnomer. Diane supports the distinction between her congenital limb deficiencies and true amputations in part on the basis of never having had phantom pains, although she knows what they are through vicarious experiences at Rancho.

- G: Are you considered an amputee?
- D: Congenital amputee.
- G: That's a strange idea.
- D: Yeah, 'cause amputees you think of being amputated. I freaked out when they put me on the amputee ward. I don't have phantom pains—never had any of those.
- G: Do you ever have the feeling that you have limbs?
- D: Oh no.
- G: Never?
- D: No. But I can understand how you would move certain parts of you to do certain things. Like dancing I can really get into. That's why I think I could show my sister Debbie a lot—she dances like a mad—because I could understand which leg you move this way and that. Which I think is kind of weird since I've never done it. And I learned to walk really quick in my legs, get my balance, and use my arms really quick. But I

never feel like I have them. It's just that I know because I think about it a lot.

G: You talk with your hands.

D: But I never feel it like they do. I never get phantom pains.

G: Do they have the pains their whole life or just after the operation?

D: Some get it for quite a while. A guy at Rancho explained it better than anyone. He lost his leg ten years ago. They gave him an artificial leg. It's like putting a leg into a very tight cast. I could imagine what that could feel like—**just** awful. It's really painful, **like** your leg is in another thing, all cramped. It was really bad, so he would hardly wear it.

To call up an image of Diane in the company of people who have had an arm or leg cut off leaves something to be desired. Her "arms" and "legs" can only be postulated. They exist in a state of potential as much as in a state of loss. This is clearest with respect to Diane's arms. She does in fact have arms, in the form of two upper stumps of about equal length.

Diane's legs are more problematical. For all practical purposes, she was considered to be lacking legs. At CAPP she was diagnosed as having "congenital absence of both legs at the hips." In an early clinical description, however, Diane was reported to "ambulate" by swinging the left and right sides of the pelvis alternately forward. Diane would call this "walking." Six months after coming to CAPP, she received her first pair of artificial legs, two stubby pylons set into a pelvic platform. In them, Diane continued to walk by means of pelvic rotation. Even at this early date, the CAPP staff anticipated that for Diane walking would be achieved only with much difficulty because she lacked stumps to which artificial legs might be independently attached.

The language used to describe Diane's lower limb deficiencies itself evokes the presence of limbs. Notes at Diane's admitting examination at CAPP state: "There appears clinically and by x-ray to be a femoral head only on the right, and no bony components on the left lower extremity." Thus there is the suggestion that Diane has at least a rudimentary right lower extremity. Over the years other statements appear in the reports, such as: "The legs are represented only by soft tender nodules in the antero-inferior aspect of the groin-buttocks area. There's good anterior and posterior flexion of this tissue mass." While the word "stump" is never used to describe this area, the possibility of attaching prostheses independently to each buttock was considered. Diane's physical therapy at age 11, for example, included mat exercises to improve the strength in her gluteal muscles.

Today Diane thinks of herself as having the ability to walk **and** in some sense as having legs. She reports: "They discovered I had hip bones

when the doctors were standing around in preparation for my first surgery. I was walking already."

G: Walking?

D: Walking. On the floor. Scooting around.

G: How?

D: I just moved my hips back and forth. I still do it when I have to.

G: Give it to me in more detail.

D: I sit on the floor on my butt, and I move each. . . Well, these, I call them legs, 'cause they *are* in a way. Just move each one with your hip. Just like anyone else would. Just move the top of their leg. And I got around like that. You know, around the house, not outside.

G: Walking on the front part? What would be your thigh? Or on the point of it?

D: Just like I'm sitting right now. Except walking.

G: It's hard for me to visualize exactly what you have there.

D: When I was younger, it was just my butt. But then I realized I could move each and they were separate. So they were legs, you know. I walked on them. When I was younger and thinner it was easier I could bounce around. I used to be able to stand on my head! That amazes me when I think about it. I was really *light* then. They discovered I had **hips** and that surprised me, because I figured that if I'm walking, of course I had them.

Diane feels she does have independent legs, to the extent that she could move each hip in the prosthesis and "one leg would go out and then the other." But she does not concur with CAPP that "I don't have long separate legs. You know, stumps."

The ambiguous presence/absence of Diane's legs is exaggerated in the more symbolic and disembodied modes of being. Diane sometimes has legs in dreams and visions. She has referred to the battery for her electric wheelchair as "my legs" and to the mobility she gains in her wheelchair as "walking." Since she tells me that, given legs, her proportions would be tall, I am certain that she has imagined herself that way. She is familiar enough with what legs do and how they feel to coach her sister in dancing and to empathize with the phantom pains of a true amputee. And there are the jokes that are shared among friends and the banter in which Diane's legs are made conspicuous by their absence. At a birthday party, her friend Alice announced as we entered, "Hey, don't nobody step on Diane's toes." Later she threatened, "Ciane, if you don't have a drink, I'm going to sit on your legs." Preparing me for the sight of a black eye, Diane once mentioned that she had "walked into a fist." Is it just Diane and her friend who joke this way? "Everyone I know says things like that. It's only natural, I guess, 'cause I've always done it, so they pick up on it." Diane's mother is the only one, she says, who "freaks out" when Diane talks that way. "Debbie's always teasing Ma.

She's always saying, 'Yeah, when I was born, God gave Diane the boobs and gave me the arms and legs!'"

FUNCTIONING WITH AND WITHOUT ARTIFICIAL LIMBS

When Diane DeVries was brought in 1955, at age 5, to the Child Amputee Prosthetics Project, she was immediately fitted with a pair of artificial arms. Six months later she was fitted on an experimental basis for ambulation with a pelvic platform, a bucket with stubby feet. The goal of treatment at CAPP was "to provide limb deficient or amputee children with the means and motivation to lead as nearly normal, productive and satisfying lives as possible." In an interview with Diane's parents in 1959, her future was presented by the CAPP staff as a choice between being a *dependent person* with institutional type care or being an *independent person* with limited but attainable employment skills and capacity to take care of herself. To be "independent" would require prosthesis use. Thus Diane was trained to use prostheses—both upper and lower—from roughly age 4 to 18 to "increase her functioning," although it was felt that Diane would always be very dependent on others.

The clinical ideals for normalizing Diane's life conflicted with the choices she made for herself. Over time, she rejected the use of artificial arms. What she wanted passionately, however, was to walk. When Diane was 12, her occupational therapist wrote: "Diane's non-wearing at home and at school, her pleas for freedom from anything which tends to be heavy, her limited, but perhaps impressive ability with her stumps, her overgrowth problems and her frequent absences make it difficult to carry out a well-ordered therapy. But we do feel," the report continued, "that a substitute which will provide reach, firm grasp and motions which resemble those of the normal arm is advantageous and that the advantage will be more obvious in the future."

It was apparent from the very beginning that no matter how competently Diane learned to use her artificial arms, she would always need to have someone place things in her reach, pre-position her terminal hooks, or prearrange objects that she needed to handle. What advantage she might gain in reach and grasp using these complex devices was canceled by the restrictions imposed by the confining equipment. Many of the tasks she learned to perform slowly and with great effort using upper prostheses—writing, reading a book, or holding a cup—were ones she could perform with her stumps. It should be kept in mind that the pattern of Diane's childhood was a constant round of surgeries, brief periods of healing, physical and occupational therapy with and without prostheses, enforced wearing of prostheses at school, adjustment to new

prostheses as old ones were outgrown or mastered, growth of the bones in her stumps, consequent tenderness and irritation, and more surgeries. Punctuating this cycle were the bouts with respiratory illnesses and constipation. Wearing artificial arms complicated Diane's life and forced her to choose between her native capabilities and a questionable substitute. Artificial legs did not pose these problems.

In an interview about her various prostheses, Diane talked exclusively about the lower, and distinguished them with names of her own. First were "the little legs" (the pelvic platform)—straight, about a foot high off the ground, with feet that were "normal shaped." The tone of her recollection of them is casual:

The bucket top was a little bit of plaster on the butt and then when it came up to the waist it had leather going all around the waist. And then it just buckled in the front. Then coming down from this bucket thing were the two legs. They were made of, at that time, the plaster also. The skin-colored plaster. And then two little feet. So I could move around. And the legs, since they were so short, they had no knees or anything. Like two sticks, almost, with feet on them. So I could walk around. That's all I really needed them for, was just to reach tables—school tables. They weren't that useful to me. I could walk around in them. But I could walk around without them at that time. It didn't matter.

Diane was successful enough with the pelvic platform to be graduated within a year to a new prosthesis. This was a Canadian hip disarticulation type, modified over time to have rocker feet, locking knees, and solid functional feet.

Concurrently, she was given a three-wheeled scooter. The scooter was positively exciting. It was "like a tripod thing," Diane recalls. "It had three wheels. Two in the front and one in the back. And it stands on something like a pole, this bucket goody. You sit in it. First they gave me two crutches, because they were convinced I wouldn't give my arms up—no crutch does." She described the joy of a 5-year-old suddenly able to propel herself across the room:

D: I put my arms on and used the two crutches they designed and they put me in the scooter. And I came across the room and I *dug* it, 'cause it was so easy. And I thought, "Wow. Far out." I just tripped around the room, and they didn't want me to take it home that day, 'cause they had a few repairs and all. And I was mad. I was crying when I came home, 'cause I wanted it. But I got it a couple of days later. It was all finished. I had it until I was about 12.

G: What did it enable you to do that you couldn't do before?

D: Go outside by myself when I was home. Get around by myself. I did give the arms up. Then I needed only a crutch. I did it with my right arm perfectly, since it's the longest one. So I used it, and could go see my neighbor friends by myself.

G: What about stairs?

D: I was so light, I'd go over my friend's house and whoever was there would just carry me **up** the stairs.

G: What about stairs at your house?

D: Yeah. I'd have to go out the den. I always stayed in the den or in our room—Debbie's and mine. From our bedroom there's a little porch thing, then one stair and a den. I **got** down **that** stair by holding onto the door on one side, and **pit** my crutch on the other.

G: How did you get back **up**?

D: I'd just go over and hold the door with my left arm. Then I'd push up with the crutch just enough to get the right wheel up and then I'd push **on up**. I had good balance. I had to. I fell over several times, at school, going too fast, and there were bumps.

G: **So** you could go outside.

D: I could visit friends outside by myself. Get around school by myself. Didn't have to wait for someone to help me out of my desk or anything. I was already **up**, because I was in that thing all the time. I could reach things better because it was a more normal height for someone my age. It was really neat. The reason they took it **away**, at 12 you start realizing how you look to other people.

Diane gave up wearing artificial **arms** sometime after the tenth or twelfth pair. They were "more of a hassle than a help," she recalls. "Anything took longer. Turning pages. I can remember turning pages. For therapy they'd make me hold the book down for someone else. I used to hate that." It felt unnatural to practice using both arms equally, "which I'd hate because I was right-handed, so I'd always use this arm [gestures. They made me use them all the time. I hated it." Using just her stumps, Diane could color, simulate eating and drinking, and handle doll dishes, according to a diagnostic examination at age 9. Except for bilateral lifting, the right stump was used almost exclusively. Her range of "reach" (quotation marks in the original report) was limited and she asked to have objects put into her range so they might be skillfully manipulated with **her** stumps. She frequently used her head as a holding assist, requiring her to lean over the table, making her field of vision and posture poor. While her trunk stability was extremely good, and the lower exsremity prosthesis was "used well" for ambulation, the first appearance of Diane's scoliosis is noted. The evaluation resulted in a decision "to solve" Diane's upper extremity prosthesis problems before initiating changes in the lower. CAPP's goal now was to add length and grasp to the artificial arms, with the anticipation of making Diane's field of vision more normal, enhancing her balance, and preventing further scoliosis.

Despite the mixed results with artificial **arms**, and the contrasting picture of Diane's strength and coordination in her artificial legs, a

decision was made when she was 12 years old to end her training with lower extremity prostheses:

This child has had a five to six-year program during which she used experimental legs of various types. This program was not successful. It is felt that a significant part of her present enthusiasm for the use of the upper extremities is due to her release from the ordeal of struggling with lower extremity legs which gave her such limited function and satisfaction. Therefore, it is recommended that her visits to physical therapy be discontinued and her time more profitably spent in Occupational Therapy.

From a layperson's point of view, this conclusion seems difficult to understand when the earlier evaluations are taken into consideration. One physical therapy report from the period 1957 to 1959 states that in her prostheses with rocker feet Diane "never complains of her lower extremities and walks around school a great deal. Although it is slow she has mastered the use of them very well." She was never seen by the therapist to lose her balance on them. She was adept at walking in them by pelvic rotation and also the hip-hiking method. CAPP's decision in 1962 to abandon training with the artificial legs must have been both puzzling and frustrating to Diane. It was, in any event, a decision she later struggled unsuccessfully to reverse.

According to the CAPP files, Irene Fields reported in 1963 that her daughter wanted to be fitted with functional legs. It was then that Rancho Los Amigos Hospital was first mentioned as a resource with the possibility of Diane's placement in residence there. She was admitted there as an in-patient in 1964, at the age of 14, and a decision to fit her with functional legs was made based on evaluations by the psychiatry and orthopedic departments. She spent most of her days in her scooter, with only about 20 minutes of independent ambulation "hopping on gluteal mass with axillary crutches" on level ground, stairs of standard size, and ramps. The weight of standard lower prostheses and the instability of full-height components were considered too difficult for Diane to manage. The staff at Rancho agreed to work with the prosthetics department of CAPP. They would use simple, lightweight components at first, graduated in height. Diane was sent home until such time as CAPP would be ready to start.

In 1966, Diane's mother reported to CAPP that Rancho's staff decided against the lower extremity prosthesis. Making legs that Diane could walk on was "impossible." Now grown too big to fit the bucket of her cart, Diane used a standard electric wheelchair and a manual junior-size wheelchair to fit under the desks at school. According to her mother, Diane accepted the fact that she could not have functional legs.

Nevertheless, when asked in a psychological interview, at age 16, what she hoped to gain by being at Rancho, Diane responded: "Artificial legs—walk!" According to her mother's report, however, Diane wanted CAPP's help to obtain cosmetic legs to wear in the wheelchair. It was emphasized to Diane that cosmetic legs would make it harder for her to be transported during transfers and that she had to lose weight, particularly in the area of her hips. Months later, she received a ready-made pair no longer needed by another patient. Although Diane described these legs to me as "stupid" and insisted that she hated them, her feelings toward them appear ambivalent:

D: They had . . . the plaster wasn't a bucket. It was just a piece in the front. It took up my whole front and went around the other side.

G: From where to where? Around your waist?

D: It went around my waist down to the end of my leg and around to the sides. The legs were coming off the front of this thing. The legs looked really nice. They were real-looking, if you put nylons on them. I used to put five pairs of nylons on to cover up the wooden marks.

G: Really?

D: Yeah, and those were just the plain-colored ones. And in those times, when I had those legs, the colored nylons were in. It was good for me, 'cause I could hide a lot of weird things on my legs—screws and shit. And they were a great shape. They were long. But everyone tells me if I had legs I would be tall. But I don't know if I'd have been *that* tall. They were pretty long. Anyway, then I would sit on the two straps. There were these straps and they would come across each hip up to the front end strap. And you pulled it tight as hell. I mean *tight*. Because after you get them on—when I was wearing them, then, you'd put them on me and the taxi driver would come to take me to school. By the time he picks me up and puts me in the cab, they're loose. So you got to put them on *really* tight to last all day—four transfers. I hated them. I just hated them because they were clumsy and they'd get loose. One time at school, the cab driver picked me up out of the cab and the legs just landed on the floor. Dumb things.

In the following year, physical and family crises resulted in Diane's hospitalization and living away from home. She was eventually readmitted as an in-patient at Rancho until she completed her high school education. She was graduated in 1968, while living there. That fall, Diane was discharged from Rancho into her own apartment in the care of a full-time attendant. Diane was on her own and 18 years of age.

In 1973, Diane contacted her old surgeon friend, Dr. Cameron Hall, at CAPP for help in obtaining functional legs. The persistence of her desire to walk was expressed fully and urgently in a letter carefully handwritten by Diane on 16 pages of lined notebook paper. Diane explained that she was in crisis in her relationship with a man with

whom she had been living and who had left town for a year. He returned to tell Diane that her handicap was, for him, the obstacle to their marriage. Diane asked for the surgeon's help:

He has finally admitted our problem was my handicap. He said he lied about it because he didn't want me to think it made him love me less. He said we just can't go on this way because we are destroying ourselves as well as each other.

Dr. Hall. I told you our story in such detail because I want you to know how much Jim and I love each other and to show you how much we have gone through for five years. I have made up my mind this time I have to try something for Jim and I. I have had many "boyfriends" but all of them, except for 2 just wanted to see what it was like to have sexual intercourse with a girl without arms and legs. God has been good to me. Not many people which are handicapped have such an exciting life as I do and not many are lucky enough to find a man to love me as much as Jim does.

I was brought from Texas when I was 3 year; old to UCLA. They trained me completely. They taught me everything I would need to know. They never thought of what I might do if I got married. I love UCLA and all the doctors, therapists, and surgeons connected with it. I know I was more or less their "guinea pig," but in order for me to survive I had to be. Now, I am asking for their help.

They must have something which can help me do for my man. Even if they have to transplant arms and legs on me. No matter what they come up with, I'll try. I'll train for as long as I have to, but I guarantee I'll learn sooner than they expect me to, just as I did when they were first training me.

When I was going to Benjamin F. Tucker Handicap School, I had a pair of legs where I could actually walk in, and they looked fairly real. I also had crutches and my artificial arms. In therapy, I was learning to walk in the parallel bars *without* my crutches. Then I gave up my arms because "they" realized I could do more without them. I was then sent to Rancho, for 2 years, to get *functional legs* and I designed a pair of crutches I could use without artificial arms. They made the crutches and I had therapy. They made the "bucket" and told me to get my shoes. On rounds one day, after two years of hard work, Dr. Perry told me I couldn't have legs to walk in because I had no leg stumps. Dr. Hall, I know I can walk if someone would take the time to help me.

Although CAPP was a children's facility, Diane was accepted because of her "extremely poor family situation." As she was now reportedly obese, with all muscular tissues soft and flabby, CAPP's medical director characterized Diane's desire to walk as totally unrealistic. Nevertheless, some possible methods were discussed. The following year, the request was again evaluated: "In terms of lower extremities, Diane would like very much to try to walk on legs to whatever extent she can. Legs for cosmesis have no meaning to her as her friends know her and accept her without legs, and she feels no need to 'cover up' when she goes out. However, the wish to try to walk is long-standing and strong." The report continues: "The expenditure of energy as opposed to the amount of function she would actually get does not seem

to matter to her, as her fantasy is of standing on her own, on legs, and moving however far she can, even if only a few feet." Diane was told she would have to start with an upper extremity prosthesis, with which she began working again. Reports of low back, right hip, and stump pain appear. A corset was recommended for the low back pain but it interfered with the trunk movements Diane needed to make in transfers and nearly all other activities. Surgical fusion of the spine was suggested by CAPP but rejected by Diane. In the fall 1975, Diane began her first quarter as a student at UCLA and moved to an apartment with an attendant in the area of Westwood. The Department of Rehabilitation provided Diane with a van for transportation to and from campus. A new upper extremity prosthesis was checked out for her the following summer. The CAPP files on Diane DeVries end here. Diane's request for functional legs and decision to enroll in college reflected her wish, as reported at the time, not to be "simply sitting in her wheelchair doing nothing" in another ten years. While she was successful in fulfilling that wish, it was not with functional legs but in her wheelchair that she did so.

SELF-IMAGE AND IMPRESSION MANAGEMENT

Diane DeVries has always been aware of looking different, but her conscious management of the impression she makes on other people has evolved over time. It is largely the result of her experience in the company of peers with disabilities at Benjamin F. Tucker School for Handicapped Children, then at the Los Angeles County Crippled Children's Society Camp, and later in a teenage ward at Rancho Los Amigos Hospital. In a sense, Diane grew up to be bicultural, adapting to settings geared to disability and to ones that are not (Frank 1984). Diane's present body image and style of self-presentation seem to have been established at least by age 15, when a psychiatrist wrote: "She has formed a fairly rigid self-concept that does not include the attachment of 'mechanical devices.' Before she will at all consider the use of prostheses, especially for the upper extremities, she will need to see clearly the advantage of learning to use such devices. Even then, she will resist altering her body image." Diane's description of herself prior to entering Rancho supports this picture:

G: What image did you have of your body before Rancho?

D: . . . It's hard to say because I still had more or less the same. . . I always liked my body when I had nothing connected with it.

G: What about clothes?

D: I hated clothes. We have home movies of a childhood friend and I, movies of us doing things together. I never had any clothes on. I always