



Mental Retardation as Social Identity

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The Question of the Profoundly Mentally Retarded Child

This is the beginning of an enquiry into the life of a person who cannot speak for herself and who is dependent upon others to voice who she is, what she needs, her place in the world. In fact, this person is so dependent upon others that who she is belongs to those of us who imagine her.

This person, however, does not wander about nameless, as no one. Many have made their claims upon her. Indeed, around the event of her birth, she was stretched between two established identities: that of child and that of profound mental retardation. Yet, these two identities do not fit well together; they sever in two the life they claim. For to be a child is to be endowed with expectations and to be profoundly retarded is to be endowed with their lack. To be a profoundly retarded child, then, is to lie locked within the stillpoint of what was expected and what was given out. It is to become one who evokes fundamental questions.

The Narrative of This Child's Negation

I am not speaking from this person's point of view. She did not locate herself at this disjuncture between what was expected and what was given out, and she did not throw herself into this place of questioning. I have placed her here: I thereby speak to that which I have wrested from the history of our relation.

This person did not generate a phenomenological epoch when she failed to roll over in her bed, to reach out for a toy, to utter "mama," to take her first step. That is, she did not provide a disruption which freed us for a meditation upon the habitual course of children and parents in family life. We did not become theoretical so easily, for the expectations she violated were of a nature so fundamental to the conception of a life together that, when they were not met, many of us withdrew in terror.

Terror is the most radical of distanciations. Through it we become estranged not only from that other who evoked it, but from ourselves such that we lose all sense of who we are, our needs, our place in the world: we become speechless. Where we are terrorized we are vulnerable to our dissolution and become intent upon one thing—the way to recovery. Through terror we become instrumental and not reflective about our lives. We orient to the

contingencies of our survival and not to our communal and ideal ends.

When this person failed to realize a life already charted out for her—in the minimal contours of mundane competencies—she was named as something other than a child to be nurtured on her way to adulthood. She was named as profoundly mentally retarded and, to the extent that we could cede over to her the claims of this new name, we had been given a shorthand recovery from the terror. For she would always fail our expectations and at the source of this did not lie a question about ourselves—what we demanded, needed, relied upon—but rather the fact of her sheer technical incapacity. The name profound mental retardation was an announcement that this person's familial identity had been shattered and re-referenced to an institutional identity of deviance, public welfare, and rehabilitation.

The bonds of family require more than a new name for their dissolution. The name must realize its power in an empirical act, one which annihilates the reminding presence of what was wrought, of what was given to one of us. Such an empirical act could be murder—although this has been called the cessation of life support systems. It could be exile to the peripheral life of large-scale institutions—although this has been called custodial care. In either case, the one who terrorized us, having been construed as one who lies outside the parameters of ordinary childhood, of the claim for a place within the family, is pressed elsewhere.

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This person was only four years old when she left our family. I was eight and had no notion of the narrative in which we both were to play our parts. And yet I remember asking this: "Will she ever walk or talk? Will she ever come home? Will she ever be normal?" The no that was the answer was the cutting off. I retreated behind a now familiar line: her and I/abnormal and normal. Thus the narrative's beginnings were re-enacted within the family.

The Recovery of This Child's Place

This person cannot speak through word or gesture to make explicit who and what she is. Her life remains at the threshold of language and as such is evocative of interpretive possibilities. Thus where I speak on her behalf, I am never certain if I have drawn out her identity correctly, appropriately, justly. I cannot turn to her for resistance to or confirmation of that which I have claimed. Of necessity, this person requires that I become self-reflective; I acknowledge that where I address her, I address myself.

Where I try to engage this person, I encounter first a repetitive pattern of concept and of feeling. The pattern is the legacy of our participation in the narrative of negation. It is a gross dialectic of a re-

gretted commonality and the achievement of a normative difference. It stands between us, blocking the realization of a response to the event of her life.

The pattern begins with a sense of threshold, a barrier that must be crossed. The entrance to the Hospital School and beyond that to the door that leads into her ward, these are the threshold's literal symbols. The philanthropist's charge where a sense of duty—sheer and abstract—provides for, allows for, the crossing over. This is the threshold's analytic content. For the crossing over is always mechanical and stilted as if in literal imitation of the spirit which impels it—bereft of anticipation, desire, a longing to be there, but demanded as a compensation for something forgotten. It is a general paying of dues and its object is impersonal.

Within the ward, the pattern enfolds as a concentration to maintain composure. The sense of duty struggles against that old familiar terror. For there are many children: splayed, it seems, across the floor, some tied in order to sit up, others tied in order not to mutilate themselves, and there is a smell of food and waste that hangs in the air. I fight back repulsion. The children do not appear as children but as a sea of crippled limbs and speechless mouths that cry and scream. There is then the terror's rush for primitive recovery: in one moment a running away and in another a monstrous annihilation. Neither envisioning calms the terror but, rather, incites it. For whatever possibility I pursue in my imagination, the children succumb passively, indifferently, interchangeably, giving themselves as mute material to that which compels me. The meaning of their sheer technical incapacity is revealed. It is the beginning of my own unregulated power over them. Unregulated because standing in their midst, its source is transparent as derivative from that which lies beyond my control: the children appear as products of an awesome accident. I understand the shock sticks used upon them as a weapon in a battle for control. The terror is thus that of a definitive circumscription which embraces us both and within the rubric of which their weakness and my strength are inconsequential. Our difference lies in the difference between a real and a potential victim neither of which is achieved but rather brutally given. The realm of physical vulnerability is our common ground against which an interpreted world of normal and deviant behaviors seems pretense, a house of cards. This is the point of speechlessness where I stand one with them.

The commonality is struggled against. I rely intuitively upon a remembering of the experience of interpretation, familiar devices for making sense. In making the terror intelligible, I re-achieve the dividing line between us. I begin to organize their fault in terms of behavioral differences, I can achieve the possibility for my own survival; they cannot. It is only this which allows for the persona

(i.e., the role) of strength and thereby my return to the philanthropic stance of pity. I can articulate and organize our differences. They cannot. This is the point where I stand over and against them.

The person, however, whom I have come to visit does not make herself amenable to my schematizations. Who and what she is will not depart from my existential knowing of her as my sister, my blood and kin. Where I stand within her presence, who and what she is will not permit such a general occasion. The pattern breaks down here, and in the immediacy of my engagement with her, I am taken on another track, back to the first shattering of expectation and the life it implicated for us both.

Where we are children, we are vulnerable in this essential way. We need our families as a literal and symbolic circle against all external threat. Where we are kin, we stand equidistant from this circle's source: the power and the compassion of our elders. Where one of us is thrown outside this protective circle, it is not a curiosity or an exception, but rather an unmediated and concrete sign of our common child's vulnerability. That to which we extend our trust, not deliberately, but naturally, is revealed to us as suffering its own limitations, the consequences of which make unimaginable a child's life.

This person has remained a child, abjectly vulnerable, because she has no other resources for her life than the power and the compassion of those who surround her. She cannot move beyond the need for protection through enjoyment, talent, achievement, growth. She is the concrete embodiment of the fear—shared by children and by adults—“as I am now at the moment of my deepest vulnerability, is how I will end up.” She does not stand at the transitional juncture between dependency and autonomy. She is eternally child as she is eternally vulnerable.

From the child's point of view, the expectations violated are those of life beginning as a securing of protection from those to whom we as children naively extend our trust. From the child's point of view, the profoundly retarded child lies locked at the stillpoint between the expectation for a protected life and a life of abject vulnerability. This is the child's own stillpoint. That it is concretely revealed through the handicap and the exclusion of next of kin is thus not a distilled observation, but rather an interior knowing that what is needed cannot unconditionally be counted upon. That the child draws back in terror from such an interior knowing is a strategic move to protect the trust from its untimely dissolution. From the child's point of view, the stillpoint cannot give way to questioning but to its own pressing away as belonging to a life distinct and different from her own.

From the adult's point of view, the expectations violated are those of her own resources for extending protection against the threat of ac-

cident and circumstance. That is, the expectations violated devolve upon the adult's capacity to provide for life's beginnings. And as such, the stillpoint evoked in the life of the profoundly retarded child is not that of the need for a particular trust *in others*, but rather for an enduring faith in oneself as strong enough, as compassionate enough, to sustain a life *for others* where that life eclipses the possibility for the adult's full and unconditional control. Where this faith is absent, the adult draws back in terror without resources to engage that which life reveals as his or her own limitations. Where this faith is emergent, the stillpoint begins to crack upon as a contemplative moment, and addressal of oneself as partaking in the contingent, the fateful—the sheerly technical conditions for survival—and yet still capable of wresting out on behalf of this life its worth, its weight, its moral dignity. Here the life of the profoundly retarded child gives way to a sense of our own weakness which thereby demands not strategies for technical control, but rather the response of more profound strength: where we are able to apprehend this child as one with us in the vulnerability of our common beginnings and so a reminder of the need to provide protection and care.

My sister cannot speak or reach for things, and she does not know who I am. Yet she demands more of me than any other human being. She demands that I get beyond the stillpoint to the question of my own limitations and responsibilities. In recovering this, I could begin to speak on her behalf.

Aspects of the Technical Management of Incompetence

In my work, I have been looking at mental retardation not so much as a pathological condition that exists within the individual, but as a painful social identity that is suffered by retarded and non-retarded persons alike. I have been particularly interested in how this identity emerges and is lived out between the retarded and non-retarded next-of-kin.

Social identity is thus central to my work. By this I mean any working definition of who and what another person is or ought to be: what he or she stands for, what he or she has in common with us, what he or she does not. In these terms, largely taken from Georg Simmel, social identity derives from the interpretive practices of daily life, where our texts are other people and where our reading of them results in how we estimate them and place them vis-à-vis ourselves within the community.

Some social identities, as the studies in the stereotyping of minorities and other special groups have so well-documented, are more encompassing, more totalizing than others. Some of our readings cut more sharply and monolithically into the various possibilities of the human text before us. Some of our interpretive practices make types

or caricatures of the persons in our midst, producing rigorously delimited but superficial accounts that gloss and freeze the individual life that lies beneath.

It is my contention that mental retardation is one of the most totalizing social identities that our society has produced. Once a person has been perceived and labeled as mentally retarded, his or her personhood—the fulness, the tension, and the tendency of his or her individuality—becomes difficult to sense, grasp, work with, and interpret. This is because the dialogues that placed this personhood first, the dialogues of family, friendship, and love, are paved over, forgotten, and repressed; they are superseded by a different kind of dialogue, one launched and justified by our society's league of professional labelers and diagnosticians and accepted by our society's laity: namely, you and me.

I wish now to discuss some of the ramifications of this totalized social identity for mentally retarded people and their non-retarded next-of-kin. I begin by re-analyzing my relationship to my profoundly retarded sister. From this, I attempt to make some generalizations about the relation between those who are retarded and those who are not in our society.

Although there would be many ways to introduce the problematic biographical character of my relation to my profoundly retarded sister, the characterization most resonant with what this relation has in fact, in feeling, and in concept undergone is that of what it is to suffer a negative social identity of lack of a place within the community. The following account serves to amplify this characterization.

Two sets of facts, technical and social or existential, have seemed to constrict this relation from the start. The first is that my profoundly retarded sister can technically not speak and the second, more elusive in origin and interconnection though no less consequential, is that her identity has always belonged to others who have had to wrench from her speechlessness a sense of who she is, what she needs, her place in the world. And whereas my sister's incapacity to affirm or to resist the identities found or imagined for her would have seemingly allowed an anarchy of possibilities regarding the meaning of her life, such anarchy or full subjective freedom has not been the legacy of her interpreters. Rather, making sense of my sister's life has been embedded in a network of institutional practices that has come to define the relatively segregated world of mental retardation. That is, a network of conceptions and programs and strategies for managing human incapacity, a network manifesting its social and political power over a world managed by the incapable and their caretakers, provided both biographically and historically the vantage point for making sense of my sister's life; such had already set the precedent for wresting from her speechlessness, her

awkwardness, her incompetency an identity for her that would silence the question of or close down the possibilities for her identity.

More specifically, the mediation of an expert knowledge had laid the grounds for reading her speechlessness as an accident or technical fault in her genetic make-up and a place readied for her in the relatively segregated world of mental retardation *had already inscribed this technically damaged identity with its social meaning*. For her, failure to meet the requirements of ordinary human development marked the beginning of her exile, first from the family to state wardship, then from the life of the community to the social death of the large-scale institution. The expectations she violated (of child, of adult, of person) hence formed the justification for pressing her away (in fact, in feeling, in concept) into a separate membership; such had already exhausted the interpretative possibilities for the meaning of her life in categories of deviance, normalization, social welfare.

In the appropriation of my sister's identity as a publicly managed property of scientific and social welfare institutions, the shattering of our familial identity as sisters had almost been fully achieved. Traces of a life together became absorbed in interlocking oppositions of normalcy and deviance, health and handicap, development and retardation. Our commonality came to be overshadowed by our difference, our familiarity by our estrangement. That is, in the process of the institutionalization of my sister's identity, not only was it her identity as a human being that was weakened and broken, but so too was the identity of our relation. Gradually, almost imperceptibly, our relation came to house ghostly and unreal figures of fear, repulsion, and despair as we each came to represent different and warring sides of a normatively defined and professionally managed boundary between the capable and the incapable. Who and what we were—the meaning and limits of our relation—came to be split between the silence of personal pain and the existential emptiness of scientific and administrative categories.

To have a private problem is to be powerless to articulate it or to transform it into a story or a shareable account. This powerlessness might be technical. One might lack the means: cognitive skills, rule mastery, information, conversational techniques, and so on. That is, what stands behind one's inarticulateness might be incompetency that may or may not be remediable. The powerlessness of being inarticulate, however, might reference something deeper. Something might have gone wrong that cuts into the fabric of one's lifeworld, instituting at the level of everyday interaction a blocked and nightmarish structure of estranged and distorted social relations. That is, the private problem, and the inarticulateness that co-presences with it, might reference a crisis that manifests itself in the speaker's incompetency, but has its roots in the breakdown of one's lifeworld,

in the collapse between one's capacity for technical mastery and one's capacity to envisage and realize in speech and action meaningful and existentially sufficient relations with others. Both kinds of inarticulateness are implicit as central problems in the biographical narrative. For whereas my sister suffers a technical inarticulateness—and absent or limited capacity to master the rules of speech and interaction such that she is dependent upon others to have her interests, wants, needs expressed and represented in the community for her—what I suffered (and perhaps our society in general suffers) was a practical inarticulateness vis-à-vis mentally retarded people. And by that I mean to be caught in a stalemate between technically being capable of managing an identity, or generating intelligible descriptions of mental retardation, and being at a practical loss as to how to endow that identity or those descriptions with any existential content or lifeworld meaning.

In the case of the biographical narrative, whereas my retarded sister may have lacked the capacity to become a competent speaker, I lacked the capacity to use whatever competencies I had developed as a speaker to articulate to myself and to others what this relation had meant to me, how it had marked and moved and formed me as an individual, and what moral demands it had placed upon me as her sister and as a human being. Thus, if she could have been faulted for her incapacity to tell me who she was, what she needed, her place in the world, I could have been more deeply faulted for my incapacity to generate an identity for her, myself, and our relation. Such was our mutual inarticulateness. Such was our mutual powerlessness before the theories and practices for mental retardation managed through organized precedent.

Since the mid-19th century,¹ when mental retardation was first distinguished from mental illness and programs were first introduced for the care and cure of mentally retarded people, its official identity has basically been managed by warring factions in the nature/nurture controversy—by those who have emphasized the natural or biogenetic aspects of the handicaps and by those who have emphasized the nurturing or social aspect. Those who have emphasized the former have defined it as a pathological condition that exists within the individual and can be diagnosed by clinically trained professionals using standardized assessment techniques: those who have emphasized the latter have defined it as an ascribed social status that is linked with poverty and disadvantage and is a relative measure both of prevailing standards for achievement and productivity and of unequal opportunities for meeting such standards.²

Where the pathological model has prevailed (from the late 19th to the mid 20th century), mental retardation has been treated as a more or less irreparable condition; research and development have tended to focus on preventative measures, and retarded people have

suffered the fate of those deemed hopeless candidates for “ordinary” membership in society: that is, large-scale institutionalization, sterilization, and stigmatization. Alternatively, where the ascribed social status model has prevailed (at the dawn of the movement, 1850-1870, and in the past several decades) mental retardation has been treated as a more or less reparable condition; research and development have tended to focus on rehabilitative measures, and retarded people have suffered the fate of those deemed hopeful candidates for “ordinary” society: that is, progressive normalization programs, which, largely through behavioral modification techniques, seek to instill adequate performance behaviors.

It is what both models share, though, that has the most significance for our effort to understand the kind of relation to mentally retarded people structured through the theories and practices of organized precedent. This is the conception of the retarded person as a victim, on the one hand, of a malfunctioning in nature (or disease in the organism) and, on the other hand, of a malfunctioning in nurture (or deficiency in socialization). Because this malfunctioning is technically conceived, the one whose life has been disrupted by the malfunctioning is the one whose life has begun with, will proceed through, and will end with the scar of a meaningless accident. That is, his or her defectiveness will embody an accidental defectiveness in the order of nature or society; his or her life will be perceived as having fallen prey to or having been victimized by something not expected or desired by the human community. As such, it is not coincidental that the models are supported by and advocate the scientific response to defectiveness and accident, which is repair or cure, and the philanthropic response, which is pity, paternalism, and custodial care.

It is almost impossible to imagine a relation to another that is haunted by the accidental nature of the other's birth, sustained by feeling sorry that the other was the victim and kept alive only by the possibility of some miraculous repair. For such a relation embodies nothing of intrinsic value—nothing that one would want to remember or to reflect upon, nothing that one would want to affirm, protect, and work for. Such a relation would indeed beg to be forgotten and the retarded person, whose damaged life potential has wrought such negativity, pushed into oblivion. That this, in fact, has been the destiny of many retarded people in our society is one measure of the extent to which the scientific and sympathetic responses fail to provide a reason for us—a guide or a support—to carry on with retarded people as their family, friends, and educators.

Where one is already involved in such a relation through family ties, forgetfulness is not so easy since a distorted dialectic of intimacy and estrangement perpetuates a nightmarish involvement. The retarded person is the other whom one would never choose to be, but

by virtue of a meaningless accident, one could always become. The retarded person is both measured by what measures one's own life (normatively sanctioned standards of competency, productivity, and achievement) and what does not. Your retarded child, brother, or sister is burdened with the sense of being an opposition without content, more of a negative possibility for your own life rather than a really existent other. Through this dialectic, your retarded kin becomes a fearful figure who haunts, provokes, reminds you of your own vulnerability to the accidents of nature and the circumstances of society. And through this dialectic, a dreary history is produced and reproduced—alternately repairing and segregating those whose very presence haunts and speaks of our weakness and vulnerability as human beings, potential victims (as opposed to masters) of our physical and social worlds.

Notes

1. For an historical overview of developments in the care and conception of the mentally retarded in Europe and North America, see Rosen et al., 1976.
2. For an excellent discussion of the clinical and social systems perspectives on mental retardation, see Mercer, 1973.

References

- Mercer, J. (1973). *Labeling the mentally retarded*. London.
- Rosen, Clark, & Kivitz. (1976). *The history of mental retardation: Collected papers*, (Vols. 1 and 2). London.