



Understanding Lifeworlds of Handicapped Children by Chizuko Maeda, Unpublished Doctoral Dissertation, University of Alberta, 1989

Understanding Lifeworlds of Handicapped Children by Chizuko Maeda, offers the reader reflective narratives about the author's interactions with and observation of atypical children, children the system has labeled autistic, mentally handicapped, or cerebral palsied. Maeda refers to these children collectively as "mentally handicapped."

The first reaction I felt reading this thesis was a deep appreciation for the choice of topic: a very difficult one, one that asks great emotional vigilance, sensitive persistence and patient reflectiveness. It is not a topic many researchers would feel they could take on. My second reaction was one of appreciation for the beauty of the narratives, the direct language, at once sensitive and reflective. Then, focusing on the research question, confusion entered my thoughts.

The purpose of these narratives as stated is to "seek ways to understand mentally handicapped children as they are as unique individuals" (abstract). The desire to understand these children "as they are" is mentioned throughout the study. I interpreted the phrases "unique individuals" and "as they are" to refer to how these children live their own unique lives, not as we see them in comparison to us. However, as I continued my reading, I found the research question focused differently elsewhere: "In what way are *they* different from us? What causes the difference? Is the difference we perceive solely in them, or is it partly due to the way we see them? Are they so different as we usually assume they are?" (p. 16). Reading on, I came to believe that, rather than offering answers to either purpose as stated, what this study really offers is something different still: namely, a clear, sensitive, and insightful picture of how the researcher herself struggled with making meaning of her own consciousness in relating to these children who do not communicate on our terms. Throughout there are many reflections on self such as the following:

The sky I see through my fingers changes its patterns and brightness according to the finger movements. This *is* interesting, I think. "Is this how you do it, Matt?" I ask Matthew, who has a glimpse of me and goes back to his fingerplay again, without showing any interest in what I am doing. I continue to flick my fingers for a while. "Don't you think I am doing well?" I ask him again, which receives the same lack of reaction from him. I feel uneasy about his ignoring me this time. What am I going to do if he won't stop his finger play? (p. 60)

Or:

Above all, when he smiled at me, it did not make me smile back at him. I could not smile back at him in a way I would do with other children. Or, perhaps it would have been easier for me to respond to him if he had not smiled at all. (p. 101)

Who is the researcher really trying to understand? I must ask myself as I have so many times, is it ever possible to do more than project ourselves when we think we are understanding the other—never mind the many methodologies, postivist or post-positivist, that claim to be able to do so? With those who communicate in ways similar to ourselves we can easily be led into believing that we understand them. With the children such illusion is not easily engaged. Might it be, as the ancient philosophies tell us, that whatever we say, even if presumably about the other, is always about ourselves and cannot be anything but; that our words can be no more (and no less) than the externalization of our own inner consciousness? This is not to say that this would prevent mutually beneficial relationships to develop between people, including atypical persons. I will comment on that later.

Maeda is, of course, aware of the problem inherent in claiming to understand another. Relying on Heidegger she states: "It is not an easy task to realize not only what is revealed (children) but also what reveals (myself), since, as Heidegger says, as far as I am what reveals, I also am what veils" (p. 50). Yet, there is the implied claim of having "understood them" (p. 50) through the process of "continuous questioning with openness ... and freedom," and by asking questions such as, "why I think that I have understood them; and how I have changed through the process of revealing." One senses the tension: I cannot understand the other, but perhaps if I do such and such and ask myself these particular questions, I can understand. This tension is, of course, not unique to Maeda's dissertation but to the entire field of human science research. Perhaps I am becoming weary of all this need to understand. As the years pass, in both my personal and professional life, I am coming to believe that the ancient sages are right. Not that this perspective I now hold would make Maeda's dissertation less valuable in my view, or would prevent us from forming good relationships with one another. On the contrary. I would only like to see the stated purpose changed to something like: "The life world of a researcher interacting with atypical children: A reflective narrative" or something close. This to me reflects more accurately what these beautiful narratives are really about.

Each of these stories is told in clear, direct language, the kind of prose that feels as if it flows directly from the experience onto the paper. There is no pretentiousness of sophisticated language or of laboring over poetic images. Reading these stories I felt I had been there, as if I had been the one attempting to interact with these children.

The narratives are organized around six themes of everyday experience: finger play, eating, smiling, self-talk, seeing and listening, and don't touch me. They involve a dozen different children, mostly interacting with the author, and in some cases with other adult care takers or with each other. Maeda spent her time with these children in her role as teacher, volunteer, or visitor.

There is Matthew, who is not responding to the schoolbell but is still sitting alone on the grass, flicking his fingers, moving them "in the air, close to his face, twirling and twisting each other, overlapping and being overlapped by one another" (p. 59). Matthew's finger flicking is compared to Chris' enjoyment of swinging (Chris is not handicapped). The sameness is seen in the fact that both activities bring about sensations in the body, and both give the person engaged

in them control over changing how the outer world appears to them. But there is also a difference:

I felt uneasy when Matthew ignored me and continued his finger play, while I was quite comfortable even when Chris was absorbed in swinging and talked to herself. That is because I was afraid Matthew might not come out of his own world of finger play whereas I knew Chris would come out of her own world of swinging at any time. (p. 70)

Maeda describes the swinging as not endless, not isolated: it can be broken by the child herself. Chris will come out of her world of absorption in swinging to our world. Matthew will not.

There is Karen, who has cerebral palsy. Karen lacks control over her eating habits. The self-feeding skills program, carried out in the typical behavior modification manner, turns lunch hour into an unpleasant experience for everyone. This is nicely described through the reflections of the staff who are involved in the self-feeding training. These ponderings by the staff provide a fine critique of the isolated and contextless nature of these self-feeding skill programs and point to the important social dimension of eating together, also in the company of these children. We are then reminded of our proverbial renowned professor who too has terrible eating habits (eating fast, speaking with his mouth full so food spills from his mouth onto his clothes) but whose poor eating habits are not seen as a problem, but rather as an eccentricity.

There is Anthony, an autistic boy who screams and cries when he is in distress but who otherwise only whispers:

“Throw me away, Chico” (he whispers in the swimming pool). We repeat the same thing again and again ... “Carry me Chico, please” ... Through five months of my visit to the school, that was the only time I heard Anthony spontaneously say what he wanted ... That was also the only time I saw Anthony smile while he was talking. There seemed, at least to me, to be a shared situation. The talk was much like a whisper as usual. The smile was not directly addressed to me. He did not even appear to see me once, either ... Yet, however softly he whispered, and however vague his smile, he whispered on his own will, and his smile did not fade away when he came to me. (p. 105)

Again and again, we hear the attempt by Maeda to see the person hidden in these handicapped youngsters. Even if only for this reason, the dissertation should be read widely.

There is Ken, a boy with Down’s syndrome, engaged in self-talk. There is Jeffry, who insists that the other repeats every sentence exactly as he does. He speaks well but does not say much, as compared with Karen, who has cerebral palsy, who says much although she does not speak well. Again, the comparisons are sensitively drawn and provide pedagogically relevant insights.

Throughout these narratives Maeda tries to interpret for us what these children might be thinking, feeling, or trying to accomplish. Some linkages are made to the literature in the field of special education. Maeda refers to what she sees as the two theoretical positions in special education, the traditional model (the medical, psychological, and cognitive models) and the social perspective, both of which she sees as inadequate. The discussion is rather thin here and the

conclusions drawn do not always reflect a grasp of the field of special education. For instance, the social model does not hold that "there is no difference between mentally handicapped persons and non-handicapped persons and that only the label of mental retardation creates this apparent difference" (p. 34) I do not know of any researcher within the social model perspective who holds such a simplistic view. Rather, the social model poses far more complex questions, such as: Under what conditions, and how and why do certain people or groups of people (schools, psychologists, churches, government agencies) label certain others as "retarded"? How does such labeling vary across gender, social class, and economic status? What societal values play themselves out in these processes?

There are other relevant theories to address. For instance, there are ecological models, and there is a growing body of ethnographic/qualitative research that addresses the phenomena of exceptionality from an experiential perspective. Maeda discusses only a small part of it. Further, there is a vast amount of biographical and autobiographical literature by cerebral palsied persons and by mentally handicapped persons, or by their relatives or caretakers, certainly some of it reflecting the directness of lived experience in the lives of handicapped children that Maeda seeks. There is no reference to this literature. I further must object to the label "mentally handicapped" to collectively refer to children seen as autistic, mentally retarded, or cerebral palsied. These are very different conditions. Labels used may not make much difference to the human science researcher interested in atypical persons, but they do make a world of difference in the field of special education and to the persons themselves and their relatives. Persons with cerebral palsy whose mental abilities are perfectly intact although their muscle control will not allow expression of it (at least not in ways familiar to us) would definitely not be pleased to hear themselves referred to as mentally handicapped. The label "atypical" would perhaps have been more appropriate.

The theoretical framework emerges from a sameness-and-difference conception of exceptionality: How are these children the same as nonhandicapped persons, and how are they different? Maeda seeks the sameness through the difference in an attempt to transcend what she sees as the one-dimensionality of typical models in special education that focus either on difference or on sameness. This theoretical framework is used throughout the dissertation when making sense of the narratives and is exclusively used in the discussion chapter. Maeda explains:

If and when we focus on the difference, our understanding of them will be based on a comparison between them and non-handicapped children with the obvious advantage of the latter over the former ... In contrast, when we focus on commonality then our understanding will remain somewhat superficial without the recognition of the particular, the difference. In this sense how we cope with the issue of sameness and difference seems to be one of the critical moments for the search for alternative ways of understanding mentally handicapped children. (p. 157)

Maeda then proposes to escape the limitations of focusing on only difference or only sameness, by focusing on both. Initially, I saw the sameness-and-difference framework alternatively as intriguing, inadequate, making a lot of sense, not making a lot of sense. Then I started realizing, I think, the nature of the

confusion inherent in my contradictory reactions. Maeda's theoretical framework assumes that we can indeed understand "them" by comparing them with "normal" children. While she draws comparisons in insightful, creative, and complex ways, this theoretical position nevertheless perpetuates the medical model it wants to transcend. While the narratives themselves are thoroughly embedded in reflections on the nature of the relationship between the author and the children, the theoretical framework and the conclusions no longer reflect this major focus and falls back on drawing comparisons between a population and the norm which is the backbone of the medical model. The theoretical framework leaves out what, to me, is so precious in this dissertation: the critical role of our own consciousness in attempting to make sense out of their behavior when interacting with atypical children. I believe this is characteristic of much of human science research: We admit the central role of our own consciousness in the methodology, but leave it out when discussing the findings and theoretical frameworks. It is as if we think we can decide when "it" (our consciousness) is allowed to stay and when it has to go. We don't have such control however. Fortunately, I believe, we cannot play God.

Maeda draws comparisons in a way that surpasses the reductionistic simplicity of the medical model in all ways. Her comparisons strike me as sensitive, thoughtful, creative, and complex. They also provide fine pedagogical insights refocusing us on the central importance of context and meaning that, in our interactions with atypical children, we so easily forget. Karen, the child with cerebral palsy, for instance, also has visual impairments. The formal diagnosis leads one to focus on Karen's visual problems as isolated features, which brings about inconsistencies for the careful observer who sees Karen thread beads into a necklace for her favorite student teacher. How is it possible, ponders Anne, the student teacher, that a girl who cannot find a block on the floor can manipulate those small toy cars and thread a necklace?

This lovely comparative narrative reminds us once more that we all, handicapped or not, select what is meaningful and what is not, and that no formal diagnosis predicts what can or cannot be done in all circumstances.

Although the dialectic tension Maeda has built into her comparisons provides us with a far more complex picture of these children, I cannot say that they come out equal to or ahead of the "normal" child or "normal" person with whom they are compared. Yet the quote I used earlier in which Maeda explains her sameness and difference framework seems to indicate at least the hope that that might happen. But any framework of comparison between a certain population and the norm by definition introduces competitiveness. When it comes to comparing normal children and handicapped children, however, guess who will always lose in the end. For instance, although the comparison of Karen's poor eating habits (due to cerebral palsy) to the poor eating habits of our renowned professor makes us think in more complex ways about what to do, or not to do, about poor eating habits with children such as Karen, there is no question who has the advantage. Chris, absorbed in swinging, clearly has the advantage over Matthew who is absorbed in autistic finger flicking. The normative, traditional framework stays alive and well.

Not that there would be no purpose in drawing comparisons as Maeda has done. They enhance our understanding of the complexity involved and help us think

through our pedagogical actions. Had the purpose of the study been to develop a more complex social model of special education than the one we have available, the comparisons and the theoretical framework from which they emerge would be relevant and intriguing. I believe that is where my initial positive reactions to the theoretical framework came from. But because the purpose was not to develop a more complex social model, but to grasp these children's lived experience (if this is what the most central purpose indeed was), the theoretical position would run counter to the purpose of the study and, however unintentionally, perpetuate the traditional, normative conceptualizations instead.

One way to get away from comparison and therefore from competition and from perpetuating a normative model would be to develop a theoretical framework consistent with what the narratives do so beautifully: painting exceptionality and our understanding of it as an expression of our own relationship with these children. I am not aware of anyone having formally attempted to do so.

My comments, then, on the theoretical framework relate to what I perceive to be a lack of internal coherence between the nature of the narratives and the theoretical framework Maeda uses to make sense of the narratives. Perhaps my comments may be seen as pointing to the extremely difficult task of trying to stay clear of the normative, medical models into which we are so indoctrinated.

The wish to be understood, and to understand, and the inevitable disappointment that comes with the evidence that the other does not understand us, or that we don't understand the other—not really anyway—turns out to be a great source of anxiety and of loneliness for most of us. But should it be? Perhaps we need to change the question. Perhaps the point of any relationship is not to be understood, or to understand the other, but to share experience while feeling valued, connected, and worthwhile. Perhaps that is all we can do for each other, and that is enough. Perhaps the point of any relationship (including a relationship with the children as those in this study) is that through interacting with the other we are offered the opportunity to see ourselves acting and reacting, thereby gaining greater understanding of self. Then we may come upon ways of interacting that are beneficial to our mutual lives, not because we can claim to understand the other but because we have found a good relationship. And that is only possible if we become aware of and reflect on our own motivations, prejudices, anxieties, and wishes as we interact with the other, which these narratives do so beautifully.

After reading the dissertation I can say that I can identify better with the attempts, questions, sensitivities, and humility needed to establish a relationship with these youngsters. I can say these stories move me, enlighten me, not because they show me these youngsters "as they are" but because they show me who I might be if I were to interact with them. Few dissertations do us such service.

Lous Heshusius
York University