SYMBOLIC INTERACTION IN INCLUSIVE
FOURTH AND FIFTH GRADE CLASSROOMS:
“CAN SHE PINCH ME GOODBYE?”

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DEDICATION

This dissertation is dedicated, with profound love and respect,

to my grandmother: Anna Ammann (“Shorty”) Campbell.
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I would like to express my deepest appreciation to my family: my husband Pat, who put his dreams on hold so I could chase mine; my son Toby, who never asked (but must have wondered) when his mother would decide what she wanted to be when she grew up; and the Bentleys—Patrick, Tina, Chelsea and Isabella—whose talent, sweetness, openness, and creativity is a constant inspiration.

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ABSTRACT

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A Foucauldian genealogy was combined with symbolic interactionism to investigate disability and inclusion, and the interactions and meanings attached to these concepts. The research revealed excluding and including interactions within self-described inclusive practices. Excluding interactions with Ashley (pseudonym), an 11-year-old, nonverbal girl with Rett syndrome, included: unspeakability, medical Othering, infantilization; academic exclusion through low expectations and limited participation; and role erasure. Excluding interactions tended to support existing meanings of disability and inclusion. Including interactions, most often observed between Ashley and her peers with and without disabilities, included: speakability, medical sharing, age-appropriate expectations, academic inclusion, and role presence. Including interactions tended to transform existing meanings of disability and inclusion. Symbolic interactionist definitions—symbolic inclusion and symbolic exclusion—were posited. Children’s instinctive meanings and interactions were shown to be in line with current thinking on some instructional and assessment strategies in special education. Symbolic inclusion was considered to be applicable to issues of school improvement and social justice that are not confined to special education.
CHAPTER I

INTRODUCTION

It was my first year teaching “special” education. My high school students, a paraeducator, and I were concealed behind a wobbly partition and several sheets of taped-up black construction paper, in a “self-contained life skills classroom.” We were taking up valuable space the principal had claimed for us, from the domain of a veteran content mastery teacher. The first time we passed through this teacher’s truncated classroom on our way to contain ourselves, she drop-kicked a wastebasket.

We were so contained we had to back a student’s wheelchair out of the “room” to turn it around. We were so contained our partition crept slowly and relentlessly inward, like a dungeon wall in a dark fairy tale. On Mondays I’d come in early to move it back out. I misspent time and energy that way, moving symbolic and physical walls back and forth, mere inches at a time. It was my student Sylvia who made the walls come down.

Sylvia was a 15-year-old girl with qualifying labels of mental retardation and Down syndrome. It hadn’t been easy to persuade administrators to change Sylvia’s placement from middle school to high school. When they finally relented, they cautioned me that she was “still awfully small for her age.”

And so she was. Sylvia was about the size of a ten-year-old. She staggered up the steps of the school bus, nearly toppled by her laptop communication device, a backpack stuffed with books she couldn’t read, and fragile works of art involving macaroni, glitter,
or clay. As I steadied her and passed her on to the bus driver, I pictured the sign on the entrance of the roller coaster at our county fair: “WARNING. If you are too small to reach this bar, you are too small to ride this ride!”

Was Sylvia too small for my classroom as well? Did the principal see our little dungeon as an education roller coaster, with breathtaking heights and depths? It was a gratifying possibility. Sylvia was no stranger to risk and excitement. She’d encountered plenty of both, living and working on a ranch with her mother, brother, sister, and grandma.

One day, while everyone else was out in the fields, Sylvia prepared a complete, balanced meal for her family. She set the table, with silverware and napkins all in their proper places. She welcomed them back from the mud and the blood with her unique and profound hospitality: “C’mon,” she said. “Sit.” Sylvia had rarely rattled a pot before that day.

Mom’s theory was that Sylvia spent a lot of time “getting ready” to learn; then she leaped to mastery. Although she’d shown no classic signs of emergent literacy, Mom said Sylvia was “getting ready” to read. At the intersection of theory and practice, I stood both poised and puzzled. I’d just completed a behaviorist-oriented special education masters’ program; so I felt an urge to observe and measure something. I decided to produce a comprehensive list of Sylvia’s expressive vocabulary. With a battery of innovative lesson plans, high-tech and low-tech augmentative and alternative communication devices, and rewards both primary (burgers and fries) and secondary (verbal praise), Sylvia produced about fifteen functional words. Most of them lingered shyly outside the framework of an actual sentence. “Coke.” “No.” “O.K.” “Mom.” In
bursts of frustration, she’d delight me with three complete sentences: “Shut up!” “Don’t touch!” and “Go to your room!”

One day a “normal” student brought me a wide-eyed field mouse he’d tried to feed alive to a snake. The snake didn’t want it; but we did. In silent collaboration, Sylvia and I constructed a luxurious habitat for the mouse and placed it on her desk. Clever as the mythical mice in those unreadable books Mom tucked in Sylvia’s backpack, our class mouse opened his tiny cork door and escaped.

He ping-ponged around the room! The paraeducator screamed! As we scrambled to catch him, Sylvia let loose a barrage of new words: “He’s mine! He’s mine! Here! Here! No, no! Careful! He’s mine! Get back! Look out! Get away!”

When the mouse was self-contained again, I asked Sylvia to name him. “Ralph,” she said. Mom said they didn’t know any Ralphs. She’d never heard Sylvia say “Ralph” before. The next day we mainstreamed Ralph. We placed him back in the world of adolescent boys, hungry snakes, and other local wildlife. In the week following Ralph’s emancipation, Sylvia read her first word: “mouse.”

Ever since, as a teacher, researcher, and advocate for inclusive education, this is my philosophy: One’s task, as a teacher of children with “severe” disabilities, is to tenderly balance the security and limited expectations of keeping Ralph in, with the thrills and possibilities of letting Ralph out.

In the Postmodern Tradition

Ralph was both a mouse and a metaphor. As a mouse, he was simply a mouse. As a metaphor, he was the postmodern condition: the unexpected, unpredictable, little fact that is capable of gnawing holes in great, global narratives of educational theory and
practice. When Lyotard (1984) sought to translate “the postmodern condition” (p. 3), he began by defining modernism.

Modern society, said Lyotard, was dependent on “metanarratives” (1984, p. 35)—grand stories by which a culture defined and perpetuated its values and practices. Lyotard saw the work of postmodernism as the critical deconstruction of these metanarratives.

Derrida (1997) defined the process:

Deconstruction is the act of opening, exposing, expanding, and complexifying, toward releasing unheard-of, undreamt-of possibilities to come. The very meaning and mission of deconstruction is to show that things – texts, institutions, traditions, societies, beliefs, and practices of whatever size and sort you need – do not have definable meanings and determinable missions, that they are always more than any mission would impose, that they exceed the boundaries they currently occupy. (Derrida, 1997, p. 31)

Ralph led Sylvia and me to exceed our boundaries. He was our undreamt-of possibility, deconstructing 15 years of reading instruction. Even more undreamt-of possibilities followed in his tiny footsteps. Capitalizing on her new reputation as a breakthrough scholar, Sylvia was invited to participate in a high school algebra class, where she kept a meticulous notebook, discovered the visual and tactual pleasures of a calculator, and copied notes from the board. One day she walked into class, sat down, and drew the coordinate plane with plot points.

With her passion and her vision, Sylvia managed to deconstruct learning itself, expanding and complexifying its meaning and its missions. Following Sylvia’s example,
there are many educational boundaries available for judicious deconstruction.

Significance of the Study

One of those educational boundaries is the powerful medical/scientific metanarrative that defines “disability.” Disability can be viewed on a continuum of meanings, from justifying euthanasia (Singer, 1993), to a vision of “a social environment where to be legless is [not abnormal, or normal, but] irrelevant” (Oliver 1978, p. 137, as cited in Oliver, 1996, p. 96). Though widely opposed, these metanarratives are based on locating pathologies and deficits in disabled individuals, or in the society in which they live.

Students are placed in special education based upon a battery of assessments. They “qualify” for special education services if their intelligence falls below a “normal” range, and their medical “abnormalities” require “interventions.” Although current definitions of disabilities have evolved to more functional categorizations, students are still defined and tracked by specific medical diagnoses. Autism, cerebral palsy, epilepsy, spina bifida, deaf-blindness, sickle cell anemia, Down syndrome, and mental retardation are some of the most generally recognized developmental disabilities, and are labeled as such for the purpose of providing special education services (Westling & Fox, 2004).

Since the enactment of Public Law 94-142 in 1975 (now the Individuals With Disabilities Education Act [IDEA]), the United States government has required public school students with all types of disabilities to be educated in the least restrictive environment—“to the maximum extent possible . . . with children who do not have disabilities” (20 U.S.C., section 1412 [5] [B]). The percentage of students with disabilities placed in K-12 regular classrooms for at least 80% of the day increased
between 1988-1989 and 1998-1999. But the smallest increase occurred among students with multiple disabilities, from only 7% to 11% (National Center for Education Statistics, 2004). Even in schools where students with disabilities are included in general education, the practice may entail “little more than the relocation of disabled students into general education classrooms” (Ware, 2002, p. 154). It appears that students with mental retardation and developmental disabilities are destined to remain, literally and epistemologically, in a class by themselves.

Inclusive education itself is a contentiously constructed phenomenon, subject to an “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85) among various defining discourses and disciplines. Seemingly irresolvable tensions exist between equity and excellence (Hargreaves, 2004; Skrtic, 1991b), between civil rights ideals and pragmatic practices (Skrtic, 1991a; Kavale, 2002; Kavale & Forness, 2000; Erevelles, 2002; Society for Disability Studies, n.d.), and between standards-based education reform and the call for collaborative, multicultural learning communities (Artiles, 2003; Pajak, 2001; Pajak & Green, 2003; Skrtic, 1991b). However, even the most dominant meanings which have been constructed can be deconstructed, if educators will turn their attention to the task.

Can we learn to re-define and re-imagine disability as something other than a tragic collection of symptoms, prohibitions, and limitations? Can we re-imagine the possibilities of disabled lives worth living? If the contribution of students with disabilities to school and society can be recognized and communicated, can educators’ resistance to inclusion be overcome? Can equity and excellence join forces to transform our schools?
Deconstructing the metanarratives of disability is a worthy goal for postmodern scholar-practitioners of special education. However, deconstruction and destruction are not synonymous. The postmodern scholar-practitioner of special education operates within prevailing metanarratives, deconstructing them from the inside out. Scholar-practitionership continually explores, expands, and facilitates the "unheard-of, undreamt-of possibilities" (Derrida, 1997, p. 31) that contains the possibility to transform not just education, but the lived world.

With a goal of transformation, the purpose of this study is to explore symbolic interactions (Blumer, 1969) in inclusive classrooms to reveal some meanings of disability, mental retardation, and inclusion—primarily from children’s perspectives. The study is focused on the interactions of an eleven-year-old girl diagnosed with Rett syndrome, and her interactions with her peers with and without disabilities, her paraeducators and her teachers. A genealogical perspective (Foucault, 1984/1971, 1995/1975; Prado, 2000) informs this work, to reveal relations between power, knowledge, and the body associated with the emergence of the full inclusion movement in systemic education reform.

The Research Question

The research question is: What are the patterns of interaction and meaning between one particular eleven-year-old girl diagnosed with Rett syndrome—Ashley (pseudonym)—her fourth- and fifth-grade peers with and without disabilities, her paraeducators and her teachers? Elaborate investigation of this question may permit our meanings of disability and inclusion to be transformed through a deeper understanding of a small circle of friends and educators.
Definition of Terms

Inclusive education for students with intellectual and developmental disabilities occurs within a context of contentious, confusing expectations and definitions. The resulting terminology—the language of disability—takes on meanings that stir the emotions, confuse the mind, and disrupt the discourse. It is difficult to explore the topic without offending various stakeholders. The language of disability in education is derived from a medical model; therefore, the definitions of disability in this text, except as otherwise noted, will reflect the prevalence of the medical model and incorporate its terminology.

*Developmental disability* means a severe, chronic disability of a person five years of age or older, which is attributable to mental and/or physical impairments. A developmental disability is manifested before age 22, and is likely to continue indefinitely. It results in substantial functional limitations in three or more of the following life activities: self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (*Developmental Disabilities Assistance and Bill of Rights Act*, 2000).

*Mental retardation* is a developmental disability that often accompanies other developmental disabilities. The current, functional definition by the American Association on Mental Retardation (2003, ¶ 5-6) is as follows: “Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.”
Severe and severe disabilities refer to professional determination of an individual’s need for supports, and the extent of an individual’s limitations in the functional categories enumerated by the American Association on Mental Retardation (2003) and the Developmental Disabilities Assistance and Bill of Rights Act (2000). Professional determination of severity is accomplished through medical, intellectual, and adaptive behavior assessments administered by qualified practitioners (Westling & Fox, 2004).

Genealogy, in the tradition of Foucault (1984/1971; 1995/1975), explores the “history of thought” (Foucault, 1988b) that led people to do what they were doing, and led them to believe in what they did (Foucault, 1984/1971; Skrtic, 1991a).

Mainstreaming refers to the physical, academic, and social integration into general education classes and extracurricular activities of children with “mild” disabilities: mild mental retardation, emotional disturbance, and learning disabilities, without questioning or restructuring existing structures and practices. Mainstreaming was a prevailing philosophy in the 1970s. (Skrtic, 1991a)

The Regular Education Initiative (REI) refers to an overarching belief that the goal of special education should be continued, incremental progress toward more socially-inclusive educational placements. Proponents of the Regular Education Initiative were divided on which students should be included in general education—“mildly” disabled children or “most” children. The position of most REI proponents on students with “severe” disabilities was that they should remain in self-contained classes. Paradoxically, some REI proponents advocated for a restructuring and merger of general and special education. Some proponents advocated retaining and improving special education as a
parallel system. The REI was a prevalent discourse in the 1980s. The REI is focused on improving academic knowledge and skills. (Skrtic, 1991a)

The Full Inclusion Movement refers to a philosophy that calls for a merger of special and general education, and the abandonment of labeling and self-contained classes, with the retention of specialized services. Full inclusion is focused on improving social competencies. (Skrtic, 1991a)

Phenomenology, as a philosophy, refers to the social construction of meaning through a reciprocal interaction of mind and body, thought and object. As a research method, phenomenology is the study of lived experience from the point of view of the individual who is having the experience. (Van Manen, 1990)

A symbol is anything to which a person intentionally attends and responds. Symbols enable humans to name and respond to things outside of immediate time and place (Mead, 1962/1934).

Symbolic Interactionism is based on the premises that: 1) Human beings act toward things on the basis of the meanings those things have for them; 2) the meaning of things is derived from social interaction; and 3) meanings change with understanding (Blumer, 1969).
CHAPTER II

REVIEW OF THE LITERATURE

The purpose of this chapter is to explore existing, deep-rooted meanings of disability and inclusion from a genealogical perspective, in order to uncover “truth[s] of power” (Foucault, 1980, p. 93) that have given rise to enduring disability stereotypes and contentious, confusing definitions of inclusive education. The first section describes Foucault’s (1980, 1995/1975) genealogical perspective, as it relates to concepts of power, knowledge, and the body. The second section discusses the application of a genealogical perspective to education research. The third, fourth, and fifth sections utilize a genealogical lens to explore existing meanings of disability, mental retardation, and inclusive education. The sixth section explores relevant legislation and its concomitant influence on the inclusive educational experiences of children with disabilities. The final section presents a summary of the intersecting forces of power and knowledge that comprise the current context of this study.

The Genealogical Perspective

In reference to his life’s work, of which genealogy was a significant part, Foucault (1988a) described himself as “a historian of thought” (p. 10). An historian shows us what people were doing in a particular time and place. An historian of thought—a genealogist—shows us what led people to do what they were doing, and what led them to believe in what they did (Foucault, 1984/1971; Skrtic, 1991a). A Foucauldian
genealogy offers a holistic interpretation of events. It elevates the “marginal” over the presumably “central,” emphasizes the “constructed” over the “natural,” and elevates the value of the accidental over the “allegedly inevitable” (Prado, 2000, p. 33).

Power, Knowledge, and the Body

Foucault (1995/1975) began his classic treatise on power with a graphic description of the March 1757 drawing and quartering of Damiens, the regicide. If an execution can be described as going well, or not going well for the victim, Damiens’ execution did not go well. When four horses could not pull him apart, they tried again with six. When six horses failed, the executioners hacked at Damiens’ joints and sinews to facilitate the quartering. Attempts to burn Damiens’ body flamed out; and it proved so difficult for the executioner to tear away Damiens’ flesh that he had to “set about the same spot two or three times” (Gazette de Amsterdam, 1757, April 1, as cited in Foucault, 1995/1975, p. 3).

Damiens’ body was individually punished for his crime; and he also suffered on behalf of the “social body” (Foucault, 1980, p. 93). The hideous, public nature of Damiens’ punishment was designed to reestablish the absolute authority of the monarch over all his subjects. Such a display punished the guilty, and warned others that they were vulnerable to the same consequences (Foucault, 1995/1975; Prado, 2000).

The Nature of Sovereign Power

In Damiens’ day, the sovereign wielded a power that was both spectacular and unlimited. However, the spectacle of public execution provided only irregular and discontinuous reminders of the sovereign’s control (Foucault, 1995/1975). The tortured and the executed were sometimes perceived as heroes by their fellow subjects, rather than
reviled as criminals. The barbarity of their executions could inspire pity and empathy, as well as fear (Foucault, 1995/1975).

_Towards the end of the 17th Century, public executions and public torture began to decline. Historically, this decline has been attributed to the development of a more enlightened and humane attitude toward one’s fellow human beings (Prado, 2000). From Foucault’s (1980, 1984/1971) holistic, genealogical perspective, this decline marked a new way of controlling human beings. This new management concept was *disciplinary power* (Foucault, 1995/1975). Disciplinary power fomented in the social spaces outside the knowledge and gaze of the sovereign, where subjects were “free to practice a constant illegality” until and unless they were caught (Foucault, 1995/1975, p. 88). It was the intersection of these two forces—sovereign power and the freedom to escape that power—that created a space for disciplinary power to emerge (Foucault, 1995/1975; Prado, 2000).

_The Nature of Disciplinary Power_

Whereas sovereign power punished the individual and social body, disciplinary power was a force that both invented and invaded the “soul” (Foucault, 1995/1975, p. 138). Foucault explained:

> It would be wrong to say that the soul is an illusion, or an ideological effect. . . . It is produced permanently around, or within the body by the functioning of a power that is exercised on those punished—and, in a more general way, on those one supervises, trains and corrects, over madmen, children at home and at school, the colonized, over those who are stuck at a machine and supervised for the rest of
their lives. This is the historical reality of this soul, which, unlike the soul represented by Christian theology, is not born in sin and subject to punishment, but is born rather out of methods of punishment, supervision and constraint. (Foucault, 1995/1975, p. 29, emphasis added).

With the emergence of disciplinary power, the target of judgments became souls, rather than bodies and their actions. Individuals were judged with a goal of managing and controlling their behavior from the inside—from the soul (Foucault, 1980, 1995/1975; Prado, 2000).

*Power and the Body*

Under sovereign power, Damiens was the literal subject of a sovereign who controlled and punished his physical body. The spectators at Damiens’ execution were also the property of the sovereign. Their presence was required to witness, fear, and therefore participate in the king’s vengeance (Foucault, 1995/1975). Sovereign power subjected the individual’s body to regulation by individual sovereigns.

Disciplinary power emerged as a corollary to sovereign power; and it cut even deeper, making subjugation more complex. Now the individual’s goals, desires, and self-image were also subject to control (Foucault, 1980, 1995/1975). Disciplinary power was a “policy of coercions” (Foucault, 1995/1975, p. 138) that produced “docile bodies,”—subjects who were willing to conform to goals and practices defined by policies and politics—or “disciplines.” In order for disciplinary power to define and subjugate individual and social bodies, it was necessary for each discipline to develop its own, specialized discourse.
Power, Discourse, and Truth

Foucault (1980) saw the role of discourse as providing “limits to the rights of power,” and “discourse . . . par excellence [as] concerned with truth” (p. 93). Discourse constructed the truths—the specialized knowledge—that society needed to function. Each discipline, possessing its own discourse, engendered its own version of truth, resulting in “a multiplicity of new domains of understanding” (p. 106). Each truth, as its discourse evolved, became a “truth of power” (p. 93) that resulted in a body of specialized knowledge.

Power, Truth, and Normalization

As sovereign power evolved to accommodate larger populations, it became juridical power—a truth of power that resided within the law. Foucault (1980) drew a sharp distinction between juridical power—“the discourse of right,” which dealt with “law, rule, or sovereign will,” and the discourse of discipline. The discourse of discipline derived from “a natural rule, a norm;” and it referenced “a theoretical horizon” (p. 106). This discourse of discipline belonged to the domain of “human [social] science;” and its form of knowledge was “clinical” (p. 107).

Specialized Knowledge Creates an Inevitable Binary

When specialized knowledge took on the status of a discipline, such as a “human [or social] science” (Foucault, 1980, p. 107), it brought into being a necessary binary—a distinction between what was right and what was wrong, and between what was “normal” and what was not. Foucault (1980, 1995/1975) traced this inevitable binary to the constant interplay between two types of discourse, derived from the exercise of the two types of power: juridical and disciplinary.
Foucault’s (1995/1975) classic example of the binary is found in his description of the act of defining criminal behavior. Defining the criminal created the need for “tacit recognition of the ‘normal’ person . . . a sort of substantive shadow of the lawbreaker” (Prado, 2000, p. 60). With the emergence of disciplinary power, it was no longer just the sovereign who was offended and damaged by the act of a subject. “Normal” individual and social bodies were offended as well. It was no longer effective to merely frighten and punish the body. Under disciplinary power, the body could be repaired and reformed. It could be “normalized.” Foucault declared, “We punish, but this is a way of saying that we wish to obtain a cure” (1995/1975, p. 22, emphasis added).

Observation, Examination, and the Universal Reign of the Normative

Foucault (1995/1975) maintained that in order to repair, reform and cure offending bodies, they must be intensely inspected and compared to entrenched norms. This was done by means of observation and examination. Observation and examination were modeled on the “Panopticon” (Bentham, 1791, as cited in Foucault, 1995/1975, p. 200)—an architectural design for a prison. The Panopticon consisted of a central tower surrounded by circular configurations of cells. From the tower, the guards could constantly observe the shadows of the prisoners. But the inmates could only observe the tower, which served as a symbol of constant surveillance and power. Side walls prevented the prisoner from seeing either the guard or the other prisoners:

And this invisibility is a guarantee of order. If the inmates are convicts, there is no danger of a plot, . . . escape, or . . . planning new crimes . . . ; if they are patients, there is no danger of contagion; if they are madmen there is no risk of their committing violence upon one another; if they are schoolchildren, there is no
Observation was hierarchical, because the observer held more power, and therefore presided over the definition of normal. The examination came about to fulfill the need for information to be passed from lower to higher levels, in situations and institutions where a single observer would not suffice (Foucault, 1995/1975). And “the judges of normality” were “everywhere . . . the teacher-judge, the doctor-judge, the educator-judge, the ‘social worker’-judge; it is on them that the universal reign of the normative is based” (Foucault, 1995/1975, p. 304, emphasis added).

Foucault (1980, 1984/1971, 1995/1975) asserted that specialized knowledge, disciplinary discourse, and intense surveillance turned obedience into habit, and habit into internalization of norms. In this way, physical/judicial control of the body became control of the soul, through the imposition of “values, beliefs, and self-identity” (Prado, 2000, p. 61).

Foucault (1980) claimed the force of normalization was strengthened by the constant interaction of the two forms of power: juridical and disciplinary. He noted: “Their incompatibility with each other is ever more acutely felt and apparent: some kind of arbitrating [normalizing] discourse is made ever more necessary” (Foucault, 1980, p. 107). The result of the constant interaction of these incompatible forces was an “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85), which left little room for transformation of the self. The stronger the norms, the deeper they would be internalized into one’s soul; and the norms were strengthened by the constant interaction of the two types of power. But, in Foucault’s later work (1980, 1984/1971, 1988b), he explored the
productive, transformative aspects of the individual, as the individual turned himself or herself into a subject.

*Foucault Acknowledges the Possibility of Resistance and Self-transformation*

In an interview published two years after his death, Foucault (1988b) had come to terms with a new role for his life and work:

My role . . . is to show people that they are much freer than they feel, that people accept as truth, as evidence, some themes which have been built up at a certain moment during history, and that this so-called evidence can be criticized and destroyed. . . . (Foucault, 1988b, pp. 10)


The Uses of Foucault in Education

As educational researchers turned to Foucault to analyze policy and practice, they also began to critique “the uses of Foucault” in education (Mayo, 2000, p. 103). Butin (2001) approached Foucault’s analysis of disciplinary mechanisms as a discourse. He
identified an emergent discourse of “reactionary criticism” (p. 160) of educational practices. Within this competing discourse, Butin cited three “Foucauldian fallacies” (p. 157) in the disposition of educational researchers, which produced a view of pedagogy and administration as punitive, normalizing, and controlling: “1) the negation of agency, 2) the exclusion of the potential for resistance to domination, and 3) the capitulation to radical relativism” (p. 156). According to Butin (p. 158), many educational researchers appropriated Foucault’s notion of resistance to expose allegedly empowering practices of schooling, concluding that they merely led to “their own dystopias” (p. 158). He suggested that such “gloom and doom’ analyses may say more about the researchers’ theoretical dispositions than of Foucault’s own stance” (p. 158).

Cheshier (2002), Rorty (1990), and Scheurich and McKenzie (2004) did not ascribe to gloom and doom analysis. Cheshier (p. 4) found in Foucault’s later work “the implicit assumption that individuals can transform their circumstances (or their relationship to them) by asserting their own influence (deploying their own power).” He insisted that “Foucault did not reject the idea of ‘education’ as inevitably dominating or coercive.” Rorty (1990, ¶ 19) declared that Foucault, “whether he wanted to be or not . . . was a useful citizen of a democratic country—a man who did his best to make its institutions fairer and more decent.” Scheurich and McKenzie (2004, p. 23) viewed Foucault’s descriptive accounts of “the complexities of disciplines, social arenas, and institutions . . . [as leaving room for] spaces of resistance, counterattack, appropriation and construction.” Mayo (2000), in his analysis of Foucault’s “underexamined narratives of the self” (¶ 1), contended, “Perhaps more than anything else, Foucault asks us to leave
home, encounter difficulties, and struggle against normalization to free ourselves: nothing more than the task of education in its best sense" (¶ 31).

Using Foucault in Education Research to Explore Deep-rooted Meanings

When applied to education research, Foucauldian genealogy (1984/1971), and Foucault’s concepts of power and knowledge (1980, 1995/1975), provide a context for exploring deep-rooted meanings of disability and mental retardation in the 20th and 21st Centuries. These meanings reflect a struggle against governing norms—an “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85). As disparate meanings of disability and mental retardation intersect and interact, they also reveal liberating endeavors to “constitute . . . a new self” (Foucault, 1988a, p. 49).

Power, Knowledge, and Existing Meanings of Disability

Existing meanings of disability can be viewed on a continuum of specialized discourses, from justified euthanasia (Singer, 1993) to a vision of “a social environment where to be legless is irrelevant” (Oliver 1978, p. 137, as cited in Oliver, 1996, p. 96). Though widely opposed, specialized discourses of disability are primarily discourses of embodied pathologies and deficits. In the present moment, there are multiple discourses that exert significant power over disabled bodies, in order to reform, reshape, or remove them. They may be “stretches of language as short as a conversational exchange, or as long as the literature of an academic discipline” (Barton, 2001, p. 169).

A Bioethical Discourse on Disability

Singer (1993) insisted that “seriously disabled” human infants, and “older children or adults whose mental age is and has always been that of an infant” (1993, p. 181) are not persons. Personhood requires “rationality, autonomy, [and] self-
consciousness” (p. 182), which Singer claims individuals with intellectual and developmental disabilities cannot attain. He justifies the killing of any infant “born with a serious disability” because the infant’s parents “may, with good reason, regret that a disabled child was ever born” (p. 183). If the child could be “replaced” (p. 186) by a healthy child who would have “better prospects” (p. 185) for a happier life, Singer said “it would be right to kill him,” because the lives of all disabled people are “less worth living” (p. 188) than the lives of people who are not disabled. Singer’s discourse tacitly defined a “normal” life as the only “life worth living.”

A Medical Discourse on Disability

The medical discourse of disability is also focused on individual pathology (Johnson, 2003; Mairs, 1996, 2002; Mitchell, 2002; Oliver, 1996; Smith, 1999; Ware, 2002). Persons with disabilities are identified and described by specific symptoms and syndromes that represent dis-ease and limitations, with a goal of curing or “fixing” that which is “narrated outside the norm” (Mitchell, 2002, p. 17).

Linda Ware, whose son Justin was diagnosed with cerebral palsy-like symptoms a few months after his birth, described her encounter (Ware, 2002, p. 147) with the medical model through the lens of her experience as an educator, researcher, and disability rights activist. Immediately after the diagnosis, her “once ‘oh-so-healthy’ baby became ‘obviously blighted’ ‘defective’ and ‘damaged’—marked by his medical fate . . . .” Ware’s neurosurgeon advised institutionalization. “In an ordinary and matter-of-fact tone, he said, ‘given your age, this event could spoil the rest of your life.’” Vygotsky (1978/1934) introduced a theoretical departure from the medical model, with a sociological discourse on disability.
A Sociological Discourse on Disability

Vygotsky’s (1978/1934) social development theory was a movement toward a social constructivist definition of disability. According to Vygotsky, learning was a social phenomenon, and disability was a phenomenon of sociocultural development. A disability was perceived as other than “normal” only in its social context. Learning did not require a “normal” hierarchical profile of biological maturation. One need not reach (or have the capacity to reach) a fixed state of readiness, or a certain chronological age, to be able to learn something. By de-emphasizing this fixed hierarchy, Vygotsky weakened the emphasis on the medical pathology of disability. He argued for the dynamic nature of disability, and insisted that constant changes in the structure and content of a disability took place during development, under the influence of education and remediation. The nature of these changes could be positive or negative.

Based upon his understanding of dynamic development, Vygotsky (1978/1934) described two types of handicapping conditions: one, biology; and two, social deprivation. For Vygotsky, the two conditions were inseparable; and the social disability was seen as far more handicapping than the biological predisposition. He called for a school curriculum that recognized and incorporated the compensatory strategies and social complications of disability.

A Sociopolitical Discourse on Disability

Oliver (1996) also found a disabling deficit in society:

It is not individual limitations, of whatever kind, which are the cause of the problem, but society’s failure to provide appropriate services and adequately
ensure the needs of disabled people are fully taken into account in its social organization (Oliver, 1996, p. 32).

The seed of Oliver’s (1996) social model of disability was contained in a “little red book” produced by the Union of the Physically Impaired Against Segregation (UPIAS), and “not widely available” (Oliver, 1999, p. 8). The position articulated by the UPIAS appears to have much in common with Vygotsky’s (1978/1934) social development theory. The UPIAS position states that disability is something imposed on top of impairments by the way individuals with disabilities are, without reason, isolated and excluded from full participation in society. The difference between Vygotsky’s social development theory and the UPIAS statement is that the UPIAS statement is formulated from the beliefs and experiences of people with disabilities. The UPIAS declares: “Disabled people are therefore an oppressed group in society” (as cited in Oliver, 1999, p. 8). Oliver (1996) credited the little red book with shaping his own understanding of disability, and that of others with disabilities:

The genesis, development and articulation of the social model of disability by disabled people themselves are a rejection of [medicalisation and personal tragedy models]. It does not deny the problem of disability but locates it squarely within society. (Oliver, 1966, p. 32).

Oliver insisted that disability research can and should be properly conducted only by individuals with disabilities. From his perspective, the power to separate the disabled and ableist cultures is exerted by persons with disabilities, who construct their own meanings of disability and a normal life.
A Charity Discourse on Disability

Barton (2001) uncovered a powerful disability discourse that emerged along with the United Way charities in the early 1950s, giving rise to some enduring disability stereotypes. America in the 1950s was experiencing an economic and reproductive boom time, right after WWII. It was a war with clear binaries between good and evil (Anderson, 1995); and America was on the side of the good. Veterans who earned their disabilities in the war were publicly hailed as heroes. But there was also an undercurrent of uneasiness about the presence of “disabled Others” (Barton, 2001, p. 170) in postwar society.

Polio was a particularly fearsome disabling disease, blight on the country’s bright new future. In this context, disability became a complex social experience of difference, which was neither owned nor constructed by the disabled. Instead, disability was constructed by the nondisabled majority, through a charity discourse, which consisted of three “textual practices of erasure” (Barton, 2001, p. 172).

Erasure: The Poster Child

The first of these practices of erasure (Barton, 2001) was the use of the “poster child” in advertising. A poster child was selected from among children with a specific disability to serve as a “model” for that disability, for an honorary term of one year (Fleischer & Zames, 2001). The cuter the child, the better s/he was able to invoke pity and fear, erasing the legitimate interests of persons with disabilities in their own independence and autonomy (Barton, 2001; Fleischer & Zames, 2001). With the advent of television in the 1960s, poster children were paraded across a stage and viewed by millions of people, while numbers moved across the screen, tallying the amount of funds
raised for their cure or rehabilitation. Children with disabilities held their own fearful stereotypes about the poster children they saw as the only representatives of their kind (Fleischer & Zames, 2001). Some of them thought they would all be cured by the time they reached adulthood. Some thought they would die before they grew up.

Jerry Lewis and the Enduring Pity Discourse

The annual Jerry Lewis telethon for Muscular Dystrophy is reviled by disability rights activists for its pity discourse, which aims for “an end to impairment, but not an end to disability” (Fritsch, 2004, p. 4). A statement by Lewis on CBS Sunday Morning (2001, May 20) confirms the contention that the charity discourse invokes pity to manipulate potential donors (Barton, 2001; Fleischer & Zames, 2001). “If it’s pity, we’ll get money. You don’t want to be pitied because you’re a cripple in a wheelchair? Stay in your house!” (CBS Sunday Morning, 2001, May 20). The Jerry Lewis Muscular Dystrophy Association telethon is still an annual Labor Day event.

By the 1970s, the poster child shared the context of erasure with the disabled adult, who was now a full-grown burden on society (Barton, 2001; Wehmeyer, 2000). A Torch Drive poster in 1975 featured an adult with mental retardation: “The toughest handicap for a retarded child,” the poster declared, “is that he becomes a retarded adult” (Walter P. Reuther Library, Wayne State University, as cited in Barton, 2001).

Erasure: The Supercrip

The second practice of erasure (Barton, 2001) was the use of extraordinary (rather than ordinary) individuals in campaigns that emphasized achievement and success, thus portraying individuals with disabilities as “supercrips”—persons who lived out the popular representation of disability as an adversity to be overcome against all odds. It
was a disability version of the classic American success story. Stories about one-armed baseball players, ocean-sailing blind men, and mountain-climbers who used wheelchairs portrayed disabled persons as deviant because they achieved superhuman feats, or lived a normal life in spite of their disability (Haller, 2000). Christopher Reeve was criticized by the disability rights community for reaffirming disability as a tragedy that could be cured with medical expertise and money for research (Brown, 1996; Fritsch, 2004):

Christopher Reeve, who doesn’t advocate for access, only for cure . . . get[s] to talk with the President. . . . First the media and now Bill Clinton have anointed him the leader of people with disabilities. We should all protest this . . . able-bodied arrogance. (Brown, 1996, ¶ 1)

Erasure: Slowing Down Productivity

Barton’s (2001, p. 172) third practice of erasure was a new focus on the charitable organization itself, in campaigns portraying the United Way as “a model of American business.” The slogan “give once and for all” (United Way, as cited in Barton, 2001, p. 188) portrayed charity drives and donations as interruptions of work. If American workers need only tolerate this interruption once (and for all), the burden of disability would not slow down production.

Galvanizing the Divide Between Self and Other

Barton (2001, p. 197) saw these practices of erasure as galvanizing the divide between normal and disabled—Self and Other. She traced practices of erasure to enduring stereotypes of dependence, transcendence, and difference: “Taken together, these stereotypes establish and maintain the cultural position of individuals with
disabilities as Other, segregated from the workplace and erased from much of the rest of social life as well.”

*Normalizing Truths of Power: Bioethical, Medical, and Charity Discourses*

The bioethical (Singer, 1993) medical (Johnson, 2003; Mairs, 1996, 2002; Oliver, 1996; Ware, 2002) and charity (Barton, 2001) discourses of disability are primarily focused on pathology and deficit. They may be seen as “truth[s] of power” (Foucault, 1980, p. 93) that operate from a position of examination, observation, and imposed norms that force persons with disabilities into a role of Other, and “punish . . . as a way of saying that we wish to obtain a cure” (Foucault, 1995/1975, p. 22). There are other truths, which resist these norms, and seek to re-imagine disability.

*Power, Knowledge and Transformation: Discourses that Seek to Re-imagine Disability*

Gill’s (1994) ultimate goal was that society would accept a disability culture as part of human diversity. Turnbull and Turnbull (2000, p. 13) called for “casting aside the old assumption of disability rootedness, of the chronic tether of disability.” They offered a vision “that, in the next millennium, families [will] be no more affected by their children’s disability than . . . the musical gifts, mathematical genius, athleticism, or plain ordinariness of their other children.”

Nancy Mairs, (1996, p. 4) an accomplished writer who was diagnosed with multiple sclerosis at age 29 and began to live a “progressively crippled life,” writes with humor and optimism about her disability experience:

Here I was, after all: an attractive young woman of intellectual and artistic promise . . . cut down in my prime. Here I am now, a quarter of a century later, prime well past, hunched and twisted and powerless but for two twelve-volt
batteries beneath my ass. Woe is me! Except that, on the whole, woe isn’t me. (Mairs, 1996, p. 31)

Harriet McBryde Johnson (2003), an attorney in Charleston, South Carolina, was born with a developmental disability. She asserts her body of truth in the personal space between positive and negative discourses.

It’s not that I’m ugly. It’s more that most people don’t know how to look at me. The sight of me is routinely discombobulating. . . . I’m Karen Carpenter thin, flesh mostly vanished, a jumble of bones in a floppy bag of skin. . . . At 15, I threw away [my] back brace and let my spine reshape itself. . . . I lean forward, rest my rib cage on my lap, plant my elbows beside my knees. Since my backbone found its natural shape, I’ve been entirely comfortable in my skin. Most often [people’s] reactions [to me] are decidedly negative. Strangers on the street are moved to comment: “If I had to live like you, I think I’d kill myself.” I used to try to explain that in fact I enjoy my life. But they don’t want to know. They think they know everything there is to know, just by looking at me. That’s how stereotypes work (Johnson, 2003, ¶ 12-16).

Scholars in Disability Studies—a nascent branch of the humanities—also seek to re-imagine disability. They are represented by the Society for Disability Studies.

A Scholarly Discourse on Re-imagining Disability

The Society for Disability Studies invites scholars, activists, artists, and practitioners from a variety of disciplines to study disability “as a key aspect of human experience, on a par with race, class, gender, sex, and sexual orientation” (Society for Disability Studies, n.d.). The Society’s stated purpose is to elevate the place of disabled
people within society, and to add perspective on a broad range of ideas, issues and
policies beyond the disability community. In 2004, the Society drafted a mission
statement of the following guidelines for any program that describes itself as Disability
Studies:

1. It should be interdisciplinary/multidisciplinary . . . [encouraging] a curriculum
that allows students, activists, teachers, artists, practitioners, and researchers to
engage subject matter from various disciplinary perspectives.

2. It should challenge the view of disability as an individual deficit or defect that
can be remedied solely through medical intervention or rehabilitation by “experts”
. . . . [and] explore models and theories that examine social, political, economic
and cultural factors that define disability and help determine personal and
collective responses to difference . . . [and] interrogate the connections
between medical practice and stigmatizing disability.

3. It should study national and international perspectives, policies, literature,
culture, and history . . . [to] place current ideas of disability within their broadest
possible context.

4. It should actively encourage participation by disabled students and faculty, and
should ensure physical and intellectual access.

5. It should make it a priority to have leadership positions held by disabled people
. . . [but] create an environment where contributions from anyone who shares the
above goals are welcome. (Society for Disability Studies, n.d.)
The field of disability studies in education has begun to challenge Foucauldian binaries (normal/pathological, autonomous/dependent) in curriculum, popular culture, and politics, supporting the interests of persons with disabilities as a social class (Erevelles, 2002). The field has also challenged the practices of special education (Danforth, 2000, 2001; Erevelles, 2000, 2002; Skrtic, 1991a, 1991b).

Existing meanings of disability, explored in this section, encompass both physical and mental disabilities. However, within the social construct of disability, developmental disabilities and mental retardation have acquired both shared and separate meanings. Persons with physical disabilities and sensory disabilities (such as vision and hearing impairments) have aligned themselves with the disability rights movement since the 1960s. They have, in fact, dominated that movement to the point that it has been criticized for its homogeneity (Danforth, 2001; McCarthy, 2003), leaving persons with mental retardation to find their own sources of power, knowledge, and social justice. The following section explores some existing meanings of mental retardation.

Power, Knowledge, and Existing Meanings of Mental Retardation

Persons with mental retardation have been subject to three “waves” (Wehmeyer, 2000, ¶ 1) of specialized knowledge and discourse. The first wave began early in the 20th Century, when mental retardation was becoming a distinct field of specialized knowledge, exerting its own power within the broader fields of medicine, psychology, and education (Wehmeyer, 2000).

*The First Wave of Discourse in Mental Retardation: Professional*

The Professional Wave encompassed a discourse grounded in “Mendelian eugenics” (Selden, 1998, p. 1), a program of sterilization and segregation designed to
protect society from “feeble-minded” individuals, who were held responsible for the
“social sores” (Goddard, 1926, p. 116) of humanity—including crime, poverty,
promiscuity, and the decline of civilization:

[Feeble-mindedness] is mostly hereditary; ... it underlies all our social problems;
... and . . . since [it] is in all probability transmitted in accordance with . . .
heredity, the way is open for eugenic procedure which shall mean much for the
future welfare of the race. (Goddard, 1926, pp. 589-590)

Eugenics and Euthanasia

Eugenicists believed that nature was both discrete and paramount in human
development. Environment could not compensate for inferior genes (Selden, 1998). The
20th Century saw a worldwide network of committed eugenicist organizations, fueled by
a revival of interest in Gregor Mendel’s 19th Century theories of genetic dominance and
inheritance, derived from his experiments with plants. In the United States, the movement
began with a subcommittee of the American Breeders Association, and developed
through the influential Galton Society, into the powerful, nationally-recognized American
Eugenics Society (AES). The AES generated medical and professional discourses that
dominated definitions of disability throughout the 20th Century, and continue in their
influence.

In 1919, the eugenic subcommittee of the American Breeders’ Association drafted
a model sterilization law to be applied to deaf people, blind people, and people with
developmental disabilities. Some eugenicists advocated “mercy killing” (Fleischer &
Zames, 2001, p. 12) of persons with epilepsy and mental retardation.
Not everyone in a professional capacity advocated the extreme measures of eugenics. But the lives of people with mental retardation were subject to observation, examination, and strict control by the physicians and humanitarians whose power fueled the First Wave (Beirne-Smith, Ittenback, & Patton, 1998; Hamill & Everington, 2002; MacMillan, 1982; Selden, 1988; Turnbull & Turnbull, 2000; Wehmeyer, 2000).

*Intelligence Testing*

In 1905, Alfred Binet developed an intelligence scale for the French government, to identify children who would benefit from extra help in school. Henry H. Goddard, a leading proponent of eugenics, translated and popularized Binet’s intelligence scale for American consumption. Goddard developed a hierarchical terminology associated with intelligence measurement, classifying increasingly sub-normal individuals as “morons” “idiots” and “imbeciles” (Green, n.d).

In 1916, Terman’s classic treatise, “The Uses of Intelligence Tests,” made a case for testing the intelligence of school children, to avoid “wasting energy in the vain attempt to hold mentally slow and defective children” to the same educational standards and progress as “normal” children (¶ 2). Terman (1916) was an early advocate for special classes based upon the diagnosis and classification of educational potential:

It is not sufficient to establish any number of special classes, if they are to be made the dumping-ground for all kinds of troublesome cases—the feeble-minded, the physically defective, the merely backward, the truants, the incorrigibles, etc. Without scientific diagnosis and classification of these children the educational work of the special class must blunder along in the dark. In such diagnosis and
classification our main reliance must always be in mental tests, properly used and properly interpreted. (Terman, 1916, ¶ 7).

The power exercised by the scientific discipline of IQ testing perpetuated the pathological connotation of mental retardation for decades.

The IQ test confused biological and psychological theories of deviance within the medical model of mental retardation (Mercer, 1973). In the discourse of biology, there was one overarching binary—normal/abnormal. Within the binary there was one type of abnormality, associated with the presence or absence of biological symptoms. Symptoms that interfered with system preservation were bad (abnormal); and symptoms that enhanced the life of the organism were good (normal).

The IQ test placed intelligence on a frequency distribution known as the “normal curve,” and defined abnormality by the extent to which an individual varied from the average of a population without disability (the “norm”). On the normal curve there were two types of abnormality—abnormally large and abnormally small amounts of the same characteristic. When the normal curve was associated with IQ testing, and intellectual capacity was measured in relation to a “norm,” it was good to be “abnormally” high and bad to be “abnormally” low.

Biological theorists measured the biological manifestations of mental retardation. Statistical theory—the “normal” curve—measured its behaviors. But, since most people with mental retardation did not have visible biological abnormalities, statistical theory became confounded with biological theory. Low IQ scores came to be accepted as symptoms of pathology (Mercer, 1973; Skrtic, 1991a)—which were detrimental to the preservation of the species.
Persons diagnosed with below normal intelligence were considered too feebleminded to benefit from education and treatment. They were segregated from society, deprived of schooling, and forbidden to procreate or enlist in military service (Hamill & Everington, 2002; Turnbull & Turnbull, 2000; Wehmeyer, 2000; Westling & Fox, 2004; Wolfensberger, 1983).

**Institutionalization**

Under the Professional Wave, the parents of children with mental retardation considered themselves subject to the professionals who identified their children’s “abnormality” and decided their fate (Turbull & Turnbull, 2000; Wehmeyer, 2000). The implication of this doctor-knows-best philosophy was that parents were to blame for their children’s mental retardation. Institutions were needed to take over the family’s role (Turnbull & Turnbull, 2000).

By the early 20th Century, most states had residential institutions for persons with mental retardation. But in a few cities, such as Providence, Rhode Island; Boston, Newton, and Springfield, Massachusetts; Chicago and Elgin, Illinois; New York and Rochester, New York; Washington, D.C.; Los Angeles, California; Bridgeport, Connecticut; Detroit, Michigan; Philadelphia, Pennsylvania; and Trenton, New Jersey, children with mental retardation were being served by special classes in neighborhood schools (Smith, 1998). As these alternatives to residential care became more numerous, they helped to set the stage for the second wave: parental advocacy.

**The Second Wave of Discourse in Mental Retardation: Parental Advocacy**

At the midpoint of the 20th Century, new developments in medicine increased the lifespan of persons with developmental disabilities. Vaccines for disabling diseases such
as polio were developed. Charity discourses portrayed the disabled as pitiful, innocent victims of their afflictions, and burdens upon their parents and society (Barton, 2001; Turnbull & Turnbull, 2000; Wehmeyer, 2000). Marked by this portrayal and the mental age score calculated by intelligence tests, people with mental retardation came to be perceived as eternal children, in need of protection and care (Barton, 2001; Salend, 1994 Wehmeyer, 2000).

Economic prosperity after World War II fostered a dramatic increase in the birthrate—the baby boom of 1945-1964. The nuclear family, with a wage-earning father, homemaking mother, and at least one child of each gender was the new American ideal. Opinion polls in 1957 revealed that only 9% of Americans believed that an unmarried person could be happy (Anderson, 1995). A popular woman’s magazine of the day declared, “Except for the sick, the badly crippled, the deformed, the emotionally warped and mentally defective, almost everyone has an opportunity to marry” (Anderson, 1995, p. 21). With the advent of television in the 1960s, mass media became a powerful venue for the instantaneous and pervasive portrayal of what was “normal” in America (Anderson, 1995). Television portrayed bland, patriarchal families like “Ozzie and Harriet,” and “Leave it to Beaver,” in which fathers worked outside the home, mothers dressed up in heels to keep house, children were cute and responsible, and “nothing ever happened” (Anderson, 1995, p 23; Billingsley, 1961; Lillico, 1993; Radio and Television Museum, n.d.). The baby boom also produced more babies with disabilities, whose family portraits did not fit the normal frame; and the dogma that blamed parents for their children’s mental retardation was beginning to change (Turnbull & Turnbull, 2000).
By the 1960s, a conversion in public perceptions of parents whose children had mental retardation was emerging. This change was symbolized by the public “comings out” (Turnbull & Turnbull, 2000, p. 5) of parents with national stature, who spoke with love and courage of their children with mental retardation. These influential parents included President John F. Kennedy’s mother Rose, and author Pearl Buck, who each had a daughter with mental retardation, and film and television personalities Dale Evans and Roy Rogers who adopted children with disabilities (Turnbull & Turnbull, 2000).

Many non-famous parents of children with mental retardation and developmental disabilities began “coming out” to form support groups, and address their concerns (Turnbull & Turnbull, 2000). The Arc (formerly the Association for Retarded Citizens of the United States) was founded in 1950, as the National Association of Parents and Friends of Mentally Retarded Children. Other influential groups included: United Cerebral Palsy Associations, Inc. (UCP), which began in 1949; the National Society for Autistic Children, formed in 1961; the Learning Disability Association of America (LDA), founded in 1963; and the Epilepsy Foundation of America, begun in 1968 (Smith, 1998). Group members were concerned about poor institutional programs, and the exclusion of children with mental retardation and other disabilities from public schools. At the same time, they realized that existing public school programs were not designed for their children. They wanted to gather and disseminate knowledge about disabilities. As these groups engaged in specialized discourse, they gained power and visibility, emerging as formal organizations (Salend, 1994; Smith, 1998; Turnbull & Turnbull, 2000).
Even as their parents were gaining power and influence on their behalf, persons with mental retardation were becoming subject to the entrenched stigma of race. “[In the 1960s,] if given the finger, young men might respond, ‘Is that your IQ or your number of white parents?’” (Anderson, 1995, p. 28). This shared stigma also lent persons with disabilities the emergent force of a nationwide civil rights movement (Fleischer & Zames, 2001; Salend, 1994; Zirkel & Cantor, 2004), which led to the third and current wave of discourse: Self-Determination.

The Third Wave of Discourse in Mental Retardation: Self-determination

The discourse of determinism can be traced to the human science (Foucault, 1995/1975) of personality psychology, as this discipline explored the degree to which human behavior was determined by internal and/or external forces (Wehmeyer, 2000). Borrowing from political science, the personality psychologists of the 1940s chose the term “self-determination,” to describe the mastery of one’s own fate or choice of action, without coercion. Nirje (1969, 1972) applied the construct of self-determination to persons with mental retardation. Nirje used the term “normalization,” but its meaning was constructed in a way that was different from Foucault’s (1995/1975).

Different Meanings of Normalization

Foucault (1995/1975) saw normalization as a result of the interplay between competing disciplines and discourses, a force that served to strengthen the binary distinction between what was “normal” and what was not. Nirje’s (1969, 1972) version of normalization endeavored to transcend the binary, or at least extend its borders, by granting persons with mental retardation some power to construct their own version of a
“normal” life. Nirje advocated for persons with mental retardation to assert their right to become fully human:

One major facet of the normalization principle is to create conditions through which a handicapped person experiences the normal respect to which any human is entitled. Thus the choices, wishes, desires, and aspirations of a handicapped person have to be taken into consideration as much as possible in actions affecting him.... To assert oneself with family, friends, neighbors, co-workers, other people... is... especially difficult for someone who has a disability or is otherwise perceived as devalued. But in the end, even the impaired person has to manage as a distinct individual, and thus has his identity defined to himself and to others through the circumstances and conditions of his existence. (Nirje, 1972, p. 177)

Nirje (1969, 1972) paved the way for persons with mental retardation to re-invent themselves as subjects who resisted domination. He described self-determination for this specific group of subjects as their inherent right and human capacity for making choices and decisions, asserting and managing themselves, attaining realistic self-knowledge, advocating for themselves, and becoming more independent, self-efficacious, autonomous, and independent. Current research in self-determination theory (Deci & Ryan, 2000; Ryan & Deci, 2000) defines self-determination in terms of innate psychological needs for competence, autonomy, and relatedness. These needs are satisfied through goal-directed behavior (Deci & Ryan, 2000), and their fulfillment is severely limited by social isolation (Blank & Langone, 1997; Bronfenbrenner, 1979; Gindis, 1999; Vygotsky, 1978/1934; Wehmeyer, Agran, & Hughes, 2000).
As old stereotypes of mental retardation were exposed and shattered, and institutional isolation was abolished, self-determination became an acknowledged force in the lives of persons with mental retardation (Salend, 1994; Smith, 1998; Turnbull & Turnbull, 2000; Wehmeyer, 2000), while their parents took on a new role of advocacy.

Deinstitutionalization as a Force for Self-determination

In 1966, Blatt and Kaplan published *Christmas in Purgatory, A Photographic Essay on Mental Retardation*. They exposed the filth, solitary confinement, restraint, nakedness, neglect and sedation that made the lives of institutionalized infants, children and adults with mental retardation “a hell on earth” (Blatt & Kaplan, 1966, p. v). At this time, parents of children with mental retardation were well organized into formal support groups, and the Arc was gaining power. More and more disability-specific organizations took on a role of advocacy on behalf of children, and on behalf of the parents themselves (Turnbull & Turnbull, 2000). Families provided support and made decisions for their children. They exerted this power by contributing money, time, and energy to advocacy organizations, providing and operating services for children with mental retardation and other disabilities, and lobbying for public funding for education, employment, and residential living.

As it became public knowledge that institutional living was unconscionable (Blatt & Kaplan, 1966), it was also declared unconstitutional (*Halderman v. Pennhurst State School and Hospital*, 1987; *Romeo v. Youngberg*, 1984; *Wyatt v. Stickney*, 1972). The exclusion from school or the misclassification of children with disabilities was declared unconstitutional as well (*Mills v. Board of Education of the District of Columbia*, 1972;
Efforts to reform institutions were largely unsuccessful (Blatt, Ozoliins & McNally, 1979; Wehmeyer, 2000). When Blatt revisited Purgatory in 1979, he found conditions much the same. Even many of the residential schools for children with mental retardation had become abhorrent institutions, and remained so until the 1970s (Smith, 1998). These schools were often located in isolated, rural areas. Students continued to live there even as adults; and many of them lived there for the rest of their lives. They spent their time with other students with disabilities and rarely interacted with noninstitutionalized peers. Though Nirje (1969, 1972) had stressed the need for “normal” rhythms of the day, and “normal” patterns of life, children in institutions and residential schools did not live “normally.” Blatt, et al. (1979, p. 144) demanded that “every institution for the mentally retarded in the United States be closed.” Public efforts were redirected toward preventing people from being placed in institutions, and getting people dismissed from them. In order for people with mental retardation to escape institutionalization, they needed education, community-based services, and freedom from discrimination on the basis of disability. Legislation—juridical power—was enacted to address these options in the 1970s, as the “truth[s] of power” (Foucault, 1980, p. 93) wielded by physicians and institutions were challenged by the power of personal and parental advocacy for persons with disabilities and mental retardation. But legislation did not lead to an untroubled transformation of special education.

In the Foreword to “Family Papers: A Return to Purgatory,” Sarason (1979, p. 11) declared, “Institutional change cannot be brought about by fiat, legislation, or even
money. Our capacity, either in our individual lives or in our institutional roles, to fool ourselves should never be underestimated.” Sarason’s commentary on institutional change applies, as well, to our nation’s public schools, where conflicting meanings of “inclusion” continue to co-exist as an “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85). These conflicting meanings have not been resolved—by fiat, legislation, or money.

Power, Knowledge, and Existing Meanings of Inclusion

The field of special education has been subject to three definitive discourses, each generating its own model of inclusive education: mainstreaming, the regular education initiative, and full inclusion (Alper, 2003; Kavale, 2002; Kavale & Forness, 2000; Skrtic, 1991a, 1991b). It is relevant to note that these discourses were conducted primarily within the field of special education, although their focus was inclusion in general education. Civil rights discourse of the 1960s led to “mainstreaming,” and solidified the professionalism of special educators and related service providers (Salend, 1994; Skrtic, 1991a). The Regular Education Initiative (REI) of the mid-1970s attempted to solve problems associated with mainstreaming, questioning and troubling the professional discourse (Alper, 2003; Fuchs & Fuchs, 1994; Howard, 2004; Skrtic, 1991a, 1991b). The full inclusion movement of the 1990s sought to discontinue traditional models and practices of special education (Skrtic, 1991a; Stainback & Stainback, 1992).

Public Law 94-142 (Education for All Handicapped Children Act, 1975; reauthorized as the Individuals with Disabilities Education Act, 1990 [hereafter IDEA]) defined the practice of special education in the U.S. The key mandates were: 1) the provision of a free, appropriate public education for students with all types of disabilities,
2) in the least restrictive environment, or as much as possible with their same-age, nondisabled peers (Kavale, 2002; Kavale & Forness, 2000; Skrtic, 1991a; Smith, 1998). Free, appropriate public education addressed curriculum and instruction, and least restrictive environment focused on the integration of students with disabilities into general education. Free, appropriate public education—perhaps as a result of the purposely ambiguous connotation of “appropriate”—has been defined as an education program which does not need to produce maximum educational benefit, but only meaningful, appreciable, and adequate gains (Collins, 2003; Drasgow, Yell & Robinson, 2001; Howard, 2004; Johnson, 2004). Least restrictive environment, also vaguely defined, has been misinterpreted as a place: the general education classroom (Doyle, 2003; Howard, 2004; Johnson, 2004; Kavale, 2002; Sarason, 1996; Skrtic, 1991a).

To implement IDEA and ensure compliance, school districts were required make available a continuum of placement options (Hocutt, 1996). The general education classroom was intended as an option on this continuum; and the self-contained classroom, exclusively for students with disabilities was another option (Kavale, 2002; Kavale & Forness, 2000).

Mainstreaming: Integrating Children with Mild Disabilities into Traditional General Education

Almost immediately after the passage of IDEA, as the U.S. education system began to implement its precepts, a movement known as mainstreaming was gaining momentum and inciting debate. Many of the stipulations of mainstreaming resembled the implementation of free, appropriate public education and least restrictive environment, with one important difference: Mainstreaming was concerned primarily with the
education of students with "mild" disabilities ("mild" mental retardation, emotional disturbance, and learning disabilities) in general education classrooms (Alper, 2003; Kavale, 2002; Skrtic, 1991a). For these students mainstreaming offered three basic components: integration, educational planning, and clarification of responsibilities (Kauffman, Gottleib, Agard & Kubic, 1975).

Integration was to be physical, academic, and social. Children with mild disabilities were expected to be placed in the general education classroom, where they would be provided with opportunities to participate in instructional activities and interact socially with nondisabled peers in learning and in extracurricular activities (Kauffman, et al., 1975).

Educational planning for mainstreaming was to be accomplished by a team of general and special educators, working with the parent and the student with disabilities (Kauffman, et al., 1975). Mainstreaming advocates stressed the idea that mere physical placement in the classroom was not sufficient to provide an appropriate education for students with disabilities (Alper, 2003). Open and direct communication and collaboration between parents and educators was considered imperative for the implementation of mainstreaming (Alper, 2003). Kauffman et al. (1975) called for a clear, written specification of the responsibilities of all professionals who participated in the education of each individual student with disabilities.

Other definitive forces at work in education at the time of the mainstreaming initiative included sweeping reforms in school organization that gave rise to the practices of team teaching, ungraded primary and open classrooms, and grouping children according to heterogeneous academic strengths (Kavale, 2002). Computers and
instructional television programs, such as Sesame Street™, were beginning to influence curriculum and instruction by providing creative technology that could be accessed by individual students while teachers were dealing with group instruction. These pervasive change forces were seen as consistent with mainstreaming, because they allowed general education to better accommodate individual differences (Skrtic, 1991a).

Mainstreaming advocates argued for greater access to general education within the traditional organizational configuration of schools. Participants in mainstreaming did not critically question the adequacy of the existing general education program (Kavale, 2002; Skrtic, 1991a). The general education teacher retained sole authority over his or her classroom (Sailor, Gee & Karasoff, 2000). Students with disabilities were allowed access at specific times, by agreement with individual teachers. Special education teachers were responsible for negotiating collaborative teacher partnerships, in which students with disabilities had to “prove their ability to belong” (Sailor, et al., 2000, p. 10). They were “just as likely to lose” their general education access “if they [were] deemed a distraction to others” (p. 11). Under these conditions, with such unequal and tentative collaboration, administrators, teachers, parents and students with disabilities were unprepared and unable to meet the needs of mainstreamed students (Alper, 2003; Kavale, 2002; Kavale & Forness, 2000; Salend, 1994; Skrtic, 1991a).

Skrtic (1991a) identified four basic assumptions that had shaped the power, knowledge, and discourse of special education since the 1960s. He suggested that these assumptions remained unchallenged by IDEA, and by the proponents and professionals associated with mainstreaming. These assumptions were:

1. Disabilities are pathological conditions that students have.
2. Differential diagnosis [disabled/nondisabled] is objective and useful.

3. Special education is a rationally conceived and coordinated system of services that benefits diagnosed students.

4. Progress results from incremental technological improvements in diagnosis and instructional interventions. (Skrtic, 1991a, p. 54)

The Regular Education Initiative began to question some of these assumptions.

*The Regular Education Initiative: A Sociological Discourse and Critique of Special Education*

Just one year after its passage, an emerging discourse criticized IDEA in the language of what was to become an alternative discourse to mainstreaming: the Regular Education Initiative (REI). Madeleine Will, Assistant Secretary for the Office of Special Education Programs in the Reagan administration, codified the discourse in 1984, with her Regular Education Initiative (Skrtic, 1991a). The REI discourse insisted “that the entire history of special education [was] (and should continue to be) one of incremental progress toward more socially inclusive instructional placements for students with disabilities” (Skrtic, 1991a, p. 60).

This incremental progress was to be accomplished by a restructuring and merger of special and general education into one “inclusive” system (Fuchs & Fuchs, 1994). Tactics for achieving this merger included the modification or elimination of the continuum of services. One solution called for an elimination of the bottom of the continuum, by closing residential and day schools, and moving the children from these settings into self-contained classes and resource rooms in neighborhood schools. The Adaptive Learning Environments Model (ALEM) was developed to replace resource
rooms, by individualizing instruction for all students. This model included a prescriptive learning component of hierarchical curricula for basic skills development, an exploratory learning component, and classroom management procedures. The variety of Regular Education Initiative proposals reinforced critics’ concerns that Regular Education Initiative proponents wanted sweeping ideological change, without careful planning (Fuchs & Fuchs, 1994; Kavale & Forness, 2000; Skrtic, 1991a).

Proponents of the Regular Education Initiative presented two lines of argument: one against the current special education system and mainstreaming, and one for certain reforms that were intended to correct the situation (Skrtic, 1991a). Yet they were united in two important respects: They were willing to critique special education (Fuchs & Fuchs, 1994; Skrtic, 1991a); and they believed that the field must not continue as a separate order. It must collaborate and coordinate with general education (Fuchs & Fuchs, 1994; Kavale, 2002; Kavale, & Forness, 2000; Skrtic, 1991a).

Regular Education Initiative proponents agreed that the diagnostic and instructional practices associated with IDEA and mainstreaming were fundamentally flawed, particularly for students diagnosed as mildly handicapped. At that time (the 1980s) these students represented 68-90% of all students served under IDEA (Skrtic, 1991a). Unlike the mainstreaming initiative, which attempted to include mildly disabled students into the existing structures and practices of general education, the Regular Education Initiative attempted an empirical critique of the field’s then-current practices, which had been criticized as tentative and inconclusive (Kavale & Forness, 2000; Salend & Garrick-Duhaney, 1999).
At the height of the Regular Education Initiative debate, proponents invoked the civil rights arguments that originally led to IDEA and mainstreaming (Kavale & Forness, 2000; Skrtic, 1991a). They characterized Regular Education Initiative opponents as segregationists, and compared the existing special education system to slavery and apartheid. An alternate name for the Regular Education Initiative was “integration” (Collins, 2003). Kauffman (1989) portrayed some of its proponents as naïve liberals. Proponents of the Regular Education Initiative claimed that the current educational service delivery system was ineffective, inefficient, and costly; that it labeled and stigmatized students; it ignored the needs students with disabilities who were not labeled; and it was fragmented by “pull-out” programs such as special education, migrant education, and related services such as occupational, physical, and speech therapy (Fuchs & Fuchs, 1994; Howard, 2004; Salend, 1994).

Skrtic (1991a, p. 63) suggested that if one could cut through the rhetoric, the Regular Education Initiative debate was centered on two sets of issues: the “ethics and efficacy of diagnostic and instructional practices,” and the “wisdom and feasibility of the Regular Education Initiative reform proposals.” Regular Education Initiative supporters who were focused on “mild” disabilities set the goals for the movement and established the goals of the debate (Fuchs & Fuchs, 1994).

Fuchs and Fuchs (1994) identified three goals of the Regular Education Initiative: 1) to restructure special and general education into a merged, inclusive system; 2) to dramatically increase the number of children with mild disabilities in mainstream classrooms; and 3) to strengthen the academic achievement of students with mild and moderate disabilities. and underachievers without disabilities. The Regular Education
Initiative’s emphasis on academic achievement was conceived in a sociopolitical climate of standards-based education reform, and the discourse of “A Nation at Risk,” a call to action issued by the National Commission on Excellence in Education (1983).

*Standards-based Reform Emphasizes Academic Achievement*

“A Nation at Risk” (National Commission on Excellence in Education, 1983) is considered by many educators to be the seminal event of the modern standards movement in U.S. education (Mid-Continent Research for Education and Learning, n.d.; Riley, 2002; Wise & Liebbrand, 2001). The document described the foundations of our society as “being eroded by a rising tide of mediocrity that threatens our future as a nation and a people . . . an act of unilateral educational disarmament” (National Commission on Excellence in Education, 1983, p. 5).

In response to the challenge posed by “A Nation at Risk” (National Commission on Excellence in Education, 1983), individual states, and the profession as a whole, were inspired to reorganize and create new standards for students and teachers (Wise & Liebbrand, 2001). Two types of standards were created: content standards and performance standards. Content standards are explicit statements that define what students should know and be able to do (National Council for Accreditation of Teacher Education [NCATE], 2002). Performance standards define how well students must perform to demonstrate adequate knowledge and skills (Thurlow, 2000).

Educators began meticulously defining content standards, subject by subject, in the early 1990s. The standards were prepared by associations of educators in academic subjects, ad hoc groups, scientific organizations and individual states. Content standards were followed by performance standards—assessment designed to measure and ensure
accountability for the achievement of the content standards (Wise & Liebbrand, 2001),
(i.e. standards to measure “how good is good enough” [Thurlow, 2000, ¶ 2]). Standards
for teachers were followed by standards for teacher preparation programs and educational
leadership (Wilmore, 2002). Standards for special education programs were established
by the Council for Exceptional Children in 1993. Standards for individual school
administrators were also developed in 1996, by the Interstate School Leaders Licensure
Consortium (ISLLC), a program of the Council of Chief State School Officers (CCSSO),
“to raise the bar for the practice of school leadership” (Council of Chief State School
Officers, 1996, p. iii). The CCSSO is a national organization of leaders of state
departments of education, heads of departments of elementary and secondary education,
members of the Department of Defense Education Activity, officials from the District of
Columbia, and other extra-state jurisdictions (Wilmore, 2002).

In 2000, NCATE revised its accreditation process, shifting to a performance­
based paradigm, for the purpose of ensuring that graduates would be prepared to function
in real-world settings (National Policy Board for Educational Administration, 2002). In
2002, new Standards for Advanced Programs in Educational Leadership preparation were
developed jointly by the National Policy Board of the Educational Leadership
Constituent Council (ELCC) and the Interstate School Leaders Licensure Consortium
(ISLLC). They were created to align educational leadership preparation standards with
the standards for teacher evaluation prepared by NCATE. Adherence to these standards
was thought to prepare “educational leaders who have the knowledge and ability to
promote the success of all students” (National Policy Board for Educational
Administration, 2002, p. 2).
At the same time, the enactment of the federal *No Child Left Behind Act* (2001) made performance-based accountability a federal mandate (Hess, 2003). Pajak (2001) noted that the federal imposition of performance standards, and the resulting, high-stakes monitoring of student outcomes, has created areas of incompatibility in the current "standards-based environment" (p. 233). From an evaluation of the California Beginning Teacher Support and Assessment Program by Mitchell, et al. (1999, as cited in Pajak, 2001), Pajak extrapolated six points of tension:

1. Creating records while focusing on supports;
2. Standardizing program design while maintaining local initiative;
3. Creating a context of support for new teacher induction while maintaining a focus on student teaching;
4. Responding to new teacher felt needs while moving the teachers toward established norms;
5. Linking assessment to support in an environment not accustomed to providing either to beginning teachers; and
6. Maintaining program quality while expanding rapidly to serve all new teachers.

(Pajak, 2001, p. 233).

*Regular Education Initiative Proponents and Opponents Came to Some Agreement*

As standards and standardized testing exerted escalating power over education reform, both proponents and opponents of Regular Education Initiative came to agree that blaming the inadequacy of education strictly on student deficit was inappropriate. They agreed that many students identified as mildly handicapped were not truly disabled in the pathological sense. Kauffman (1989) and Keogh (1988) opposed the REI argument on
the grounds that it leaned too heavily on a teacher deficit model. But most Regular Education Initiative proponents did recognize the student’s responsibility in the learning process (Skrtic, 1991a). Proponents of the Regular Education Initiative saw the special education system as a barrier to developing a capacity within general education to accommodate students with disabilities (Skrtic, 1991a). They agreed that distinctions between mildly disabled and nondisabled students were not objective and were embedded in “powerful economic, political and philosophical network[s]” (Keogh, 1988, p. 20). They saw no “instructionally relevant” (Skrtic, 1991a, p. 65) reasons for distinguishing between mildly disabled and nondisabled students, since all students had unique learning needs, and that many methods of instruction could be successfully employed for all of these needs (Stainback & Stainback, 1984; Wang, Reynolds & Walberg, 1986).

Regular Education Initiative Proponents and Opponents also Disagreed

Some constituencies opposed to the Regular Education Initiative argued that it lacked an adequate research base and policy analysis, assumed that general education teachers were willing and well trained to teach all students, presented no clear and detailed alternative to the current system, and was inappropriate for certain types of disabilities (Salend, 1994). Regular Education Initiative proponents advocated eliminating the special education system, with its continuum of segregated placement and specialized pull-out services, and replacing it with a restructured, collaborative system within general education. Opponents suggested the current system should be retained, and that research and development would render the system “instructionally rational” in the future (Skrtic, 1991a, p. 69).
Regular Education Initiative Proponents also Disagreed Among Themselves

Regular Education Initiative proponents were sharply divided over the question of who should be integrated into general education (Fuchs & Fuchs, 1994; Howard, 2004; Kavale, 2002; Kavale & Forness, 2000; Skrtic, 1991a). Some continued to insist that the Regular Education Initiative was targeted for students with mild disabilities (Pugach & Lilly, 1984; Reynolds & Wang, 1983), with the possibility of a more progressive inclusion, within the continuum of services. Some argued for the integration of all students, including those with the most severely and profoundly disabling conditions, and called for a merger of special and general education at the classroom level (Skrtic, 1991a). Kavale and Forness (2000) credit the Regular Education Initiative movement with “modest success in changing special, but not general, education” (p. 283), even for students with high-incidence, mild disabilities.

The Regular Education Initiative is Seen as Failing to Transform Special Education

In a discourse analysis of the Regular Education Initiative debate, Skrtic (1991a) concluded that none of the four assumptions underlying special education in the 1960s had been overthrown. He suggested that “the very nature of professionalization [made] professionals susceptible to the delusion that their knowledge tradition and its associated practices and discourses [were] objective and inherently correct” (p. 85). In the end, Skrtic decided that each of the Regular Education Initiative proposals replicated the value contradictions of mainstreaming. By retaining the entrenched classroom structure with a general education teacher in charge of the classroom, the ideal of collaboration was “deflected” (p. 189). The disagreement and debate within the Regular Education Initiative weakened its effectiveness as a force for transforming special education.
Throughout the 1980s, REI proponents tried to interest general educators in special education concerns, with little success (Fuchs & Fuchs, 1994; Lieberman, 1985; Pugach & Sapon-Shevin, 1987). Lipsky and Gartner (1991) characterized Least Restrictive Environment and the continuum of placements as “progressive when developed” but insufficient to promote “the full inclusion of all persons with disabilities in all aspects of life” (p. 52). Stainback and Stainback (1992) envisioned truly inclusive schools as schools purged of the traditional models and practices of special education, where “no students, including those with disabilities, are relegated to the fringes of the school by placement in segregated wings, trailers, or special classes” (p. 34).

The Full Inclusion Movement and 21st Century Systemic Education Reform

By the 1990s, full inclusion had become a prominent educational discourse (Fuchs & Fuchs, 1994). In 1992, The Association for Curriculum Development, The Council of Chief State School Officers, and the National Association of State Boards of Education published position papers on inclusion that were touted as evidence that general education was beginning to pay attention to special education as a partner in systemic school reform. Some prominent policy analysts (e.g., Fuchs & Fuchs, 1994; Skrtic, 1991b) characterized the special/general education divide as an inherent incompatibility between equity and excellence. The “endless play of dominations” (Foucault, 1984/1971, p. 85) inherent in the competing discourses of the Regular Education Initiative discouraged its supporters, creating a space for a vigorous and comparatively radical group to introduce a new movement (Fuchs & Fuchs, 1994; Kavale & Forness, 2000; Skrtic, 1991a).
**TASH Introduces Full Inclusion**

The Association for Persons with Severe Handicaps (TASH) was focused on a single issue, identified with a precisely defined constituency, well organized, and articulate (Fuchs & Fuchs, 1994; Kavale & Forness, 2000; Skrtic, 1991a). TASH invoked Nirje’s (1969, 1972) normalization principle, calling for an end to the continuum of placements, and full integration for students with severe disabilities into general education and extracurricular activities. TASH was an important influence in the formation of The President’s Panel on Special Education Reform and Integration, formed by the Council for Exceptional Children.

Leaders of the inclusive schools movement (Giangreco, St. Denis, Cloninger, Edelman & Schattman [1993]; Lipsky & Gartner [1991]; Stainback & Stainback [1992]) advocated the deconstruction of “special” education and the end of labeling and special classes, with the retention of necessary supports and services. Specialists of all types would follow children with disabilities into general education, where they would serve any student, labeled or not, who might need them (Fuchs & Fuchs, 1994). Another overarching goal of full inclusion was to enhance students’ social competence (Fuchs & Fuchs, 1994; Stainback & Stainback, 1984).

Fuchs and Fuchs (1994) noted a distinct contrast between the Regular Education Initiative, which focused on strengthening the academic performance of students with disabilities and those at risk for school failure, and the full inclusion movement which was focused on social skills and positive peer relationships. Of all three initiatives—mainstreaming, the Regular Education Initiative and full inclusion—only full inclusion advocated primarily for students with severe intellectual disabilities.
Inclusive schooling meant that all children belonged, and their home base would be the general education classroom (Sailor, et al., 2000). Ideally, students at all levels of ability would be included in the typical general education schedule, instructional units, and activities in all core subject areas. Outcomes and instructional expectations might be very different for individual students, and sometimes alternative instructional activities would be designed for small, heterogeneous groups (Sailor, et al., 2000). Over time, collaboration between special and general education teachers was expected to develop to a point where it would be less and less necessary to create alternatives (Gee, Graham, Sailor & Goetz, 1995).

**Domination, Resistance, Transformation**

The three “truth[s] of power” (Foucault, 1980, p. 93) that seek to define and regulate inclusion—mainstreaming, the Regular Education Initiative, and the full inclusion movement persist in their influence, as described in the following section. They may arguably be seen as an “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85). But the disability rights movement has applied strong resistance to this domination, and this resistance has transformed educational politics and policy.

**Power, Knowledge, and Politics**

*The Disability Rights Movement and its Impact on Political Agendas*

A political agenda consists of the subjects or problems to which government officials and their constituents are paying attention at any given time (Jeon & Haider-Markel, 2001). The meanings attributed to these issues define the goals of public policy, and determine their prominence in the political agenda. To achieve their goals, “political actors use narrative story lines and symbolic devices to manipulate . . . issue
characteristics” (Stone, 1989, p. 282, as cited in Jeon & Haider-Markel, 2001). Persons who are able to influence the political agenda are known as “policy entrepreneurs” (Jeon & Haider-Markel, 2001, p. 217). They identify and define problems, network in policy communities, shape the scope and terms of political debate, and build coalitions. They determine which arguments will be most effective. In the words of Foucault (1980), they may be seen as engaging in discourse to provide “limits to the rights of power” (p. 83), thereby generating “new domains of understanding” (p. 106). Some of the most influential policy entrepreneurs in disability rights and education have been persons with disabilities, who were able to become activists for their cause (Fleischer & Zames, 2001; Jeon & Haider-Markel, 2001; McCarthy, 2003; Shaw, 1994).

The Disability Rights Movement in the United States

In the late 1940s, a large number of disabled veterans of World War II utilized their educational benefits to attend a branch of the University of Illinois that was located in a former hospital. When it closed, the vets wanted to transfer to the main campus in Urbana, which was inaccessible to wheelchairs. Veteran-scholars who used wheelchairs camped on the lawn of the Governor’s mansion, in a successful demonstration that established a reputation for the campus as one that accommodated persons with disabilities (DeLoach & Greer, 1981; McCarthy, 2003).

In the 1960s, the national struggle for racial desegregation converged with movements for women’s rights and disability rights, as each group sought equal opportunity and positive recognition by society (Anderson, 1995; Jeon & Haider-Markel, 2001; McCarthy, 2003). The strategies and successes of Black Americans and feminists
inspired the leaders of the early disability rights movement (Fleisher & Zames, 2001; Scotch, 1988).

In the fall of 1962, while African-American student James Meredith was escorted past a throng of violent protestors by U.S. marshals onto the campus of the University of Southern Mississippi, Ed Roberts quietly made his way onto the campus of the University of California at Berkeley, with a power wheelchair, an iron lung, and a personal assistant. “When I first began talking with the administration,” Roberts said, “they told me, ‘We tried cripples, and they don’t work’” (as cited in Fleischer & Zames, 2001, p. 38). The education of Meredith is a symbol of the nascent battle for racial equity in higher education. The college education of Ed Roberts is generally considered to mark the emergence of the disability rights movement in the United States (McCarthy, 2003).

To accommodate Roberts’ need to sleep in his iron lung, university administrators allowed him to live in a wing of Cowell Hospital, on the edge of the Berkeley campus. Cowell soon became a sort of “crip dormitory” for Berkeley students with physical disabilities. Led by Roberts, these students formed the “Rolling Quads,” a political group funded by Roberts’ successful and innovative grant proposal that defined people with disabilities as a “minority” (Fleischer & Zames, 2001, p. 38). The Rolling Quads demonstrated for a barrier-free campus, wheelchair repair, accessible housing, and attendant care. Ten years later, they rolled out into the community to form the Center for Independent Living (CIL), an organization governed by and for people with disabilities, with Roberts at its helm. The Berkeley CIL secured the first wheelchair curb cut in the country, at the corner of Bancroft and Telegraph Avenue in Berkeley.
It was an exciting time. The protests and student movements were rising all around us and we were right there. [We] used to roll right up to the front of the demonstrations and stare down the police. What could they do? . . . They didn’t have accessible jails [:] . . . they couldn’t arrest us. (Roberts, as cited in Fleischer & Zames, 2001, p. 38)

The Independent Living Center (ILC) concept gained international prominence; and independent living centers were established throughout the U.S. They provided a core of common services after the Berkeley model, adding individualized and innovative services based upon members’ needs. In states where disability activists were well organized, Independent Living Centers were more likely to receive state funding, allowing them to join with other centers to form interstate networks (Fleischer & Zames, 2001).

The ILCs were the antithesis of rehabilitation centers; and they subscribed to different discourses (Fleischer & Zames, 2001; Jeon & Haider-Markel, 2001). Rehabilitation was aligned with the medical model of disability, which was focused on repairing and curing specific, individual pathologies. The ILCs were constructed according to the social model of disability. They focused on changing the environment, and securing the rights of people with even the most severe disabilities to have the choice of living and participating in the community (Fleischer & Zames, 2001; University of California-Berkeley, n.d.).

The emergence of persons with disabilities from institutions, at a time when strategies for independent living were being developed, created a space for disability rights leaders to become viable, active, and influential in the struggle for disability rights
Judith E. Heumann, the founder of Disabled in Action, and co-founder with Ed Roberts of the World Institute on Disability, requires attendant care for her activities of daily living. The independence and social integration of Heumann and Roberts served as a symbol of self-determination.

**Power, Knowledge, and Legislation**

The precedent for much of special education legislation is generally considered to be the Supreme Court decision in *Brown v. the Board of Education of Topeka, Kansas* (1954). *Brown* included appeals from decisions in four separate states: Kansas, Delaware, South Carolina, and Virginia. The four cases were argued on appeal to the U.S. Supreme Court in 1952, with the issue being whether segregation deprived students of equal protection under the law as guaranteed by the Fourteenth Amendment. On May 17, 1954, under the guidance of Chief Justice Earl Warren, the Supreme Court declared that separate but equal schooling was unconstitutional. This declaration served as the underlying argument in suits brought by parents to ensure that their children with disabilities received a free appropriate public education (Fleischer & Zames, 2001; Salend, 1994; Wehmeyer, 2000).

The force behind *Brown v Board of Education* (1954) and the American civil rights movement was the larger sociopolitical context of the post-war era (Ladson-Billings, 2004). America was trying to prove that a free democracy was the most civilized and secure form of government. Yet the country was under attack in the foreign press and in the United Nations, because of discriminatory practices against minority groups at home. Desegregation became a move in the national interest because the U.S. wanted to reshape the world in its own image. Black interests of improving the education
of Black children and promoting social mobility converged with the “international embarrassment” (Ladson-Billings, 2004, p. 5) of a country that had fought against the Nazis on the basis of equality and freedom, but was not living up to its own ideals.

The impetus of the civil rights movement and the precedent of *Brown v Board of Education* (1954), lent strength to the growing disability rights movement. Fleischer and Zames (2001) document the “prophetic” language of disability rights activists in the 1970s, their decade of emergence, as “reminiscent of civil rights orators” (p.48), as in this example:

> Look out, America, because I’m coming. I have always had my dream . . . I have tried and failed, cried and raged in silence . . . sat and watched because I could not keep up with you, but I never gave up. . . . You have not heard the last of me. In fact, you have not heard me at all. . . . You kept me out of sight . . . . Now . . . my voice shall rise. For I am the living proof that physical and mental perfection are not the answer. It is the inner fire that will not accept the “impossible.” (Tom Clancy, quadriplegic wheelchair user and former resident at Goldwater Hospital as a chronic care patient, as cited in Fleischer & Zames, 2001, p. 48)

As individuals with physical disabilities became activists for disability rights, the parents of individuals with mental retardation were becoming advocates for their children’s self-determination. Institutions were losing their clients to community-based, independent living centers. Despite resistance from local communities and a persistent lack of funding, individuals with disabilities began to produce and publicize their own discourse, their own “truth of power” (Foucault, 1980, p. 93). They articulated and lived their own version of a normal life. They became a force for self-transformation.
Legislation in the 1970s reflected the power of civil rights, disability rights, and self-determination for individuals with mental retardation.

**Definitive Legislation Specific to Students with Disabilities**

In *Pennsylvania Association for Retarded Children v. Pennsylvania* (1972), the court ruled that all students with mental retardation had a right to a free public education. The court’s finding stipulated that placement in a regular public school classroom was preferable to more segregated placements, and that parents had a right to be in their children’s educational program (Salend, 1994; Smith, 1998). *Mills v. Board of Education of the District of Columbia* (1972) extended the right to a free public education to all students with disabilities. These court decisions made segregation of children with disabilities no more constitutional than segregation of children of color. They galvanized disability advocates, who collaborated to pass new legislation (Pelka, 1997, pp. 111-112).

**Section 504 Consolidates the Disability Rights Movement in the U.S.**

In 1973, Congress passed the *Rehabilitation Act*, the first civil rights law for individuals with disabilities in American society. *Section 504* of this Act forbids discrimination against individuals with disabilities in any program receiving federal assistance, including education, employment, housing, and access to public programs and facilities. It also requires institutions to make architectural modifications that increase physical accessibility. *Section 504* provides all students with a right to have access to the regular education curriculum, extracurricular activities in local schools, and instructional and curriculum adaptations.

President Nixon vetoed early versions of the Act, on the grounds that the legislation was too expensive (Fleischer & Zames, 2001). Disability rights activists, led
by Judith E. Heumann, organized a sit-in to protest the vetoes. They stopped traffic on Madison Avenue in Manhattan. Nationwide protests and a march on the Capitol led to the passage of the proposed legislation (Fleischer & Zames, 2001, p. 49).

In 1990, Section 504 of the Rehabilitation Act (1973) was extended, through the Americans with Disabilities Act (1990). The Act banned disability discrimination in employment, transportation, public accommodations and telecommunications, and strengthened mandates for accessibility. The stated purpose of the Act was to allow persons with disabilities to have equal access and greater participation in the broadest possible range of environments.

The Individuals with Disabilities Education Act (IDEA)

Two years later, Congress passed Public Law 94-142, (Education for All Handicapped Children’s Act, 1975), the law that created and maintains the current system of special education. In 1990, reflecting a new sensitivity to the word “handicapped,” the reauthorized law was renamed the Individuals with Disabilities Education Act (IDEA, 1990).

Research done to inform such a law found that more than 8 million children with disabilities in the U.S. did not receive appropriate educational services which would enable them to receive equal opportunities. Eight million of these children were entirely excluded from public schools. Teachers were considered to be trained to educate these children; and effective diagnostic procedures were declared to exist. Therefore, Congress affirmed that it was in the national interest for the Federal Government to assist states in providing a free, appropriate, public education for all children with disabilities (P.L. 94-142, 20 U.S.C. section 1400[b]). The intent of the law was to “make a positive difference
in the lives of these children and their families” (Smith, 1998, p. 23), and “to insure that the rights of handicapped children and their parents or guardians are protected” (U.S. Senate Committee on Labor and Public Welfare, Subcommittee on the Handicapped, (Hearing on Education for All Handicapped Children Act of 1975, 94th Cong., 1st sess., p. 4, 1975).

*Public Law 94-142* (1975) contains eight basic provisions:

1. A free appropriate public education for children with disabilities;
2. Parental notification of their child’s assessment for placement in special education, and the right of due process for both parents and school districts, if educational and support services are not agreed upon by either party;
3. Individualized education, via an Individual Education Plan (IEP), for all children with disabilities;
4. Necessary related services, such as transportation, speech therapy, audiology, psychological services, physical and occupational therapy, adaptive physical education, assistive technology, and specific medical and counseling services were required as part of a free, appropriate public education;
5. Individualized, nondiscriminatory assessments were to be utilized and administered by trained professionals, to determine a child’s placement in special education, and the services to provide the child’s appropriate education.
6. An Individualized Education Plan (IEP) was required to be developed and agreed upon in the form of a signed document, by a team consisting of: a qualified representative of the local education agency (usually the child’s proposed special education teacher), the child’s current teacher, the parents, and the child.
7. Children with disabilities were required to be educated in the least restrictive environment (LRE), “to the maximum extent appropriate . . . with children who do not have disabilities” (20 U.S.C., §1412 [5] [b]); and

8. Federal assistance to states and school districts was allocated at 40% of the excess cost of the education and provision of services for students with disabilities.

IDEA was an expression of the sociopolitical/civil rights discourse of disability (Jeon & Haider-Markel, 2001). Skrtic (1991a) suggested that IDEA was a mechanism of symbolic compliance to the civil rights discourse, embraced “not because it was conceptually sound but because, morally and politically, it was the right thing to do” (p. 57).

In a longitudinal case study and quantitative analysis of disability policy legislation, Jeon & Haider-Markel (2001) found that policy change was significantly influenced by the increased power of the sociopolitical discourse of disability, which served to redefine disability as an issue of civil rights and de-emphasize the medical and economic definitions. The emergence of disability rights as a force for education reform parallels the emergence of the self-determination movement for persons with mental retardation, beginning in the years after World War II (Fleischer & Zames, 2001; Jeon & Haider-Markel, 2001; Turnbull & Turnbull, 2000; Wehmeyer, 2000).

Zirkel and Cantor (2004) noted that civil rights legislation expressed and defined the central role that education had come to inhabit in modern life, and expanded the meaning of democracy to include children and adults with disabilities. But legislation alone could not ensure the physical, psychological, and emotional inclusion of children of

Discourse, Truth, and Meanings of Inclusion

In the language of the law—Foucault’s (1995/1975) juridical power—Howard (2004) found the interpretation of Least Restrictive Environment (LRE) created “intense debates” (p. 167) that contributed to “misuse” (p. 169) of the terms mainstreaming and inclusion, even in the educational literature. IDEA contains “a clear preference for inclusion” (178); but this preference is not a mandate. IDEA “presumes inclusion unless such a placement is inappropriate for that child” (p. 176). Since the U.S. Supreme Court has never interpreted the Least Restrictive Environment provision of IDEA, the federal courts have adopted a variety of tests to determine whether or not the provisions of Least Restrictive Environment have been properly met by school districts. The resulting lack of uniformity among these legal tests means that a child with a disability may be placed in the general education classroom in one district, and in a separate private school in another district. Howard proposed a modified and synthesized version of the Circuit Court tests of inclusion, which would result in “uniformity of process throughout the country” (p. 177).

Current Congressional policy prefers inclusion, but does not require it (Howard, 2004). The 1997 reauthorization of IDEA sought to clarify and strengthen inclusive practices by amending the Individual Education Plan (IEP), a document required for each child served by special education (Rogers, 2001). Since 1997, the IEP must contain a statement of the extent to which the child will be involved in, and make progress in the general education curriculum, and participate in extracurricular and noncurricular
activities. If the child will not participate in the general curriculum, the IEP must explain the extent to which the child's participation will be limited. If the child will not participate in regular assessments, the IEP must state the reason(s) why. The 1999 regulations accompanying IDEA added to the emphasis on least restrictive environment (Rogers, 2001), mandating the presumption that the first placement option considered for each student with a disability is the school the child would attend if s/he did not have a disability.

Johnson (2004) recently re-examined various definitions of Free Appropriate Public Education in the context of standards-based education reform, and concluded that the traditional interpretation of "some educational benefit" (Board of Education of Hendrick Hudson Central School District v. Rowley, 458 U.S. 176, 200, 1982) is no longer an accurate reflection IDEA (1975) requirements. With Rowley, the United States Supreme Court attempted to determine the substantive standards of Free Appropriate Public Education in 1982. The plaintiff in Rowley argued that Free Appropriate Public Education required schools to maximize the potential of children with disabilities, commensurate with the opportunities provided to children without disabilities. The Supreme Court interpreted the intent of IDEA as providing a basic opportunity through access to public education, as opposed to addressing the quality of education received, except that it must permit the child to benefit from instruction (Johnson, 2004).

Subsequent decisions interpreted Rowley to mean that IDEA does not require schools to maximize the potential of students with disabilities, an argument traditionally referred to as "Cadillac versus Chevrolet" (Johnson, 2004, ¶ 14), with the student with disabilities entitled to a Chevrolet.
Johnson (2004) noted three important events that have impacted the validity of the traditional interpretation of Free Appropriate Public Education, and changed the nature of educational services schools must provide for students with disabilities: 1) state litigation over the constitutional requirements to provide an "adequate" education to students, including students with disabilities, under state constitutional law; 2) the education standards movement that established high expectations for all students, including students with disabilities, through generally applicable content and proficiency standards, and 3) the 1997 reauthorization of IDEA.

An adequate education under state constitutional law requires that students receive educational services designed to provide sufficient skills to be successful in society, some of which would require a higher level of educational services than Rowley. Standards-based education reform defines academic performance levels and provides specific substantive benchmarks that students should meet at specific points in their academic careers. The 1997 reauthorization of IDEA “expressly changed the focus . . . from access to high expectations and real educational results for children with disabilities” (Johnson, 2004, ¶ 22). The 1997 changes to IDEA emphasized that schools must provide students with disabilities with the same quality educational services already provided to students without disabilities, including access to a curriculum that incorporates state educational standards.

*Inclusion and Current Legislation*

The foremost current document that presents an official discourse on inclusion is the final report of the President’s Commission on Excellence in Special Education.
This report stated, “Children placed in special education are general education children first” (2002, p. 7).

Despite the basic fact, educators and policy-makers think about the two systems as separate and tally the cost of special education as a separate program, not as additional services with resultant add-on expense. In such a system, children with disabilities are often treated, not as children who are members of general education and whose special instructional needs can be met with scientifically based approaches, they are considered separately with unique costs—creating incentives for misidentification and academic isolation—preventing the pooling of all available resources to aid learning. General education and special education share responsibilities for children with disabilities. They are not separate at any level – cost, instruction, or even identification.” (PCESE, 2002, p. 7)

This language seems compatible with the general and special education teamwork advocates recommend as a part of systemic, inclusive education. However, the language of PCESE that relates to students with cognitive and developmental disabilities could also be interpreted as Sarason (1996) interpreted the language of IDEA—designed to protect the general education classroom (and in this case its budget) from inclusion.

“Most Expensive to Educate”

The PCESE found that students with multiple, severe disabilities were “the most expensive to educate” (2002, p. 32). Some of these expenses are directly related to their medical needs. Others are the result of necessary accommodations.
Students with cognitive and developmental disabilities may need medical care during the school day. This creates a need for nursing staff, specialized training, and a smaller student-to-teacher ratio, all at added expense (Berman, Davis, Koufman-Frederick and Urion, 2001). The Supreme Court has decreed that the medical services a student needs to remain in the regular classroom must be provided by the school, if they can be provided by someone other than a physician (Cedar Rapids Community School District v. Garret F. ex rel. Charlene F., 1999; Irving Independent School District v. Tatro, 1984). Most court decisions regarding the extent to which services can be provided, and the extent to which students can be removed from the classroom, disregard the cost or impact on nondisabled peers (Palmaffy, 2001).

Students with disabilities must be accommodated by classrooms, curricula, and instructional materials that have always been, and still are, structured for students without disabilities. This requires educators to create new strategies and pedagogies, and engage in extensive training and interdisciplinary collaboration (Dorow, Fich, Uhry & Ellsworth, 1998; Grenot-Scheyer, Fisher & Staub, 2001; Hunt & Goetz, 1997; Idol, 1997; Palmer, Borthwick-Duffy & Widaman, 1998; Salend & Garrick-Duhaney, 1999). The guiding principle of IDEA, which mandates student-centered placement based on individual assessment, individual placement decisions, and individualized curriculum, also contributes to the higher cost of educating students with cognitive and developmental disabilities.

To help cover these additional expenses, the PCESE (2002, p. 33) recommended a state-based “safety net” funding program that would allow local districts or education service agencies to seek federal reimbursement for costs exceeding an established ceiling,
and devoted to identified high-need students. Although this recommendation is designed to help districts better serve students with severe/multiple disabilities, the language that describes their current position in the schools has an exclusionary tone. Students with severe/multiple disabilities are described as “a significant financial burden . . . “jeopardizing entire budgets and “[requiring] special education services that can cost more than $100,000 per year.” The “safety-net” budgeting strategy is proposed to keep students with severe/multiple disabilities from “penalizing students with less severe disabilities as well as their classmates without disabilities” by draining the budget with expensive services (2002, p. 32).

However, preliminary research by Odom (2000) suggests inclusive special education programs may be less expensive than traditional special education. He stated: “there is virtually no published data to confirm or discount” the “suspicion” (p. 25) on the part of policymakers and administrators that the actual cost of inclusion, and the process of using available funds to support inclusion, are prohibitive. Odom reports that some states have overcome fiscal challenges related to students with severe disabilities by allowing administrators more flexibility in budgeting, pooling funds from different sources, and interpreting policy at the local level.

*Inclusion and Systemic Education Reform*

Both excellence and equity can reasonably be seen to be supported by an emerging paradigmatic discourse of systemic education reform with the following characteristics:
1. Students are members of chronologically age-appropriate general education classrooms in their normal schools of attendance or in magnet schools or in schools of choice when these options exist for students without disabilities.

2. Students move with peers to subsequent grades in school as indicated by their Individual Education Programs (IEPs).

3. No special class exists except as a place for enrichment activities for all students.

4. Disability type or severity of disability does not preclude involvement in inclusive education [emphasis added].

5. The special education and general education teachers collaborate to ensure:
   a. The student’s natural participation as a regular member of the class;
   b. The systematic instruction of the student’s IEP objectives;
   c. The adaptation of core curriculum and materials to facilitate student participation and learning; and
   d. The development and implementation of positive behavioral interventions to support students with challenging behaviors . . . .

6. Effective instructional strategies are supported and encouraged in the general education classroom. Classrooms promote student responsibility for learning through strategies such as student-led conferences and student involvement in IEPs and planning meetings. . . . (Halvorsen & Neary, 2001, pp)

7. Inclusive programs are “comprehensive, flexible, responsive, and persevering;” and
8. Inclusive programs have “a long-term, preventive orientation and a clear mission, and they continue to evolve over time” (Grenot-Scheyer, et al., 2001, p. 9).

Grenot-Scheyer et al. (2001) enumerated seven fundamental values that are key to inclusive education.

1. Inclusion and school renewal are linked.
2. Inclusion presents a clear and strong moral imperative (emphasis added).
3. Learning and belonging happen together.
4. Equity, access and support are critical.
5. Students learn in different ways.
6. Inclusive education is beneficial for all involved.
7. Collaboration is essential. (Grenot-Scheyer, et al., 2001, p. 5)

From a genealogical perspective (Foucault, 1984/1971, 1995/1975), the current context of education reform is messy and marginalized, constructed and accidental. Deep-rooted meanings of disability, mental retardation and inclusion may be resisted, but not eliminated. They seem to persist and color any new meanings that may struggle to emerge. In a genealogical context, then, why is this study important?

Significance of the Genealogical Context

Thirty years after major civil rights legislation and litigation for implementation of policies, the definition of inclusion, meanings of disability and mental retardation include entrenched stereotypes; meanings of inclusion remain confusing and contentious; and the interpretation of least restrictive environment and free, appropriate public education are still subject to disagreement and debate (Artiles, 2003; Doyle, 2003;
A genealogical context is important to recognize because, in the competing discourses and “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85), children with disabilities are still subject to “judges of normality” (Foucault, 1995/1975, p. 34). It is important because students with mental retardation and other developmental disabilities—whose bodies so visibly defy the “universal reign of the normative” (Foucault, 1995/1975, p. 304)—may be destined to remain, literally and epistemologically, in a class by themselves. Although the percentage of students with disabilities placed in K-12 regular classrooms for at least 80% of the day increased between 1988-1989 and 1998-1999, the smallest increase occurred among students with multiple disabilities, from only 7% to 11% (National Center for Education Statistics, 2004). Even in schools where inclusion is practiced, it may entail “little more than the relocation of disabled students into general education classrooms” (Ware, 2002, p. 154).

Experts in the field of special education have communicated a pervasive lack of consensus on the meaning of inclusion for students with moderate to severe disabilities (Ryndak, et al., 1999). There is no legal definition of inclusion (Grenot-Scheyer, et al., 2001). To determine the degree of a student’s involvement in inclusive education, American public schools rely on the definition of least restrictive environment set forth in IDEA (1975). But the “language of places” in IDEA, emphasizing services received rather than location of services, allows for exclusionary interpretations antithetical to the spirit of the law (Artiles, 2003; Doyle, 2003, p. 140; Kavale, 2002). Sarason (1996) saw the language of IDEA as carefully crafted to permit “educational segregation” and
“protect” the regular classroom from inclusion (p. 253). Educational reform in the 21st Century calls for a new inclusive context, where general and special education teachers work together to create a curriculum that will serve all students (Grenot-Scheyer, et al.; Smith, 1997).

From a genealogical perspective, the lingering confusion and debate surrounding the construct of “inclusive education” in the 21st Century can be traced to competing discourses and specialized knowledge comprising “truths of power” (Foucault, 1980, p. 93), rather than a straightforward progression toward more democratic schooling. Ongoing encounters exist between juridical and disciplinary power, as described by Foucault (1980). Juridical power (Foucault, 1995/1975) is represented by the considerable forces of standards-based education reform, and the continuing reinterpretation, related litigation, and reauthorization of IDEA (1975). Disciplinary power is represented by traditional, or “general” or “regular” education, by “special” education and its related professional services, by the emerging academic disciplines defined as disability studies, and by general cultural tendencies to discipline the body.

If these disciplines remain separate and unequal, they may fulfill the “gloom and doom analysis” of Foucauldian applications in educational research (Butin, 2001, p. 158; Mayo, 2000; Schrag, 1999), by creating an inescapable “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85), that defies change. If, through the competitive discourse of productive debate, some of these disciplines are willing to join forces and offer resistance to deep-seated norms and stereotypes, “inclusion” may come to exercise a transformative force in systemic education reform.
Foucault, especially in his later work (1988a, 1988b), acknowledged the possibility of transformation on an individual and societal level. In Chapter III, Method, Foucault’s genealogical perspective will be examined in relation to its suitability as a context for Symbolic Interactionism, the theory that shapes this dissertation.
CHAPTER III: METHOD

“... Phenomenology does not ask, ‘How do these children learn this particular material?’ but it asks, ‘What is the nature or essence of the experience of learning (so that I can now better understand what this particular learning experience is like for these children)?’

--Max Van Manen (1990:10)

The purpose of this study is to explore the lived experience of a student with Rett syndrome, in an administratively-defined “inclusive” educational environment. It is informed by the traditions of phenomenology and symbolic interactionism (Blumer, 1969; Hewitt, 2003; Moustakas, 1994; Sandstrom, Martin & Fine, 2003; Van Manen, 1990). The data will be reported in case study format (Miles & Huberman, 1994; Wolcott, 2001).

Three social constructivist perspectives, were utilized to collect and analyze the data: genealogy (Foucault, 1984, 1971, 1995/1975, phenomenology (Husserl, 1962/1913; Van Manen, 1990), and symbolic interaction (Blumer, 1969; Hewitt, 2003; Mead, 1962/1934). The purpose of the genealogical lens was to explore existing meanings of disability and inclusion. The purpose of the phenomenological lens was to ensure a holistic (mind/body) perception of individuals with disabilities, and to represent, as accurately as possible, observed interactions from the point of view of the participants. The purpose of the symbolic interactionist method was to explore the immediate
construction of interactions and meanings, at the intersection of individual interaction and social order. The genalogical lens was described in Chapter II. The following sections will describe the phenomenological lens, and the symbolic interactionist lens/method.

The Phenomenological Perspective

Phenomenological research is the study of lived experience, “a heedful, mindful wondering of what it means to live a life” (Van Manen, 1990, p. 12). It is a “caring act” (p. 5), because the researcher wants to truly know and deeply understand what the world is like for a specific individual or individuals (Patton, 2002; Van Manen, 1990). The phenomenological tradition aims for a clear, unbiased portrayal of the lived experience of a phenomenon, and a depiction of the individuals who participated. To achieve this rich, unbiased representation, the researcher uses “creative synthesis . . . the bringing together of the pieces that have emerged into a total experience, showing patterns and relationships” (Patton, 2002, p. 487).

Appropriateness of the Phenomenological Perspective

At the core of the phenomenological perspective is an essential and intentional interconnection of mind and body, thought and object (Husserl, 1962/1913). Viewed in this way, consciousness is seen as an intentional act of selecting the objects of which one chooses to become conscious. This essential interaction of thought and object assigns meaning to one’s world (Moustakas, 1994).

Consciousness is composed of two aspects: noesis and noema (Husserl, 1962/1913; Moustakas, 1994; Patton, 2002). Consider the example of my dog, asleep beside my chair. The noesis of my dog is his real, physical body; he is a black and white Border Collie. The noema of my dog is his interpretive form: Clyde, my dog-child;
Clyde, my playmate; Clyde, my guardian; Clyde, the clown. All this and more—physical body and rich essence of meaning—comprise “Clyde” in my consciousness.

From a phenomenological perspective, mind and body—thought and object—are “inseparable components of meaning” (Moustakas, 1994, p. 28). Phenomenological inquiry can therefore be an appropriate lens for examining the lived experience of individuals with intellectual and developmental disabilities. These individuals have minds and bodies that are discernibly different from the minds and bodies of most of the people with whom they interact. These differences may be difficult to understand, and may go largely unexamined through a holistic, phenomenological lens.

A phenomenological perspective on disability compels the researcher to consider both mind and body as an interconnected essence of lived experience. To consider the lived experience (the noema) of a person with a disability, and disregard the physical reality (the noesis) of that disability, presents the danger of constructing a “fictional, non-existent world” (Schutz, 1967, p. 8).

The intellectual separation of disability as a construct, from a multifaceted person who happens to have a disability, has been found to foster a profoundly limiting perception of the disability as the person, or the person as the disability (Johnson, 2003; Mairs, 1996; Oliver, 1996). This is perhaps the origin of such language as, “A Down’s syndrome kid,” “a retarded child,” or even “a retard.” But, when disability is considered phenomenologically, it may be seen and examined as “just another interesting way of being” (R. M. Smith, personal communication, June, 2002). The lived experience of a person with a disability involves both mind and body. “For every noema, there is a noesis; for every noesis, there is a noema” (Moustakas, 1994, p.30).
The Symbolic Interactionist Perspective and Method

Symbolic interactionism shares with phenomenology the premise that we shape our behavior by the stimuli and objects we “take into account” (Sandstrom, et al., 2003, p. 11), and how we define them. Like the phenomenological perspective, “on the methodological or research side the [symbolic interactionist] study . . . would have to be made from the position of the actor” (Blumer, 1969, p. 73).

The symbolic interactionist perspective is based on three premises set forth by Herbert Blumer (1969), who is widely regarded as the originator of symbolic interactionism, a concept he named in 1937 (Sandstrom, et al., 2003).

1. Human beings act toward things on the basis of the meanings those things have for them . . . ;
2. The meaning of . . . things is derived from . . . social interaction . . . ;
3. Meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (Blumer, 1969, p. 2)

Blumer (1969) credited George Herbert Mead (1962/1934) with the conceptualizations of symbol and self upon which he based his theory.

The Nature of Symbols

Symbolic interactionists believe that we humans are unique creatures because of our ability to use symbols (Blumer, 1969; Hewitt, 2003; Sandstrom, et al., 2003). A symbol is “a sign created and given significance” (Hewitt, p. 35) by an individual or a group, as they interpret and respond to that symbol. Symbols allow humans to have experiences that transcend the immediate environment. They allow us to respond to stimuli in terms of meanings we construct from the past, present, and future, meanings of
what is good, right, important, and so on. A symbol is an arbitrary sign, because it is associated with what it signifies by the agreement of those who use and respond to it (Blumer, 1969; Hewitt, 2003; Mead, 1962/1934; Sandstrom, et al., 2003).

**The Self as a Process**

Mead (1962/1934) and Blumer (1969) described the self as a *process* rather than a *product* of external forces. In a theory compatible with phenomenology, Mead suggested that individuals developed awareness of their own being by attending to and interacting with selected aspects of the environment. The first stage, in infancy, is a period of meaningless imitation. The second stage, in childhood, is a “play” stage in which children use imagination to take on the roles of others, switching identities and holding imaginary conversations. In this stage, the child is learning to see herself or himself from others’ perspectives. In Mead’s third stage, the “game” stage, the individual learns that the other players were somewhat consistent and predictable. The individual can identify a goal, plan a prospective line of behaviors, note the behavior of others at various steps toward the goal, and construct his or her acts by what he or she has taken into account.

**The Importance of Social Interaction**

Symbols have meaning because they are social (i.e., they are used by the members of a group in a consistent way). They make it possible to transfer mental states from one person to another (Hewitt, 1994)—not necessarily with great skill, but necessarily (Blumer, 1969).

The human being is not a mere responding organism; . . . he is an acting organism who has to . . . forge and direct his line of action. . . . He may do a poor job in constructing his act, but construct it he must. (Blumer, 1969, p. 55)
The verbal symbol of spoken language is considered to be the symbol that is “of the greatest consequence for human behavior” (Hewitt, 1994, p. 35). Sandstrom, et al. (2003) go so far as to state that we can only become “distinctively human” (p. 11) through our symbolic interactions with others. Symbolic interactionists believe that involvement in society is essential for the realization of human potential (Blumer, 1969; Hewitt, 2003; Sandstrom, et al, 2003). This belief is compatible with the sociological discourse of Vygotsky (1978/1934) and the social model of disability (Oliver, 1996, 1999) described in Chapter II.

**Symbolic Interactionism and Foucault’s Technologies**

Mead’s (1962/1934) concept of the self led symbolic interactionists to define social interaction as a process of goal-setting behaviors (Blumer, 1969; Hewitt, 1994). This concept is not incompatible with Foucault’s technologies of the self:

> which permit[ted] individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality” (Foucault, 1988, p. 18).

Foucault’s (1988a, p. 18) “technologies of sign systems” can be seen as comparable to symbolic interactionist symbols. Both involve the use of symbols to intentionally convey meanings about the internal and external state of groups and individuals. His “technologies of power,” which imposed conduct from “out there” in society, did not acknowledge the transformational possibilities allowed by symbolic
interactionists. But neither did the prevailing sociological discourse when Blumer (1969) introduced symbolic interactionism. Blumer noted,

Most sociological schemes rest on the belief that a human society exists in the form of an established order of living, with that order resolvable into adherence to sets of rules, norms, values, and sanctions that specify to people how they are to act in their different situations. . . . We have to recognize that even in the case of pre-established and repetitive joint action each instance of such joint action has to be formed anew. . . . If we recognize this, we are forced to realize that the play and fate of meanings are what is important, not the joint action in its established form. The meanings . . . may be challenged as well as affirmed, allowed to slip along without concern as well as subjected to infusions of new vigor. . . . It is the social process in group life that upholds the rules, not the rules that create and uphold group life. (Blumer, 1969, pp. 18-19, emphasis added)

Blumer’s (1969, p. 18) description of “most sociological schemes” is compatible with Foucault’s (1980) description of all “human sciences” (p. 107). Foucault saw the human sciences as disciplines derived from the internalization of external norms that defined and subjugated individual and social bodies. The fundamental difference between the two theories lies in the likelihood that Foucault (1980; 1984/1971) would see symbolic interactionism as simply another form of subjugation through specialized knowledge and discourse, as the sociological disciplines engaged in their “endlessly repeated play of dominations” (Foucault, 1984/1971, p. 85). Blumer (1969) saw symbolic interactionism as a transformational truth about human existence.
Transformation or Domination?

Symbolic interactionists believe that human beings have considerable freedom and flexibility in their choice of actions, which gives them the power to give new meanings to things, and thereby reconstruct or transform society (Blumer, 1969; Hewitt, 2003; Sandstrom, et al., 2003). Foucault (1980, 1984/1971) saw human goals as the product of both internal and external domination by meanings he called “truths of power” (1980, p. 93). These truths of power subjugated the individual creativity and choice that is recognized by symbolic interactionists. However, near the end of his life, Foucault (1988a) declared:

Perhaps I’ve insisted too much on the technology of domination and power. I am more and more interested in the interaction between oneself and other and in the technologies of individual domination, the history of how an individual acts upon himself, in the technology of the self. (Foucault, 1988a, p. 19)

_Becoming Subject or Object to Oneself_

While Foucault (1988a) described technologies of the self as the necessary act of becoming a *subject* to oneself, symbolic interactionists refer to the necessary act of becoming an *object* to oneself (Blumer, 1969; Hewitt, 2003). The capacity to become an object to oneself, from the symbolic interactionist perspective, refers to the uniquely human ability to act toward ourselves as we act toward others: “name ourselves, think about ourselves, talk to ourselves, imagine ourselves acting in various ways, love or hate ourselves, and feel proud or ashamed of ourselves” (Hewitt, 2003, p. 9). Foucault (1995/1975, p. 138) referred to these actions as the internalization of norms and the production of “docile” and “practiced” bodies.
Whether one becomes an object or a subject depends on the meaning one assigns to the actions necessary to function in society. Foucault (1988a, p. 49) declared, “from the eighteenth century to the present, the techniques of verbalization have been reinserted in a different context by the so-called human sciences . . . to constitute, positively, a new self.” Arguably, this “new self” could be the self created by symbolic interaction, as our meanings of self and other are constantly changed through interaction and understanding. Foucault (1988a), in his capacity as a historian of thought, may have captured large-scale transformations accumulated through decades of individual symbolic interactions. While Foucault looks backward, and the symbolic interactionist looks at the immediate moment, their epistemologies converge where individual interaction connects to social organization. The respective perspectives are summarized in Figure 1, on page 85.
Figure 1: Summary of the three social constructivist perspectives utilized for data collection and analysis, illustrating the divergence of Foucauldian genealogy relative to the possibility for creativity, freedom and transformation in social interaction and social order.
A Symbolic Interactionist Definition of Inclusion

In terms of public education policy, inclusion refers to the location in which a child with disabilities receives special education and related services (i.e., in general education classes, or in special education classes), or to a percentage of the day a child with disabilities spends in general education (Turnbull, Turnbull, Shank & Smith, 2004). But in terms of symbolic interaction, inclusion is not a place. It is not a quantifiable percentage of the day a student spends in general education, or in a self-contained special education classroom. From a symbolic interactionist perspective, inclusion is a construct that is not confined to special education. A new definition—symbolic inclusion—is warranted. Symbolic inclusion would then be the intentional accommodation, assimilation, appreciation and engagement of one’s interaction partner. People engage in symbolic inclusion individually, and within their organized roles in society. Because this case study was conducted in an intermediate school, symbolic interaction and symbolic inclusion were observed in classroom situations. But the classroom was a boundary that pertained only to the location—the field site—of the study. Symbolic interaction and symbolic inclusion occurred as interaction partners chose—in the social constructivist sense—to become conscious of, and to pay attention to one another.

A Special Challenge in this Study for the Symbolic Interactionist Perspective

Traditional symbolic Interactionism relies primarily on spoken language, and to a lesser degree on body postures and movements (Blumer, 1969; Hewitt, 2003; Mead, 1962/1934; Sandstrom, et al., 2003). The key participant in this study was Ashley (pseudonym), a twelve-year-old girl with Rett syndrome, whose language and body movements are profoundly non-traditional. Like most girls and women with Rett
syndrome, Ashley uses no identifiable "words." Her vocalizations vary in tone and volume, but no consistent patterns or sounds approximating phonetic syllables are discernible (Interview with Ashley's mother, October 13, 2004; Observations, August 2004-January 2005). Her behavioral repertoire is typical of Rett syndrome (Sigafoos, Woodyatt, Tucker, Roberts-Pennell & Pettendreigh, 2000), including: characteristic hand mannerisms (clasping, pinching, rubbing); eye gaze (contact, staring); facial expressions (smiling, frowning); and body movements (swinging her feet in a kicking motion, moving her head and torso towards or away). It is extremely difficult to assess whether or not these behaviors by individuals with Rett syndrome are intentional attempts to communicate; but communicative acts have been both anecdotally and empirically verified (Koppenhaver, Erickson, & Skoto, 2001; Sigafoos, et al., 2000; Skoto, Koppenhaver, & Erickson, 2004; Von Tetzchner, 1997). In order to explore symbolic interactions between Ashley and her communication partners, it is necessary to distinguish among symbolic, presymbolic and nonsymbolic communication.

Presymbolic and Nonsymbolic Communication

The communication of students with significant intellectual and developmental disabilities can be difficult to assess and interpret, even by trained, experienced professionals such as special education teachers and speech pathologists (Carter & Iacono, 2002; Snell, 2002; Sutton, Gallagher, Morford, & Shahnaz, 2002). Many of these students converse primarily by using what researchers call "prelinguistic or nonsymbolic communication," an "idiosyncratic repertoire" of sounds and gestures (Snell, 2002, p. 163). Snell defined "nonsymbolic communicators" as individuals who use "few or no conventional symbols (words, signs or picture symbols)” (emphasis added).
Infants without disabilities begin to communicate with the intention of affecting a
listener at about nine months of age (McLean, McLean, Brady & Etter, 1991). Frequent
acts of communicative intent appear to precede the emergence of spoken words in
children without disabilities (Warren & Yoder, 1998). For students with intellectual and
physical disabilities, communicative intent can be difficult to recognize and distinguish
from presymbolic communication. The responsibility of “reading” and understanding the
communication of these students presents a challenge for the communication partner,
and, in this case, the researcher. However, Sigafoos, Woodyatt, Tucker, Roberts-Pennell
& Pettendreigh (1997) argue that making a fine distinction between intentional and
preintentional communicative acts may not be relevant for some students with severe
intellectual and developmental disabilities, since all behavior should be treated as
potential communication. The key to unpacking the communication of these students lies
in whether or not their behavior shows intent.

A Working Definition of Symbolic Communication and Symbolic Interactions

For the purpose of this study, gestures, vocalizations and other nonconventional
behaviors were defined as symbolic interactions, if they appeared—to the communication
partner—to indicate intentionality. Intentionality conforms to Mead’s (1962/1934)
definition of symbolic (v. non-symbolic) interaction, and to the definition of a
communicative act developed by Wetherby & Prizant (1989). A communicative act is a
sequence of observable behaviors with three elements: a) A person performs a signal or
form, which is b) directed toward another person, and c) appears to indicate some
function or intention.
Alternative and Augmentative Communication

Individuals with significant disabilities may use alternative or augmentative communication (AAC) in the form of pictures, signing, or computerized speech, to communicate symbolically. However, AAC also presents a challenge of understanding that has not been fully explored (Sutton, et al., 2002). Symbolic interactionism offers a means of exploration that may help to unpack the complex nature of communication among individuals with mental retardation and severe disabilities, and their nondisabled peers. In whatever form it manifested in this study, all communication was given equal weight, as “language that reverberates the world” (Van Manen, 1990, p. 13).

Research Design

The Case Study

A case is a “functioning specific” (Stake, 1998, p. 87), an integrated and purposive system of working parts. Each case study is a concentrated inquiry into a single system. A case study is “both the process of learning about the case and the product of our learning.” According to Wolcott (2001, p. 91), “the case study is better regarded as a form of reporting than as a strategy for conducting research.”

This study consisted of an in-depth exploration of one case: the lived experience of Ashley, a 12-year-old girl with Rett syndrome in educational situations that presented the possibility of interaction with nondisabled peers. Ashley’s case was pervasively unique (Stake, 1998), extending to its nature, the life histories of the participants, the physical setting, and other contexts, including socioeconomic, political, cultural, and aesthetic.
I selected an “information-rich” case (Patton, 2002, p. 46) from which I expected to learn about patterns of interaction and meaning among children with and without disabilities, and their teachers and paraeducators, in the context of their academic and social activities at school. The geographical location of the case also functioned as a determining factor, with the selected location providing the maximum possible time for participant observation (Adler & Adler, 1987).

Selecting the Site and Communicating the Purpose of the Research

The co-op director communicated by email with the special education teacher at the site, explaining that I was a doctoral candidate interested in studying “inclusion” at the school. The teacher replied, with a copy to me, that she would welcome such a study. She invited me to visit her classroom and meet her students. Although only one of these special education students would be in class during the 2004-2005 school year, when the research was scheduled to begin, the teacher wrote, “You will never see anything like this [group of children] again, and I want you to see how they take care of each other.” On the occasion of the first visit, I joined the children at snack time, participated in a conversation about a recent field trip, and spent approximately one hour observing Ashley, the fourth-grader with Rett syndrome who would participate in the study as a fifth grader in the coming school year.

The special education teacher and I visited with the principal and explained the purpose of the study—to explore children’s interactions in inclusive situations. I gave the principal copies of consent contracts. It was decided that the best time to present the contracts was at the beginning of the school year. The principal requested that letters of explanation and consent contracts be printed on school stationery, and sent the researcher
a stationery template for that purpose. The principal and the classroom teacher expressed enthusiasm for the study, and related an anecdote about parents who had been opposed to “inclusion” when it began in the previous year. They said these parents had a “change of heart” after their children had experienced “inclusion” and that these stories would be “interesting” for the researcher.

Before the beginning of the school year, on May 19, 2004, I met with the assistant principal to discuss the most appropriate strategy for explaining the research method to participating teachers. The assistant principal recommended explaining the research “informally, to whoever needed to participate.” A copy of the research proposal was given to the assistant principal, to share with anyone who might be interested in reading it. The assistant principal read the proposal and passed it on to the special education life skills teacher. She, in turn, passed it on to Ashley’s parents.

Participants

The key participant and focus of the study was Ashley, a girl who was eleven years old at the time the study began, and who celebrated her 12th birthday during the study on October 27, 2004. Ashley could not talk. Her expressive communication was limited to: vocalization in varied tone and volume, smiling, frowning, whining, laughing, and crying with and without tears, (rarely) grasping objects, (rarely) pointing; walking, (rarely) making purposeful eye contact for 3-5 seconds when she was able to focus, and pointing with her nose. Ashley was diagnosed with stage four Rett syndrome (See Appendix A for an overview of Rett syndrome.) Rett syndrome is a congenital developmental disorder, whose cause is unknown. The following biological and
behavioral manifestations of Rett syndrome affected Ashley’s intellectual, physical, and symbolic interactions:

1. Apraxia (the inability to perform complex, purposeful movements, especially hand movements);
2. Reduced head circumference;
3. Stereotypic hand movements (rubbing, pinching, clasping, tapping);
4. Mental retardation;
5. Irregular sleep patterns;
6. Hypotonia (stiff, rigid muscle tone);
7. Severe seizures;
8. Scoliosis (curvature of the spine);
9. Muscle wasting;
10. Shakiness of the torso and legs when agitated or upset;
11. Unsteady, wide-based, stiff-legged walking;
12. Difficulty chewing and swallowing;
13. Small hands and feet with poor circulation;
14. Metabolic irregularities maintaining a low body weight;
15. Expressive verbal communication limited to vocalizations. Ashley could not talk. (International Rett Syndrome Association, n.d.)

Description of the Research Site

The research site was selected upon the recommendation of the special education co-op that served a public school district geographically convenient to the researcher’s home and university in the Southwestern United States. It was an intermediate school
serving Grades 4 and 5, and described by the co-op director, principal, assistant principal and participating special education life skills teacher as inclusive. There were 474 students enrolled in the school when data was collected during the 2004-2005 school year. The school is located in an area of high socioeconomic status (SES). Approximately 9% of the students received reduced or free lunch. The school was rated “Recognized” in 2003-2004 school year and “Exemplary in the previous year, by the State Board of Education.

Administrative Attitudes Toward Inclusive Schooling

The principal described the school as “pretty dang white,” and stated that s/he believed “physically and mentally challenged students” provided “another form of multiculturalism... We have to take every opportunity to present multicultural experiences” (Transcript, October 17, 2004). The principal was a former art teacher.

The Assistant Principal stated that inclusion at the school “started with me”:

I was a special education resource teacher, whose principal put me far away in a portable, as far away as he can—never invited to assemblies, ... ignored as much as possible. ... I eventually became an administrator, and concurrent with being an administrator I met [a professional educator who conducted inclusion workshops in the region]. I became his first “trainer of trainers.” ... For about five years he’d come and eat dinner at our house when he came to conferences.

[Then] I got a job with [a school district]: 80% administrator, 20% working out of the administration building trying to help the campuses become more inclusive. But that didn’t go good at all. Principals would just beam and
brag, and show me their program, and it was not in any way inclusive. . . I wasn’t patient enough, and I wouldn’t be appreciative of the efforts made and so forth, or the lack of effort.

I got rid of resource for social studies and science [in my capacity as an administrator/inclusion facilitator]. Not a need for that. . . . You’d expect an ED [Emotionally/Behaviorally Disturbed] unit or a life skills class to be out there [in the portables], ‘cause no one is gonna want to look at them, or deal with them. If they’re squandered away (emphasis added), then the teacher has to deal with all the different things that come up. I had kids come from all over the state to see how we were doing it. . . . And so I knew it could work. (Transcript, September 28, 2004)

The Assistant Principal instituted an inclusion program at the research site (which was a rural district and not the one in which he had served as administrator/inclusion facilitator) in the 2003-2004 school year. He described his experience:

The special ed. teachers were very receptive. There were a few teachers right at the start that were very receptive. And it required some scheduling. . . . [In the start-up year] we had our first almost bloody meeting. A lot of yelling and screaming. I said, “I’m constructing the schedule for next year. . . . You can’t have where the resource teacher goes up and down the hall the first couple of weeks saying, ‘I need Johnny,’ and send him out. If you have resource kids in your class you’ll teach math this time and language arts this time. . . . It wasn’t well received. . . . (Transcript, September 28, 2004)

The assistant principal quoted the teachers as saying:
You’re gonna tell me *when* I have to have language arts and math, even though it doesn’t fit my schedule. . . and nobody ever tells me when I have to do anything, and my door—I can shut the door and I’m the queen. This is my room. And you don’t tell me what to do.

I still have teachers who are fearful to be the inclusion teacher. I have two excellent teachers who have just on their own modified, and made pretty well functioning, successful kids in science and social studies. [But] the more medically fragile kids scare the hell out of ‘em. . . . Ashley we have to worry about getting bumped, and falling in the good part of her cycle when she’s ambulatory. (Transcript, September 28, 2004)

*Inclusion Confusion as Part of the Context*

During the process of site selection in April and May of 2004, Ashley’s intermediate school was described to me as “inclusive” and “fully inclusive” by the curriculum director of the special education cooperative, the principal and assistant principal, and the special education life skills teacher, who would be a key participant. During data collection, which began on the first day of the 2004-2005 school year (August 17), individual general education teachers referred to Ashley and her life skills classmates as being “always included,” “included,” and “mainstreamed” (Field Notes, August 17, 2004). On October 7 the life skills teacher came back from a meeting of an Admission, Review and Dismissal (ARD) committee with a specific, written description of her students’ education programs: resource in regular education with dual instruction and modified Individual Education Plans. “I wrote it down for you,” she said. “Technically, it’s not inclusion.”
In separate interviews (Field notes, September 29 & October 17, 2004) the assistant principal and the principal referred to the placements of Ashley and the life skills students as a "class within a class." Throughout the study, Ms. Dayton continued to refer to her students' placements as "inclusive" and "inclusion."

Ashley’s actual placement most closely resembled a version of inclusion suggested by the Regular Education Initiative, in which some proponents advocated the inclusion of students with disabilities in general education for some portion of the day, with a continuum of services and some modification of the general curriculum. Ashley attended fifth grade homeroom, science, physical education, lunch, and social studies with her nondisabled peers in general education. Her life skills classmates attended fourth grade homeroom, computer lab, science, physical education, lunch and social studies in general education. For the remainder of the day Ashley and her peers with disabilities were placed in the life skills classroom for instruction in functional environmental skills, math, and reading.

This was not mainstreaming, in which only students with mild disabilities are physically included in the existing general education curriculum. It was not full inclusion, in which students with mental retardation and developmental disabilities are included in general education and extracurricular activities, with a modified curriculum, for the entire school day. These distinctions did not appear to be clear among teachers and administrators.

In this context of inclusion confusion, and due to the controversial nature of the school’s inclusion program, which was entering its second year when I began my study, I was permitted to observe and interview only those teachers who had agreed to participate
in inclusive education for Ashley and her peers in special education life skills: the fourth
grade social studies/homeroom teacher, Ashley’s fifth grade science teacher and social
studies/homeroom teacher, the music teacher, the art teacher, and the life skills teacher. I
was permitted to observe and interview Ashley and her four (later, five) life skills special
education classmates. I was permitted to interview general education students who
volunteered for Circle of Friends, a program that was designed to facilitate inclusive
interactions within the life skills classroom. While I could observe interactions in general
education classrooms where not all students had signed consent contracts, I could not
take specific data or specifically describe interactions, unless they involved students who
had volunteered to participate in the study and in Circle of Friends. Since the study was
designed to explore “inclusive” situations, since the social construct of inclusion has been
shown to be confusing and contentious as described in Chapter II, and since symbolic
interaction occurs on a micro-level of one-on-one interaction, I accepted these
specifications as acceptable for data collection. The following description of the Circle of
Friends strategy, as executed at the research site, will describe the formal training and
instructions students received that may have influenced their symbolic interactions with
Ashley.

Description of Circle of Friends Training for Students in General Education

Circle of Friends is a program designed to help build a social support community
for students with disabilities. It is commonly employed in inclusive classrooms (Hamill
&Everington, 2002; Pearpoint, Forest, & O’Brien, 1993). The Circle of Friends program
at the school in which the study was conducted was patterned after an introductory
activity, with four basic steps.
Step one. A facilitator (in this study, the school psychologist) instructs general education students to draw a series of concentric circles, such as those shown in Figure 2.

![Figure 2: A circle of friends diagram (Hamill & Everington, 2003, p. 260)](image)

Inclusion Confusion Shapes the Field Work

During the process of site selection, Ashley’s intermediate school was described to me as “inclusive” and “fully inclusive” by the curriculum director of the special education cooperative, the principal and assistant principal, and the special education life skills teacher, Ms. Dayton, who would be a key participant. During data collection, which began August X, individual general education teachers referred to Ashley and her life skills classmates as being “always included,” “included,” and “mainstreamed.” On October 7, Ms. Dayton came back from a meeting of an Admission, Review and Dismissal (ARD) committee with a specific, written description of her students’
education programs: resource in regular education with dual instruction and modified IEPs. “I wrote it down for you,” she said. “Technically, it’s not inclusion.”

In separate interviews (Field notes, 9/29, 10/17) the assistant principal and the principal referred to the placements of Ashley and the life skills students as a “class within a class.” Throughout the study, Ms. Dayton continued to refer to her students’ placements as “inclusive” and “inclusion.”

Ashley’s actual placement most closely resembled a version of inclusion suggested by the Regular Education Initiative, in which some proponents advocated the inclusion of students with disabilities in general education for some portion of the day, with a continuum of services and some modification of the general curriculum. Ashley attended fifth grade homeroom, science, physical education, lunch, and social studies with her nondisabled peers in general education. Her Life Skills classmates attended fourth grade homeroom, computer lab, science, physical education, lunch and social studies in general education. For the remainder of the day Ashley and her peers with disabilities were placed in the life skills classroom for instruction in functional environmental skills, math, and reading.

This was not mainstreaming, in which only students with mild disabilities are physically included in the existing general education curriculum. It was not full inclusion, in which students with mental retardation and developmental disabilities are included in general education and extracurricular activities, with a modified curriculum, for the entire school day. These distinctions did not appear to be clear among teachers and administrators. As I attempted to explore various meanings, these confusing definitions revealed possible related tensions between parents and the school.
In Circle 1, children are instructed to write names of family members. In Circle 2, they are instructed to write the names of their best friends. In Circle 3, they are to write the names of people they “hang out with” because they are members of a group, such as a sports team, a scout troop, or a church group. In Circle 4, they are to write the names of people who are paid to spend time with them, such as a baby sitter, or a dentist.

**Step two.** Children volunteer to discuss who they have entered in specific circles, and why. Not all circles will be the same (Forest & Pearpoint, 1992). Students discuss the role of family and friends in their lives.

**Step Three.** The facilitator shows how the circle of a child with a disability—or a specific child with a disability—might be different. For example, the child might not be able to join any clubs or sports teams, and there might be more people paid to be with the child than there are people who “hang out” with the child. The “paid” group might include a physical therapist, a speech therapist, an occupational therapist, a paraeducator, a neurologist, a surgeon, and so on. In Step Three of the classic Circle of Friends intervention (Pearpoint, Forest, & O’Brien, 1993) the facilitator asks children who would like to volunteer to be in a particular child’s (in this case, Ashley’s) Circle of Friends, and join the circle of people who hang out with Ashley. At the research site, Ashley’s life skills teacher met with each general education homeroom a few weeks after the school psychologists’ presentation (Field notes, November 10, 2004):

I go from room to room at the beginning of the year to explain the program. And there’s groups of kids that are very flat, and there’s no response, and there are others—it just seems like it’s a consciousness of a class that happens, even in the
first few weeks, that kids don’t have any questions, don’t sign up, aren’t interested, and some the teacher can’t hold ‘em back because they wanna do it. . . . I ask, “What is a volunteer?” and some of them know and they go on about it. Others, there’s just no response. I just have to draw it out of them. . . . I say, “what’s a volunteer? You’re not gonna get paid. You’re not gonna get a grade. You’re gonna take your time out of recess or something. Why do people volunteer?” and we talk about that. Give me some examples if you volunteer around the house, or for church, or for boy scouts.” I try and make them stop and think about it, before I explain: “This is the program we offer, to come and volunteer in our room and to be a friend to our kids. Not only in here, but when you see them in the hall. And when you can’t talk in the hall, you can always wave. On the lunchroom, on the playground, just talk to them and make them feel they’re a part of the group.” They do, for the most part; but sometimes they don’t.

Transcript, November 10, 2004)

Step four. As a separate meeting, or as part of Step Three, the parent of a child with a disability comes to the school to introduce and describe the child, their strengths, the things they like, and some of the challenges presented by the child’s disability. In the second week of school, Ashley’s mother introduced Ashley in this manner to the fifth grade science and social studies general education classes, and to Ashley’s life skills classmates.

Step five. Inclusive opportunities are provided for children with and without disabilities to interact. The life skills teacher provided Circle of Friends activities for volunteers in the life skills classroom, each day from 2:45 until 3:00 p.m. and from 3:00
to 3:15 p.m. Two or three volunteers participated in cooking, playing games, doing art work, or helping Ashley’s life skills peers with their academic assignments. Ashley sat with the children and observed their activities, or participated with the children’s assistance, as described in Chapter IV.

*Step six.* The “textbook” Circle of Friends intervention prescribes weekly meetings, in which educators and student volunteers discuss issues, solve problems, and brainstorm ways to make the target child’s inclusive experiences more varied and more fun (Hamill & Everington, 2003). Ashley’s school did not provide this step. I did not observe the school psychologist’s presentation of the Circle of Friends concept. It was described to me by the life skills teacher (Field Notes, November 10, 2004). I did record and transcribe Ashley’s mother’s introduction of Ashley, and her discussion of Rett syndrome, to the students in general and special education. In Chapter V the implications of the Circle of Friends training will be specifically discussed.

**Data Collection**

A major part of data collection consisted of participant observation, a method in which a researcher takes part in the daily activities and interactions, and events of a group of people as one way to learn about certain aspects of their life routines and culture (Dewalt & Dewalt, 2002; Wolcott, 2002). Van Manen (1990, p. 69) distinguished between participant observation and “close observation”:

Close observation involves an attitude of assuming a relation that is as close as possible while retaining a hermeneutic alertness to situations that allows us to constantly step back and reflect on the meaning of those situations. It is similar to the attitude of the author who is always on the lookout for stories to tell, incidents
to remember. The method of close observation requires that one be a participant and an observer at the same time, that one maintain a certain orientation of reflectivity while guarding against the more manipulative and artificial attitude that a reflective attitude tends to insert in a social situation and relation. (Van Manen, 1990, p. 69)

I practiced close participant observation, reflecting in observation, and reflecting on observation. I expected my membership roles to flow between peripheral and active (Adler & Adler, 1987):

[Researchers with peripheral membership] seek an insider’s perspective on the people, activities, and structure of the social world, and feel that the best way to acquire this is through direct, first-hand experience. They interact closely, significantly, and frequently enough to acquire recognition by members as insiders. They do not, however, interact in the role of central members, refraining from participating in activities that stand at the core of group membership and identification. As a result, they generally do not assume functional roles within the group (Adler & Adler, 1987, p. 36).

Study participants often invited me to take an active role, as defined by Adler and Adler (1987):

[Active member researchers] do more than participate in the social activities of group members; they take part in the core activities of the group (to the extent that these core activities can be defined and agreed upon by group members). In so doing, they generally assume functional, not solely research or social roles, in their settings. Active-member-researchers, therefore, can relate members of the
setting in a qualitatively different way than do researchers in peripheral membership roles. Instead of merely sharing the status of insiders, they interact as colleagues: co-participants in a joint endeavor. (Adler & Adler, 1987, p. 50)

As the study progressed, I decided to maintain primarily a peripheral membership role, for several reasons. At the beginning of the study, peripheral membership helped me to assure teachers and paraeducators that I was not evaluating their effectiveness as educators. (Although I gave this assurance before the study, in the first few weeks of participant observation teachers tended to apologize to me for any instructional activities that did not go as planned, such as computers not functioning in a technology class. In some cases, the teacher would announce, “Boys and girls, we have a guest and we want to be on our best behavior.”) Repeated reassurances that my research was focused primarily on children’s interactions helped me become fairly “invisible” in the classroom. Presumably this peripheral membership allowed minimal interference with the natural interactions between Ashley, her peers, and educators.

Throughout the study, peripheral membership allowed me to observe participants’ patterns of interaction and meaning, without facilitating specific interactions or suggesting alternatives. Explaining the boundaries of peripheral membership enabled me to avoid acting as a consultant, when my advice was sought by adult study participants, and when Ashley’s mother asked my opinion of the school, the teachers, or methods of instruction.

I occasionally assumed an active membership role in three situations: 1) After requesting the classroom teacher’s permission, when a student asked the researcher for help with an assignment, 2) when invited by the students to join in a game, sing “Happy
Birthday,” or share a snack, and 3) when hugged by a student. (I hugged back.) Student participants came to accept my peripheral role with a characteristic pattern of interaction and meaning. After greeting me, they frequently invited me to “Come watch us!”

In addition to collecting observational data, the qualitative researcher conducts open-ended interviews with the participants, and examines artifacts related to the phenomenon under study (Creswell, 2003). In this study, interviews were conducted with students with and without disabilities, teachers, paraeducators, administrators, related service providers, and Ashley’s mother. Artifacts collected in this study included Ashley’s Individual Education Plans (IEP), academic and medical records, test scores, artwork, personal correspondence, academic permanent products created by students with and without disabilities. I used a “MOOSE Book” to organize field notes. The MOOSE Book is a schoolwide, mandatory organizational system purchased by each student. The acronym stands for Management Of Organizational Skills Every Day. It contains a calendar, school mission statement, student pledge, school behavior code, and schoolwide rules, with designated spaces to write important phone numbers, parent/teacher comments, spelling words, books read, success tips, and goals.

I did not examine the IEPs and medical definitions of students’ disabilities, or conduct a thorough search of professional literature related to Rett syndrome, until data collection was complete. This strategy was designed to help me work from a perspective that was closer to that of the student participants. During data collection, information on Rett syndrome was given to the students, paraeducators, teachers, and myself by Ashley’s mother.
Instrumentation

This study had several characteristics that justified beginning research with little prior instrumentation (Miles & Huberman 1994). Rich context description was needed, concepts would be inductively grounded in local meanings, and the study was both exploratory and inductive. Open-ended interview guides for children (see Appendix B) were the only prior instrumentation utilized. Conclusions and recommendations were grounded in the data; so the data came first.

Field Work

I spent a cumulative total of 210 hours in the field, from May 19 to December 17, 2004 observing Ashley in homeroom, physical therapy, occupational therapy, communication therapy, music therapy, social studies, science, physical education, functional environmental skills, and “Circle of Friends,” an inclusive academic and social activities hosted by the special education teacher in the life skills classroom. Interviews were conducted with the homeroom teacher, social studies teacher, school counselor, principal, assistant principal, special education teacher, school counselor, three paraeducators, Ashley’s mother, and 18 fourth and fifth grade students with and without disabilities who interacted with Ashley in classes or extracurricular activities, or volunteered for Circle of Friends. The Circle of Friends became a major focus of the study as “inclusive” themes emerged. All interviews were recorded on audio tape and transcribed by myself. Interviews with children were of approximately 15-20 minutes in duration. Interviews with adults were approximately 45 minutes in length. Interviews with children were semi-structured and open-ended (Appendix B). Interviews with adults were unstructured. Field notes were taken by hand, reviewed, and transcribed as soon as
possible after completing a day in the field. Two Circle of Friends activities were audio
taped. One occupational therapy session was videotaped.

Data Analysis

Data analysis utilized a grounded theory approach (Glaser & Strauss, 1967;
Strauss & Corbin, 1998). Blumer (1969, p. 38) referred to grounded theory as “lifting the
veils that obscure or hide what is going on.” Research did not begin with a theory or
hypothesis in mind. Theory emerged from the data, as it was evaluated, coded, and
constantly compared. Constant comparison of data also shaped the course of the research,
as potential themes began to emerge, and additional data was gathered to explicate broad
categories.

The first step in grounded theory is “conceptualizing” (Strauss & Corbin, 1998, p.
103), or “open coding” (p. 101). A “concept” is an object, event, or action that the
researcher identifies as significant to the study. Examples of concepts include an
Individual Education Plan (IEP), a child crying, and a paraeducator talking “baby talk” to
a student with a disability. Each concept stands for a given phenomenon, and each
phenomenon has complex meanings that arise from the interactions of individuals in the
case being studied. These meanings can be discerned through a process of analysis and
interpretation.

When broad categories of data (i.e. phenomena) have been identified and labeled,
subcategories are identified. Subcategories answer questions about the phenomenon:
“when, where, why, who, how, and with what consequences” (Strauss & Corbin, 1998, p.
125). This process of relating phenomena to their explanatory details is called “axial
coding” (p. 123). At this point in data analysis, the researcher may have initial hunches
about how concepts are related to one another. Strauss and Corbin (1978, p. 129) caution the qualitative researcher against rigidly categorizing the data, so that the “dynamic flow of events and the complex nature of relationships” gets lost. They advise: “Let it happen. The rigor and vigor will follow.”

Emerging theory is integrated and refined through “selective coding.” The data has reached “theoretical saturation” (Strauss & Corbin, 1978, p. 143) when the researcher concludes that no new dimensions or relationships are emerging, and the data gathering is essentially complete. The raw data is reduced and synthesized into concepts and patterns of interaction that can be used to explain “what’s going on.” The researcher’s answer to “What’s [possibly] going on here?” or “What is the essence of the lived experience here?” becomes the grounded theory. In the process and method of grounded theory, data undergoes a continuous internal process of analysis, until the last word of the final draft of the dissertation or research report is written.

Application to Education

Van Manen (1990) advocated a phenomenological, hermeneutic (interpretive), and semiotic (language-oriented) approach to educational research, “because pedagogy requires a phenomenological sensitivity to lived experience (children’s realities and life worlds)” (p. 2):

Pedagogy requires a hermeneutic ability to make interpretive sense of the phenomena of the life world in order to see the pedagogic significance of situations and relations of living with children. And pedagogy requires a way with language, in order to allow the research process of textual reflection to contribute to one’s pedagogic thoughtfulness and tact. Pedagogy is the activity of teaching,
parenting, educating, or generally living with children, that requires constant practical acting in concrete situations and relations (Van Manen, 1990, p. 2).

This approach is appropriate, but seldom utilized, for students with intellectual and developmental disabilities, perhaps because communication differences can make the lived experience of these children with disabilities more difficult to explore (Sutton, et al., 2002). Biomedical, scientific research has a long tradition of researching the noetic, physical reality of disability. But the noema of disability, and the lived experience of disability in education, remains largely unexamined (Erevelles, 2001; Lott, 2001).

O'Day and Killeen (2002) recommended qualitative research for its ability to reveal the complexity of disability, illuminate disability issues, and develop action strategies to address disability issues in education. McPhail (1995, ¶ 6) advocated “philosophical scrutiny” in special education research, for several reasons:

One of the strengths of this kind of phenomenological study is that “the other” . . . is provided the opportunity to reveal his or her ways of viewing the world. . . . As our understandings of other ways of studying human beings increase, we can create a community of special education scholars . . . that slowly circumambulates the phenomenon of special education for the purpose of identifying critical issues and problems. We might ask important questions, such as, What is the purpose of special education? (McPhail, 1995, ¶ 42-45).

Students, teachers, and were involved in the generation of new knowledge.

Internal and External Validity

Miles and Huberman (1994) suggest that internal validity in a qualitative study can be measured by asking, “Do the findings of the study make sense? Are they credible
to the people we study and to our readers? Do we have an authentic portrait of what we are looking at?” (p. 278).

The internal validity of this study depends, in large part, upon the skill of the researcher, and the guidance of the dissertation committee. Relevant queries to determine the validity of this study include these stipulations from Miles and Huberman (1994):

1. How context-rich and meaningful are the descriptions?
2. Does the account “ring true,” make sense, seem convincing, maintain a “vicarious presence” (p. 279) for the reader?
3. Is the account comprehensive and representative of the context?
4. Is triangulation achieved?
5. Are areas of uncertainty defined?
6. Were negative events and rival explanations found and considered?
7. Did the original informants consider the results to be accurate?

(Miles & Huberman, 1994)

Generalizability is a primary marker of external validity (Miles & Huberman, 1994). Relevant queries into the generalizability of this study include:

1. Are characteristics of the original sample fully described, so they can be adequately compared with other samples?
2. Have limitations been discussed?
3. Do findings include adequate description for readers to assess potential transferability to their own settings?
4. Does a range of readers find consistency with their own experience?
5. Does the report suggest settings where findings could be tested further? (Miles & Huberman, 1994, p. 279)

The proposed study is potentially generalizable by replication and extension, as recommended by Waite (personal communication, 2003).

Triangulation

By Multiple Perspectives

Appropriate triangulation for constructivist inquiry calls for reporting “multiple perspectives rather than seek[ing] a particular truth” (Patton, 2002, p. 546). The perspectives of teachers, paraeducators, students with disabilities, and students without disabilities were given equal weight when attempting to interpret the phenomenon of inclusion. Additional perspectives of administrators and students’ parents were considered in a depth and manner appropriate to the study, as determined by emergent data. However, the symbolic interactions of the students were most central to this research.

By Multiple Data Sources

This study used the following multiple data sources, in the ethnographic tradition, as suggested by Wolcott (2001, p. 90): participant observation (“experiencing”), interviewing (“enquiring”), and examination of artifacts and archival documents (“examining”).

By Expert Audit Review

Miles and Huberman (1994) suggested review by a panel of experts as an effective method of triangulation. In this study, the dissertation committee will serve as a panel of experts to evaluate the clarity, depth, and quality of the data. Their determination
that the dissertation has or has not fulfilled the requirements of the granting of a doctoral degree will be accomplished by discussing and challenging the researcher in both oral and written presentations of data, as the study unfolds. Other experts, as appropriate, may be consulted in the course of the research and writing of the dissertation. To facilitate this review, the researcher assembled detailed, accurate written and electronic records of the data that may be used for expert audit review (Miles & Huberman, 1994).

Ethical Considerations

As noted, the communication and opinions of students with intellectual and developmental disabilities are subject to misinterpretation and superficial representation. The researcher was meticulous and vigilant regarding the accuracy and reliability of input from these students. Participants’ privacy was protected, and their potential risks were minimized, under the stringent requirements of the Institutional Review Board of the university.
CHAPTER IV
DATA AND ANALYSIS

It’s the last day of school before the Christmas holiday. In the fourth grade, self-contained life skills classroom, the teacher’s desk is littered with a leaning pile of wrapping paper, trailing curls of red and green ribbon, a digital camera, cookie recipes, file folders and a hand puppet. The puppet’s name is Forgetful. Once he was only a washcloth; now he’s a panda. On the floor, a two-foot, artificial pine tree is smothered in presents. There are five smaller trees on the table in the kitchen area. They’re flat, cut out of wood; and they form a thicket around a white poinsettia. On each tree there’s a photo of one of the children who lives and learns in this classroom. The little trees wobble as the children dash around the room. They’re making last-minute preparations for a very special guest.

Annabelle (pseudonym) is dressed in velvet and lace in honor of the occasion. Her Mom has woven her long, blonde hair into two thin braids at her temples. The rest of it cascades down her back in waves. Annabelle is a notorious hugger. Just today she’s hugged several teachers and a doctoral researcher.

Ethan (pseudonym) is wearing paper antlers. His nose is painted red. He is the life skills writer in residence. He can weave all ten of the week’s spelling words into one bizarre sentence. Ethan is a Special Olympics athlete. He likes to wear his medals to school.
Katy (pseudonym), “self-contained,” is a paradox; she is virtually un-containable. Right now she’s yelling a secret: “I have a missing tooth! I have a missing tooth! It’s a very private matter!” When asked what languages she speaks besides English, Katy replies: “Magic, a little Spanish, and Sign.”

Krystal (pseudonym) picks up Forgetful and takes him over to the toy theater. She lays him down center stage, pats him, smoothes his clothly wrinkles. Krystal can restore order to an unruly classroom with the skill of a veteran teacher. She eliminates off-task conversations with a stern glance, straightens pictures on the wall, paces in front of her classmates’ desks to observe their work. Krystal often propels herself from one location in the room to another by cart wheeling.

Jim (pseudonym) is contemplating a box of Christmas cookies. He appeared in the classroom one morning with a red zipper binder, which he zipped and unzipped all day. At 12:55 p.m., he finally spoke: “I want to go home.” That was about two weeks ago. Jim still doesn’t talk very much. But last week he pointed to a cluster of pictures on the wall and said, “My picture! My picture!” The teacher quickly slipped a picture of Jim into one of the frames, to show he was part of the group. Like Annabelle, he’s gained a reputation for random acts of hugging.

Sammy (pseudonym) is a law-abiding, quietly competent child. He protests nothing. His assignments are meticulously completed. Parental signatures are promptly obtained. If someone is crying, Sammy discreetly notifies the teacher. He’s taken Jim under his wing and shown him the ropes. Most of the time, he’s been able to save Jim from getting his name written on the board for some inadvertent infraction. But today the
boys received a reprimand. They ran in the hall; and they burst into the classroom through the forbidden side entrance. Breathless, they asked: “Where’s Ashley?”

Now she’s here—Ashley, the special Christmas visitor! She’s encased in two purple casts from her ankles to her hips, looking pained and precarious on a padded wheelchair that will keep her legs thrust stiffly out in front of her, immobile, for about four weeks. Ashley’s mom and aunt let go of the wheelchair and step out of the way as the kids surround her. They’re hugging her, piling presents on her lap, signing her cast. She’s smiling. Jim grabs the wheelchair and speeds Ashley over to the snack table. With the skill of a highly paid parking valet, Kristin helps Jim maneuver the wheelchair up close to the table. It doesn’t bump into anything! The adults are quiet. They seem spellbound. Is anyone (besides me) holding their breath? The label “medically fragile” is appropriate here. But the children have never heard it.

Jim holds Ashley’s hand while Krystal helps her eat a cookie. Ashley chokes on the bit of cookie, and recovers. Ten hands help Ashley open her presents. Annabelle explains the frenzy: “We missed her long!” As the kids start to sing—“The angels on the bus go flap, flap, flap; all through the town”—I ask myself: What’s going on here?

Findings

Two types of symbolic interactions were revealed in the data collected for this study: excluding interactions and including interactions. To exclude means to keep out, to prevent from participating, to prevent from being considered (Encarta, Jan 21, 2005). Excluding interactions diminished the universe of Ashley’s social roles, and assigned negative meanings to her difference. Meanings associated with excluding interactions were compatible with existing meanings and discourses of disability—including
stereotypes. Four types of excluding interactions were identified: 1) Excluding discourse (unspeakable, medical othering, infantilization); 2) physical exclusion, 3) academic exclusion (low expectations, limited participation); and 4) role erasure.

To include means to take in, to embrace, to take account of, to bring in and involve (Encarta, 2005). Including interactions engaged and expanded Ashley’s presence in a rich variety of social roles. They assigned positive meanings to her difference, and generated new meanings. Four types of including interactions were identified: 1) discourses of inclusion (speakable, medical sharing, age-appropriate); 2) physical inclusion, 3) academic inclusion (reasonable expectations, encouraged participation); and 4) role enrichment. The following section will describe excluding and including interactions.

Excluding Discourse: Unspeakable

“Unspeakable” means disgusting, unutterable, beyond words (Encarta, 2005). Some of the adults in this study, while describing their support for inclusive education, suddenly dropped their voices to a whisper when it became necessary to give a name to mental retardation, excluding certain words from the stream of conversation.

A parent said: “It’s great that the [whispers] slower ones are in social studies so someone will talk to them” (Field Notes, October 11, 2004). Ashley’s fifth grade homeroom teacher, while describing experiences with inclusion that she “thoroughly loved,” said:

I actually had nine special ed. children last year . . . one being [whispers] mentally handicapped. . . . We had a little boy that used to come to my room and stay
during the day and he was, uh, [whispers] *very mentally handicapped*, and he would come and stay and he would have an aide. (Interview, September 28, 2004)

While “unspeakability” may derive from the euthanasia and eugenics discourse that seeks to keep people with mental retardation out of sight, out of mind, and out of the gene pool, the intent of these adults may have been to avoid speaking about mental retardation to *protect* children with mental retardation from the stereotype. The whispered, stereotypical words—“slower” and “very mentally handicapped”—may have been rendered unspeakable because the adults who spoke them found the language itself unspeakable, and not the child to whom the language referred. In a school situation, although there were no children in the room, the adults may have been protecting the children’s privacy by whispering or “unspeaking” their labels.

*Excluding Discourse: Medical Othering*

Medical othering derives from the medical model of disability. The medical model generates a powerful discourse of symptoms and syndromes. The medical model has been associated with the portrayal of a person with a disability as a person who *is* a disability—someone “other” than, and alien to, oneself—due to the marked difference created by disability (Laubscher & Powell, 2003). For example, Ashley’s physical therapist once referred to her as a “seizure kid” (Field Notes, October 26, 2004), and described her hand movements as “so Rett’s” (Field Notes, October 10, 2004).

The physical therapist and Ms. Polly (pseudonym), a paraeducator, conducted a medical discourse in Ashley’s presence, as if Ashley were not there. Barton (2001) found a similar discourse, which she called “erasure” (p. 172), in United Way charity campaigns that utilized poster children with disabilities to invoke pity and fear.
In a private room within the life skills classroom, Ms. Polly and the physical therapist inspected Ashley’s feet for blisters, discoloration and skin breakdown. They pointed out areas they said were “getting worse.” The paraeducator said: “I’m afraid she’s not sturdy on her feet, or will have a seizure. . . . I hate putting on those KAFO’s [knee-ankle-foot orthotics]. I’m so afraid I’ll hurt her (Field Notes, October 25 & 26, 2005, emphasis added).

The physical therapist said: “Ashley’s going to have surgery over Thanksgiving. She’ll be in full leg casts. They’ll do a hamstring release at the same time, and cut her heel tendon.” When she said “cut,” the physical therapist held up Ashley’s foot and made a cutting motion with her forefinger across Ashley’s heel (Field Notes, October 10, 2005). Ashley frowned and vocalized during this discussion.

Without asking Ashley’s permission, or telling Ashley what she was going to do, the physical therapist pulled up Ashley’s shirt and said, “You can see her scoliosis [spine curvature]. If they decide to correct that at the same time she’ll be in a full body cast for months. After that, with Rett’s, they usually never walk again” (Field Notes, October 20, 2004, emphasis added).

Medical othering erased Ashley’s privacy and autonomy, as adults manipulated her body and used it as a prop to discuss topics that aroused pity and fear in themselves, and could evoke self-pity and fear in Ashley—but only if they believed Ashley was “all there,” and could understand their discourse. Ashley’s parents were familiar with this type of medical othering, and tried to prevent it. They had also discussed it with the school staff. Her mother explained:
[Ashley] can understand if you’re talking about her. . . . In doctor’s appointments, we go together, so one of us can have her outside. I think that’s so rude, you know, just talk about her. . . .

So many times I told [the school staff], her diaper, you know. Don’t talk about that . . . in front of others. Or in front of her . . . It’s not like they’re mean, but . . . they came out with Ashley and two other regular ed kids, and they said right in front of this regular ed kid to Ashley and me, “Ashley pooped on the potty today.” And . . . I would have gone under a rock if there was one there . . . . I mean, you wouldn’t have asked [a regular ed. kid] that, or brought that to their attention . . . .

What does Ashley think? Does she just give up—“Well, this is the way it’s gonna be. They’re gonna talk about me like I’m just this thing for the rest of my life.” You know, I always wonder, what does she think? (Interview, October 13, 2004.)

Excluding Discourse: Infantilizing

Infantilizing discourse excluded Ashley from her appropriate social role as a maturing, eleven-year-old girl. The eternal-child role, epitomized by the “poster child” in charity advertising campaigns, has been documented as an enduring stereotype associated with disability and mental retardation (Barton, 2001; Salend, 1994; Wehmeyer, 2000).

Examples of infantilizing were observed between Ashley and Ms. Hanna (pseudonym), a paraeducator who was assigned to Ashley as a one-on-one assistant for most of the school day. Ms. Hanna customarily greeted Ashley by holding Ashley’s thumbs, waggling Ashley’s arms using the thumbs as handles, and singing lustily, “Row,
row, row, your boat!’ A less frequent, but also customary greeting by Ms. Hanna was ‘I see you! I see you! I see you, Little Girl!’ delivered in a high-pitched, sing-song voice.

During a physical therapy session, Ms. Hanna constantly touched Ashley’s nose and cheeks with her forefinger while the physical therapist was working. She put her face about one-half inch from Ashley’s face and pinched her cheeks, repeating, ‘HEE-hee! HEE-hee!’ (Field Notes, October 26, 2004). On other occasions, Ms. Hanna bounced Ashley on her knee, tapped Ashley’s leg, or shook her foot, and repeated loudly, in a high voice, ‘Leggie, leggie, leggie’ (leg) or ‘Ashley PEE-low, Ashley PEE-low, Ashley PEE-low’ (pillow). Ms. Hanna chanted ‘BEE-bew, BEE-bew, BEE-bew’ in a high-pitched voice to get Ashley’s attention, including times when Ashley was more appropriately focused on a teacher or peer (Field Notes, September 23, 2004; October 18 & 26, 2004).

Ms. Hanna described Ashley as ‘like a child, a smaller child, a baby’ (Interview, October 21, 2004). Yet, at the beginning of an interview, Ms. Hanna specifically denied infantilizing. With no prompt except, ‘So, tell me about Ashley,’’ she declared: ‘I talk to her like a regular fifth grader; because that’s the way her parents talk to her. That’s the way everyone else talks to her. And that’s what she understands.’ (Interview, October 21, 2004). The life skills teacher, in order not to single Ms. Hanna out for a reprimand, cautioned the paraeducators as a group to avoid infantilizing. But Ms. Hanna just didn’t get it. On the final day of field work, the life skills teacher said the infantilizing persisted, and she had no idea what to do to make Ms. Hanna stop (Field Notes, December 17, 2004).

Ashley’s physical characteristics may have contributed to Ms. Hanna’s perception of her as infantile. Ashley’s head, hands and feet were as tiny as a toddler’s. She was
thin, frail, and unsteady on her feet. She could not talk. In contrast, Ms. Hanna was unusually large. She stood well over six feet tall; and she was big-boned and solid, with a booming voice. When she stood in front of Ashley, Ashley was totally eclipsed.

Ashley’s instructional materials and clothing may have influenced perceptions as well. Most of her school supplies consisted of brightly colored musical toys and picture books intended for infants and children under five years of age. Her mother said it was difficult to find age-appropriate clothing for Ashley, because she was so tiny. She wore a size seven (Transcript, August 24, 2004).

One of Ashley’s fifth-grade, general education peers also described infantilizing interactions: “I love babies, and the kids in [Ashley’s life skills class] are like little children to me . . . and it’s really fun for me, ‘cause I mean I just really looove to babysit.” This particular peer had an affinity for the medical model: “I wanna be a pediatrician, ’cause I love babies so much . . . either be that or a doctor.” (Interview, October 21, 2004)

**Physical Exclusion: Absence**

Physical absence was an inevitable result of Ashley’s disability. Twenty-one seizures and a week’s absence for surgery kept Ashley out of school for 29 days in the first six months of the school year (Field Notes, December 17, 2004). Even when she was physically present, the pattern of her seizures caused her to miss classes and school activities. Before a seizure, Ashley became progressively sleepy, whining and standing in front of her bed at home, or in front of her sleeping mat at school. Eventually she would sink into such a deep sleep that it became difficult to awaken her enough to even give her
fluids. The sleepy period before a seizure might last for a week, or for several weeks. (See Appendix C for a description of Ashley’s seizure patterns written by her mother.)

*Physical Exclusion: Removal from Class*

The days immediately following a seizure allowed for Ashley’s most teachable moments. She was alert, vocal, and physically active. She was able to make better eye contact, and purposeful hand movements (Field Notes, August 18, September 23, October 4, December 11, 2004; Interview, October 13, 2004; Appendix Z). Ironically, Ashley’s lively demeanor and enthusiastic vocalizations were likely to get her physically excluded from the classroom. If her vocalizations reached the volume of the teacher’s voice, she was taken out of class. Paraeducator Ms. Polly referred to this as “getting kicked out of class for talking” (Field Notes, August 18, October 7, December 6, 2004). At the beginning of the year, Ashley’s life skills and general education teachers arranged a hand signal that would let paraeducators know when Ashley’s voice was interfering with instruction. But the paraeducators decided when to remove Ashley from the room; and they did so before they were signaled. Ms. Polly kept Ashley in her wheelchair, rather than letting her sit at her desk, so she could remove her from the room more quickly (Field Notes, October 7, 2004).

*Physical Exclusion: Untouchable*

Ashley’s post-seizure days were also the most productive for communication therapy (Appendix Z). But the speech pathologist distanced herself from Ashley by wearing rubber gloves (Field Notes, October 25, 2004) when she was working with Ashley on the skill of drinking from a cup of water. Since Ashley didn’t bite, drool, or bleed, why would she employ a precaution that is normally taken with children who do
these things? No one else used gloves when touching Ashley. It is possible that the speech pathologist was protecting Ashley from some type of contamination from a cut or rash on her own hands. I did not observe her hands outside the gloves, or question her directly about her procedure. Paraeducators said the speech pathologist wore gloves to avoid Ashley’s saliva; they shrugged and rolled their eyes when they told me this.

Ashley was also subject to interactions of academic exclusion, resulting from low expectations and limited participation. This was particularly observable in general education, the “inclusive” portion of her curriculum.

*Academic Exclusion: Low Expectations and Limited Participation*

*Excluded from art.* In art class, Ashley and Ms. Hanna sat at a cluster of desks with three general education students. The art teacher asked Ms. Hanna (not Ashley) if Ashley would like to participate in the Halloween-themed project—making a line drawing of a fall scene with crayon, and then adding a special wash to the paper that turned everything black except for the crayoned lines. Ms. Hanna refused the project on Ashley’s behalf, stating: “I’m no good at that” (Field Notes, October 18, 2004, emphasis added). Instead, Ms. Hanna drew a pumpkin and colored it. She wrote Ashley’s name on the pumpkin, then spent the rest of the class period redirecting the conversation and behavior of the children who were sitting with Ashley. She made no attempts to include Ashley in their conversation. (Field Notes, October 18, 2004)

*Excluded from music.* In music class, when the teacher handed out a sheet of paper with song lyrics to each of the children. Ashley was able to grasp her copy. She smiled and made what appeared to be purposeful, three- to five-second eye contact, in turn, with the sheet of lyrics and the piano. When the teacher played the piano and the
other children began to sing the lyrics, Ms. Hanna took the sheet away from Ashley and bopped her on the head with it, saying “BEE-bew!” and “HEE-hee!” Ashley took the sheet back from Ms. Hanna and held it close to her face again (Field Notes, September 23, 2004). At home, when Ashley’s sister played the piano, Ashley enjoyed sitting on the piano bench looking at the music and the keyboard. When she could, she liked to strike the piano keys; and she showed a preference for the lower notes (Interview with Ashley’s mother, October 13, 2004).

Excluded from Social Studies. In social studies class, the substitute teacher asked Ms. Hanna if Ashley had any paper to hand in. Ms. Hanna replied, “No. We just sit and listen” (Field Notes, September 23, 2004). During another social studies class, when the teacher passed around pictures of a donkey and an elephant (political party symbols) Ms. Hanna refused to accept the pictures for Ashley. The reason she gave was: “I’ve seen it” (October 14, 2004, emphasis added). When Ashley vocalized in a tone that said “I’m here!” Ms. Hanna put her hand over Ashley’s mouth (Field Notes, September 23, 2004).

Part of another social studies class was devoted to a visit by high school students, who lectured the fifth graders on the consequences of using alcohol, and how to resist peers who might coerce them to try it. Ashley was sitting in her wheelchair, not strapped in. The high school students performed a lively rap and a role play about peer pressure. Ashley and the other students laughed and watched the performance. When the high school students invited the children to come up and sit on the floor in the front of the room for a discussion, Ashley leaned forward in her wheelchair, as if she were going to stand up—which she could do, with minimal assistance—and join the others. Ms. Hanna
pushed Ashley back down into a seated position and said, “Where are you going?” After that, Ashley remained seated. (Field Notes, October 25, 2004)

*Excluded from school plays.* The week before the Thanksgiving holiday, Ashley joined her peers in rehearsing for two school plays. In music class, Ms. Hanna asked the music teacher if Ashley could have a part in the play, because her mother would want to know if she were included. The music teacher replied: “I don’t know. Here’s a script.” Ms. Hanna passed the script to me, and asked me to find a part for Ashley. I pointed to a scene that depicted a group of children walking across the stage, which would be transformed into a small, wintry town. I asked the music teacher if Ashley might be able to participate in that scene, and assured her it was parent-approved and safe for children to push Ashley in her wheelchair. The music teacher said: “O.K. *I never thought of that*” (Field notes, November 15, 2004, emphasis added). A similar incident occurred during rehearsal for the play to be presented by Ashley’s social studies class at a Thanksgiving assembly.

The class was staging a re-enactment of the Boston Tea Party of 1773, during which a group of American revolutionaries boarded three British ships and dumped forty-five tons of tea into the Boston Harbor as a protest against taxation. Ashley, in her wheelchair, sat at the back of the stage with Ms. Hanna, who asked, “Does Ashley have a part?” The social studies teacher, calling out directions to the children, did not appear to hear Ms. Hanna’s question. (Field Notes, November 15, 2004)

When the social studies teacher called out the names of two children assigned to pull the curtain, only one answered. One of the curtain pullers was absent. Ms. Hanna volunteered Ashley’s help with the curtain, but again the social studies teacher did not
appear to hear. Another girl was assigned. Ms. Hanna pushed Ashley’s wheelchair next to
the curtain and told the assigned children, “She’s gonna be your helper.” Ms. Hanna
ended up instructing the curtain pullers how to pull the curtain, then doing it herself.
Ashley, in her wheelchair, was parked several feet back from the curtain. (Field Notes,
November 15, 2004)

I asserted myself into a role of active participant (Adler & Adler, 1987) when a
scene calling for a “group of ladies” was rehearsed. The “ladies,” in period costume,
confronted one of the leaders of the Tea Party. One lady had a speaking part: “What’s
happening?” I asked Ms. Hanna if Ashley could have a costume and join this group of
ladies, once again with a peer pushing the wheelchair. Ms. Hanna replied: “She’s pulling
the curtain. Her mother will be satisfied.” Ashley had a seizure, and was absent from
school during both of the school plays. She missed any opportunities for participation that
might have been negotiated. (Field Notes, November 15, 2004)

Excluded by limiting communication. Ashley communicated by vocalizing,
smiling, laughing, frowning, crying, walking—and, when she was able to do so—by
making eye contact for 3-5 seconds and grasping objects and people’s hands. In her most
alert days after a seizure, her vocalizations seemed to be an exuberant expression of her
presence: “I’m here!” (Interview with Ashley’s mother, October 13, 2004; Interview with
Ashley’s peers, September 23 & October 4, 2004, Appendix D, Observations, August­
December, 2004). Paraeducators and general education teachers used several techniques
to limit Ashley’s communication during classroom instruction and peer interaction.

Limiting eye contact. Attention, in the form of eye contact, is an important symbol
of intent in communicative interaction (Reichle, Beukelman & Light, 2002). Ms. Hanna
actively limited Ashley’s eye contact with peers, teachers, and the physical therapist. Ms. Hanna used loud or whispered baby talk to regain Ashley’s attention, when it was more appropriately focused elsewhere. She was often physically in Ashley’s face while babbling, touching her nose, pinching her cheeks, and shaking her feet. (Field Notes, September 23, 2004; October 4, 18, 25 & 26, 2004; November 15, 2004; December 8, 2004)

*Limiting walking.* Ashley’s walking communication was perhaps inappropriate—perhaps just different—for a traditional general education classroom. Her family provided several examples of this walking communication. When she visited her grandparents, Ashley would tell them when she wanted to go home. She would walk to the coffee table, pick up a framed picture of her parents, and carry it to the door that led to the garage. Once, when Ashley arrived early in her elementary classroom, she found another child in her place at the snack table. She walked over to the child, stood in front of him and glared, until he became uncomfortable and gave her back “her” chair (Interview with Ashley’s mother, October 23, 2004). In the life skills classroom, where Ashley was allowed to wander a bit, she often stood in front of people with whom she wished to communicate, smiled, and made eye contact. At home, and in the life skills classroom, Ashley stood in front of her bed or sleeping mat and whined when she was sleepy and in pain, prior to a seizure (Interview, October 23, 2004; Field Notes, September 20, 2004; October 13 & 21, 2004).

Ashley’s walking communication was curtailed by Ms. Hanna, who pushed her back down in her wheelchair during social studies class, as noted on page X. Until her mother intervened, Ashley was kept out of the hallway when the children were passing
classes, because teachers and administrators were afraid she would collide with a passing peer (Interview with assistant principal, September 28, 2004; Field Notes, August 23 & November 9, 2004).

**Limiting vocalization.** Ashley tended to adjust the volume and pitch of her voice to that of whoever was speaking. At times, the general education teacher would simply “talk over” Ashley’s vocalization. Meanwhile, paraeducators would try to stifle Ashley’s vocals by putting cheddar-flavored goldfish crackers in her mouth (Field Notes, August 18, 20 & 24, 2004; September 23, 2004; October 13, 18 & 21, 2004; November 15, 2004). In a class right before lunch, Ashley might be quiet while she chewed and swallowed the goldfish. In other classes, she might store them in her cheeks and continue to vocalize. If the goldfish failed to do their job, the paraeducators took her out of class (Field Notes, August 20, 2004; December 6, 2004).

**Limiting communication alternatives.** Another type of communication limitation was a failure by some adults to engage and explore Ashley’s communicative repertoire. Her science teacher expressed concern:

> I have no training in this, and, um, no one has approached me and told me, you know, what I can do. I did watch the film that her mother gave us to look at, and I noticed them using electronic keyboards a lot with Rett syndrome children. And I asked one of the aides about it, and they said, “Well she really doesn’t like using the keyboard.” And they tried her in the computer lab, and she really doesn’t enjoy that. In fact, she hates it. (Interview, September 30, 2004)

Ashley’s science teacher believed the children understood Ashley better than the adults. This teacher really wanted her to stay in class. She relied on the paraeducators for
ideas (Interview, September 30, 2004). But they kept using the same techniques—feeding her the goldfish (Field Notes, August 18, 20 & 24, 2004; September 23, 2004; October 13, 18 & 21, 2004; November 15, 2004), or taking her out of class (Field Notes, August 20, 2004; December 6, 2004). Her science teacher wondered:

How can we keep her in here, without having to have her leave the room? . . .

I’ve asked the aides, “Is there anything? Any trick?” And one of them . . . sometimes gives her food, to try and stifle that vocalization. But, uh, it hasn’t been real successful. . . . I don’t want to be stuffing food in her mouth for no purpose except to make her quiet. I don’t like that idea, either. (Interview, September 30, 2004)

Excluding Interactions: Role Erasure

Some of the adults who interacted with Ashley described limited roles for her, in school and in life. Her role as eternal infant, already described, erased any level of maturity she achieved. Several adults who saw Ashley’s role as a teacher or example described her role as one of disabled Other, teaching others to be grateful that they were not like Ashley. While it may be a valuable experience to learn to appreciate one’s life, this role erased appreciation of Ashley as a whole, complex child.

Ms. Hanna said the purpose of Ashley’s inclusion in general education was to teach her peers:

How to appreciate, be thankful for the things around them . . . . to appreciate what they are themselves. Not to give it for granted but to appreciate it . . . and be happy. . . . If someone in her circumstance can sit in a wheelchair, or walk
around for a few moments . . . and still have a smile on her face, how are they walkin’ around gloomy? (Interview, October 21, 2004)

Ashley’s science teacher described her role as teaching her peers:

That she’s like them (eh-heh-heh)—she’s a human being, like they are. You know, she’s about their size. She can verbalize—even though it’s not English. It’s not something they can understand. (Interview, September 30, 2004)

Ms. Alice (pseudonym), a paraeducator, also saw Ashley’s role as a teacher for her nondisabled peers:

I think it makes the other students think about their lives, you know, appreciate their lives and what they can do. You know, they can run and play ball, where Ashley can’t . . . . ‘Cause there’s people like Ashley everywhere. . . . We’re teaching people to respect people like Ashley. Not to make fun of, or ridicule, ‘cause that could happen to people with MR [mental retardation] or any kind of disability. (Interview, October 21, 2004)

Including Interactions

Nearly all of the children (with the exception of the fifth grade aspiring pediatrician, as noted) interacted with Ashley in ways that were found to be inclusive. Teachers and paraeducators demonstrated inclusive interactions with Ashley as well. Inclusive interactions were the antithesis of the corresponding exclusive actions previously described.

Including Interaction: Speakability

“Speakability” is a word coined from the verb “to speak,” which means to utter words, to communicate thoughts, opinions, or feelings with one’s voice, to be on good
terms, to be significant or worth mentioning (Encarta, 2005). Ashley’s peers with and without disabilities were candid and vocal about her Rett syndrome.

In the second week of the school year, Ashley’s mother spoke to her fifth grade general education classmates, and her fourth grade life skills classmates about Rett syndrome. She explained the cause and listed the symptoms. Then she asked the children if they had any questions. General education students asked mostly disability-related questions (Field Notes, October 23, 2004):

“Can she walk?”; “Can she see?”; “Can she write?”; “Can she express her feelings?”; “Can she cry?”; “Can she hear people?”; “Does she try to talk back?”; “When something’s bothering her, how can you tell?”; “When did she get those things on her legs?”; “What are they?”; “Has she ever had a seizure at school?”; “How do you know if she’s mad?”; “Does she try to talk back?”; and “Is she gonna be stuck like that for the rest of her life?” (Field notes, August 23, 2004)

In the life skills class, where all of the children had disabilities, they asked fewer questions and shared more information about Ashley:

“She got a problem with talking.”; “She goes, “’Aaaaaah.’”; “I notice that she pinch[es] herself.”; “She doesn’t speak sign language.”; “Sometimes she’ll start crying.”; “She doesn’t speak sign language.”; “Ooh, she’s a cutie.”; “She doesn’t look like my sister. My sister has browner skin”; and “She likes that blue ball.” (Field Notes, August 24, 2004)

Some of the children’s questions in Ashley’s life skills class were disability-related: “What’s a seizure?”; “Does Ashley have to go to the doctor’s any?”; “When did
Some of their questions related to Ashley as just another interesting kid: “What kind of food does she like?”; “How about candy?”; “How about pizza?”; “Does she like Chinese food?”; “Is the coach nice to her?”; “Does she, like, draw on herself sometimes?”; and “What does your house look like?” (Transcript, August 24, 2004)

In general education and life skills classes, the children also engaged in inclusive interactions of medical sharing.

Inclusive Interactions: Medical Sharing

Adults used medial discourse to “other” Ashley, speaking about her disability and its consequences as if she were not present, or in her mother’s words, as if she were just a “thing” (Interview, October 13, 2004). The children included Ashley’s disability with their own medical experiences—portraying her not as Other, but as Same. One of them shared a disability that had been a secret for most of his life. When Ashley’s mother asked the general education students if they had any questions, the first hand that went up belonged to a boy who confessed: “I have Tourette’s syndrome. I never said before.”

More medical sharing by others followed: “I had a seizure.” “My dog had a heart attack.” (Field Notes, August 23, 2004)

In the life skills class, the students also had medical experiences to share. Sammy demonstrated his step-uncle’s seizure. Annabelle contributed: “When I was a little kid, my mom was taking a bath. I was crawling to the bathtub but I fell in” (Transcript, August 24, 2004). Katy described a trip to the hospital that “sucked”: 
When I was like three, I took my mother’s pills. I thought they were candy and they were blue. And I couldn’t speak. And guess what happened. I went to the hospital and I had to drink charcoal and then I spit up on my mom’s shoulder.

(Transcript, August 24, 2004)

Ashley’s life skills peers also questioned Ashley’s mom in a way that revealed age-appropriate expectations.

*Including Interactions: Age-appropriate Expectations*

In the life skills classroom, Ashley’s peers asked questions that acknowledged her as a maturing young woman. Krystal wanted to know: “Why doesn’t she wear regular clothes?” Ashley’s mom explained:

You know, her sister says the same thing. She says, “Mom, you need to dress her more like a fifth grader.” And I’m thinking OK, like what? She says I dress Ashley too much like a little kid. But you know what the problem is? She’s a size seven. (Transcript, August 24, 2004)

Ethan and Sammy were concerned with Ashley’s transition to adult life: “Can she drive a car when she’s older?”, Ethan asked. When Ashley’s mom said she could not, he asked a tougher question: “How’s she gonna get married?” Sammy asked: “How’s she gonna get a boyfriend?” When Ashley’s mom answered briefly: “Might not ever,” Nathan persisted: “How’s she gonna get married, though?” (Transcript, August 24, 2004).

Ashley’s mom: “She probably won’t get married because her husband would have to take care of her.”

Ethan: “What do you mean? What do you mean not get married?”
Sammy: “How’s she gonna have a baby?”
Ashley’s mom: “Well, you can’t have a baby if you’re not married.”
Ashley’s mom: “Because, you can’t have a baby if you’re not married and she’s unable to take care of one.”
Sammy (to Ethan): “She won’t know how.” (To Ashley’s mom): “How’s she gonna earn money?”
Ashley’s mom: “She probably won’t.” (Transcript, August 24, 2004)

At the same time the life skills teacher decided to speak to the paraeducators about using age-appropriate conversation with Ashley, Ashley’s sister had mentioned it at home: “Mom, people need to talk to Ashley like she’s a fifth grader” (Field Notes, August 24, 2004).

*Were the Children’s Questions and Interactions “Coached” by Adults?*

As noted in Chapter III, Ashley’s mother’s visit to the school was part of a Circle of Friends (Pearpoint, et al., 1993) intervention. The questions the children asked followed her discussion of Rett syndrome and its manifestations. The students had some coaching by Ashley’s mother, in regards to Ashley’s method of communication. She asked the children to sit on their hands, not talk, and then tell her they were hungry. They vocalized, like Ashley. Her mother helped them take Ashley’s perspective:

You’d try to think of other ways to communicate what you want, wouldn’t you? That’s what Ashley tries to do a lot. She’s trying to tell you what she wants, or what she needs. . . . When you try to tell somebody what you need and they don’t understand, isn’t that frustrating? (Transcript, August 24, 2004)
The children agreed that it was frustrating not to be understood. Her mother continued:

Well, that’s what Ashley feels a lot. Frustrated. What if your stomach was hurting and what if you couldn’t use your hands to touch your stomach. You might cry or whine. . . . She’ll cry, and she’ll pinch herself. (Field Notes August 23, 2004; Transcript, August 24, 2004)

Ashley’s mother suggested ways the life skills and general education students could help Ashley:

Offer to push her in the wheelchair. . . . Hold her lightly by the arm. Put your hand on her back. She’s very slow. You can walk with her, so she’s not alone. . . . If you do something to hurt her feelings she might cry. (Field Notes, August 23, 2004; Transcript, August 24, 2004)

Ashley’s life skills teacher suggested that the students talk to her “just like you would to each other” (Transcript, August 24, 2004) and sing to her (Field Notes, August 23, 2004). That was the extent of the information the students received when they asked the following questions. While Ashley’s mother and the life skills teacher may have influenced their interactions, the children’s questions appeared to be spontaneous and creative—even off-topic. They did more than Ashley’s mother told them to do; and they constructed their own interactions.

*Physical Inclusion*

Ashley was physically excluded by frequent absences from school, and by the reluctance of her speech therapist to touch her, except through rubber gloves (Field Notes, December 17 & October 25, 2004). Ms. Hanna physically excluded Ashley from eye contact and physical proximity to others, by usurping her attention and hovering in a
way that blocked others out (Field Notes, September 23, October 4, 18, 25 & 26, November 15 & December 8, 2004). Ashley’s peers hovered about her in a way that can be seen as inclusive, rather than exclusive; and unlike the speech therapist, they had no apparent aversion to touching her.

One of the best examples of inclusive hovering is the day Ashley returned to her life skills classroom from surgery, as described in the introduction to this chapter (Field Notes, December 17, 2004). Ashley visited her general education homeroom on that day as well, and received a similar reception (Field Notes, January 6, 2005):

Everybody was real excited to see her adorable, painted red toenails, and just the prettiness of the purple casts, and so forth. And she came in, and she seemed to be smiling back at them, and . . . they really did, kinda, just gather around her. . . . They were just “Wooooo!” and they were all signing her cast, and talking to her about Christmas. (Interview with Ashley’s homeroom teacher, January 6, 2005)

Ashley’s homeroom teacher felt the children’s closeness and hovering was a contrast to the beginning of the year, when they would keep an “uncomfortable” distance of about two feet (Interview, January 6, 2005).

When Ashley was absent, recovering from surgery, the students communicated with a constant barrage of cards, maintaining the physical connection although Ashley was at home. Her homeroom teacher noted:

They’d be thinkin’ about her, and kinda, making notes during probably the time they were finished with work. You know, the ones that are a little bit more sensitive and more aware, and so they would think of her, and the first day, definitely I was initiating it, so . . . . But I think from that part on, subsequent
[cards] probably came because they thought it up. . . . During her surgery day they sent a cookie bouquet over to her house and her Mom took pictures of it and it was just absolutely gorgeous—Ashley enjoying all the plastic wrap, and getting into it. Again, that’s another part of these students feeling connected even when she is physically absent. . . . But also feeling connected by writing the cards.

(Interview, January 6, 2005, emphasis added)

Ashley’s peers in the life skills classroom were aware of Ashley’s physical appearance and her physical needs. On “Cowboy Day,” a costume-themed day designed to replace the more religiously inflected Halloween, Annabelle rushed over to Ashley and said, “Hi, Cowgirl!” Katy, also hovering inclusively, noted: “She doesn’t have a bandanna. She can wear mine” (Field Notes, October 25, 2004). Krystal had studied the pictures on the wall above Ashley’s sleeping mat, which depicted the sequence of her physical therapy. She said she learned from the pictures how to massage Ashley’s hands—which she did expertly (Interview, November 2, 2004; Field Notes, December 6, October 4, 2004).

On the playground, I observed a girl gently pushing Ashley’s bangs out of her face when the wind blew her hair (Field Notes, May 19, 2004). Paraeducator Ms. Alice described other incidents of physical inclusion on the playground, initiated spontaneously by the children, with no coaching or assignment of “play buddies”:

A whole group of kids on the swing set went: “One, two, three. Hiiiiiiii, Ashley!” . . . One sweet little girl just always comes up and gives her a hug. And one day we were sitting out there and the kids were catching grasshoppers, and crickets, and showing her, showing her. Yeah! And she was looking at them.
A general education peer allowed Ashley to rub his head anytime she wanted, because she liked the feeling of his short hair (Interview, September 23, 2004).

**Academic Inclusion: Reasonable Expectations**

Ashley’s peers in general education attempted to include Ashley in academic activities. Their expectations for Ashley’s participation in the curriculum seemed reasonable, rather than limiting. They also appeared to spontaneously adapt instruction to Ashley’s ways of learning.

*Included in getting acquainted.* On the first day of school, August 17, Ashley’s fifth grade homeroom teacher assigned random groups of three children to interview and introduce each other to the class. Ashley was part of a group with one girl who did not consent to participate in this study, and a boy who had been in her fourth grade life skills class, but was now in general education. Her former life skills classmate—who did consent to participate in the study—introduced Ashley to the class. He said Ashley liked “books about farm animals, but not that ‘bat book.’” He said her hobby was “picking up stuff” (Field Notes, August 17, 2004). “Picking up stuff” was a reference to Ashley’s attempts to grasp objects such as picture schedules, her cup, and eating utensils, which she could sometimes achieve on the first three to five days after a seizure. (Interview, September 23, 2004).

*Included in instructional materials and activities.* Ashley’s former (fourth grade) social studies teacher—the current homeroom teacher for her life skills classmates—said that during the previous year the children:
Never let me forget [Ashley]. If I was in a hurry, and I had so many kids and I was handing out stuff, and they would say, “Don’t forget Ashley!” Why, I wasn’t going to forget Ashley. . . . But they wanted her included. They were very adamant about wanting her included in whatever they were doing. (Interview, September 24, 2004)

The general education science teacher included Ashley in her lecture by calling out to her: “Notes are important—right, Ashley?” When the teacher walked around the room, showing each student a book about continents and oceans, she passed Ashley by until the paraeducator said: “Can we show Ashley?” At the end of the class, the teacher gave the students an assignment Ashley could not do—cutting out, coloring, and pasting the shapes of the continents onto a sheet of construction paper. While the other students were working on this assignment, Ashley’s former life skills classmate walked over to Ashley and handed her a Styrofoam ball. He helped her run her hand over its surface, and she smiled (Field Notes, August 24, 2004).

*Included in social studies.* In general education social studies, the teacher had the class of 30 children count off by threes, with each group of three forming a political party. Each party was to choose a presidential candidate, design a symbol, write and deliver a campaign commercial, and coach their candidate for a debate. A mock election was held on November 2, 2004, the same day as the real U.S. Presidential election (Field Notes, October 18, 2004).

Ms. Hanna brought Ashley, in her wheelchair, into the cluster of her selected group. She explained to the group that they should use the “Nike swoosh” as their party’s symbol. When the children asked her what a “swoosh” was, Ms. Hanna said, “It means
tough. It’s Ashley’s idea.” At this point, the teacher sent Ms. Hanna out of the room to make copies (Field Notes, October 18, 2004).

When the children had a chance to interact with Ashley in Ms. Hanna’s absence, the presidential candidate held out a list of jobs (campaign worker, press contact, etc.) and waited for Ashley to point to her choice of assignments. “She picked campaign worker,” the candidate said. The children then went off to draw a tennis shoe as their party symbol, perhaps having misunderstood Ms. Hanna’s suggestion. (Field Notes, October 18, 2004). The candidate from Ashley’s group used the same technique several days later, waiting for Ashley to put her finger on the topics she would like him to debate:

We would have ideas written down, and she would keep a finger on it. . . . Yeah. We would sorta, like, check it with everyone. ‘Cause I think they were all good ideas. And we did that with the speech thing, like, what I would say in that little speech. . . . It was about, we would hafta like, we would give questions. We had like eight down, and you could only give four. And she, like, picked two . . . . Do you think you should raise tax or lower it or keep it the same? And she picked the military one. I wanted to talk about this one too. (Interview, December 1, 2004)

The candidate from Ashley’s group was elected class president.

*Included in life skills instruction.* Ashley’s life skills classmates tried to include her in the adapted curriculum and instruction they received in their self-contained classroom. But they were not always successful. For example, the children were taking turns being the “teacher,” solving a math problem on the board, and then picking another student to do the same. When it was his turn to choose the next teacher, Ethan asked:
“Can she [Ashley] be a teacher?” The life skills teacher replied: “She’s doing something different now. But thank you.” (Field Notes, August 20, 2004)

When her life skills classmates were standing at the whiteboard participating in a “living math” exercise, Ms. Dayton asked them to count themselves, and then subtract themselves by sitting down. They counted themselves: five. But Krystal noted, “If Ashley came up, we’d have six.” (Field notes, August 20, 2004). Ashley was in the bathroom at this time. The teacher did not wait for her to come out, and did not include her in the lesson. During another life skills math class, the children asked Ashley to sit with them on the floor as they used manipulatives (Field Notes, August 20, 2004).

In life skills, Ashley was allowed to walk around the room as the other students participated in a lively math class. When they sat on the floor to work with math manipulatives, Krystal asked: “Can Ashley do it today?” The paraeducator helped Ashley sit down on the floor with her classmates, who were using sticks and blocks to study place value. Krystal helped Ashley, hand-over-hand, to place a block. Then she helped her applaud for herself (Field Notes, September 23, 2004).

Inclusive Interactions: Role Enrichment

In contrast to the adult-prescribed, narrow role of teaching nondisabled students to be grateful, Ashley’s peers with and without disabilities perceived her as a child with complex social roles: friend, teacher, comedienne, even role model and hero.

Ashley as Friend

Ms. Dayton, Ashley’s life skills teacher, conducted a “Circle of Friends” (Forest & Pearpoint, n.d.) activity each day from 2:45 to 3:00 and from 3:00 to 3:15 p.m. During this activity, two groups of general education peer volunteers would come to the life
skills classroom to help the students with their work, play games, cook, or do art projects, in fifteen-minute shifts. Thirteen Circle of Friends volunteers agreed to be interviewed for this study.

Ashley’s peers with and without disabilities described a friend as: someone you “hang out with” (Interviews, September 23, October 21 & December 1, 2004); someone loyal and trustworthy (Interviews, November 4 & 10, 2004); someone you play with and have fun with (Interviews, September 23, October 4, 21, 26 & 27; November 11, 3 [three interviewees] & November 4, 2004); someone who is “caring . . . and very sweet” (Interview, November 10, 2004); someone whose house you go to (Interviews, October 26 & November 4, 2004); someone you like to be around (Interviews, September 23, October 4 & 21, 2004); someone that likes you and is friendly to you (Interviews, October 21 and November 11, 2004); someone you help (Interviews, October 4, November 2 & 3, 2004); someone you teach (Interview, October 21, 2004); someone who helps you (Interviews, October 4, November 3 & 4, 2004); someone you eat lunch with (Interview, November 2, 2004); and someone that “you feel what they’re feeling sometimes” (Interview, October 21, 2004). They found many of these qualities in Ashley, and participated in these activities with her. They described her as a “friend” (Interviews, September 23, November 2, 3 [three interviewees] & November 4, 2004).

Circle of Friends volunteers signed up for the activity with the idea of helping, or volunteering, as described by Ms. Dayton. One of her friends in general education said Ashley helped him, in return. “When I was really desperate in a test or something, she’d look over to me and smile, and I’d kind of perk back up again, and get that problem done
and move on to the next one." The same friend described Ashley as "a really sweet person." He declared, "I just like her" (Interview, October 4, 2004).

Many of her classmates said Ashley was "fun" (Interviews, September 23, October 4, 21, 26 & 27 & November 11, 2004). One of them who had been to Ashley’s house noted: “Ashley’s got the coolest toys. She’s got squishy balls and all these really cool things right in her room” (Interview, November 26, 2004). For her classmates, Ashley’s friendship was described as both a pleasure and a learning experience.

Ashley as Teacher

Ashley’s life skills teacher said she and the other teachers had learned “how to pull these kids [with disabilities] in, and support them, and uplift them, and make them feel good.” She herself had learned “these kids really can learn a lot more. The first few years, I was just teaching in here, and we learned some stuff about the human body, and different parts of the country, but I think they get more out of it when they’re with a whole group” (Transcript, November 10, 2004).

Ashley’s mother saw Ashley’s role as an “ambassador” for children with developmental disabilities:

I always think what if, one day, now, one of these kids has a special needs child? They’re gonna think back and remember Ashley, and stuff. And I think that’s a great thing. And that will give them some hope. “I remember how we treated Ashley. I remember that little girl, Ashley. She was there, and everybody loved her.” You know, it might give them some comfort.

Or, um, maybe they’ll decide – I know a lot of people go into special ed., or a neurologist, or that way, because of some people they knew before. There are
a lot of siblings like that. When you have a child like this, you have this huge responsibility. They have to be an ambassador for others. And be out there. . . . Every once in a while I just think, “You know, I just want to keep her at home. I just want to keep her home.” I mean, I think that. I don’t tell her that. But that’s so selfish. Then I think, “No! Ashley likes to go to school. She’s valuable there.”

(Transcript, October 13, 2004)

The principal saw Ashley’s teaching role as providing a multicultural experience—the goal expressed by Gill (1994) who sought to re-imagine disability culture as part of human diversity:

As our regular ed. kids work alongside these mainstreamed or inclusionary kids, they develop an acceptance or understanding of all kinds of people. I think the most valuable benefit for them is the social aspect. Like learning to coexist and cooperate and collaborate with children with special needs. . . . I think that every child’s experience with students of different – that just look different from they do—whether they speak a different language or have a different skin color . . . there’s a life-changing, life-learning experience. That’s my fear for our kids here. . . . We have to take every opportunity to present multicultural experiences for them. . . . Physically and mentally challenged students are another form of multiculturalism. Different culture in school. (Transcript, October 17, 2004)

The assistant principal saw the role of students like Ashley as teaching “appreciation for diversity . . . . that you don’t have to be afraid of a kid in a wheelchair. Don’t have to be afraid of seizures. That they’re gonna be neat kids, otherwise”

(Transcript, September 29, 2004). The removal of the fear of disability may help to
transform existing stereotypes that seem to have arisen from the medical model and its portrayal of disability as pathology that should not be contagious and must be cured, and from the eugenics mindset that would remove all “pathological” difference from the gene pool.

Circle of Friends volunteers said Ashley had taught them the following lessons, which appeared to help to dispel some fears and re-imagine disability:

A life skills peer said: “I know that she couldn’t talk, and, uh, I was kinda scared the first time I met her. . . . She’s like, “Help meeee!” in her mind. [But now] if she’s about to get hurt, I’ll save her!” (Interview, November 3, 2004). A general education student learned:

People that’s in a wheelchair, they can’t go play kickball or anything like that. That doesn’t mean that she can’t be a good friend, or that you can’t hang out with her. You can always do something else and you can always make good friends and relationships with them. . . . There’s so many things in the world that you will not know about until you try them, how fun they are, and I thought that, “Oh, my gosh. This is gonna be so boring.” But then I figured out that it wasn’t. . . . They’re just like you, except in a different way. (Circle of Friends Volunteer, Interview, October 21, 2004)

She’ll get stuff and bring it to you, kind of like, you know, little kids. You know how they’re kinda like pests, sometimes? I hated my little sister at one time. But Ashley um—I started liking my little sister because of Ashley. Ashley would bring me a toy and I’d play with her. Stuff like that, it’s really nice. . . . (Former life skills classmate, Interview, September 23, 2004)
Three volunteers said they learned not to judge a person by their outward appearance (Interviews, September 23, October 26 & November 3, 2004).

A general education student identified as gifted and talented said that being with Ashley gave him a chance to practice his leadership skills. He also learned “not to judge people by just what they do in class” (Interview, November 3, 2004). Spending time with Ashley taught him a new definition of talented: “Even though [Ashley] can’t walk by herself, or talk, that she’s still one of the most talented people here. Since she’s gone through all that” (Interview, November 3, 2004).

Another classmate said: “[Ashley] taught me how to be patient and, um, she taught me that you need to help other kids when they’re in need” (Interview, October 4, 2004). A general education classmate said she learned that even though people like Ashley were different, you could have fun with them as well as help them. She said helping Ashley had made her “a better person” (Interview, October 2, 2004).

Two children specifically articulated new meanings of disability after spending time with Ashley. One of them described Ashley and the other life skills students as “very gifted” (Interview, November 10, 2004). Another life skills classmate said he enjoyed learning about Rett syndrome, because “I never knew anybody like that . . . It’s pretty cool . . . ‘cause it’s a different person.”

A general education classmate said knowing Ashley had helped her understand the difference between being popular and being happy:

There’s nothing wrong with being different. ‘Cause when I was in the third grade, I always wanted to be the most popular girl and stuff like that. But being different—[Ashley]’s so much happier than, probably, the most popular girl in
school, and . . . she’s not popular at all. . . . Everyone wants to hang out with [the most popular girl] just because maybe she has these cool items, or maybe she acts cool, maybe she brags a lot. They’re not the nicest people, you know. Sometimes they start being mean to the people who aren’t popular. (Interview, October 26, 2004)

A life skills classmate learned: “She’s normal from all peoples, and that’s the way she was born, and, and, she’s just like all, she’s just like your friend, like if you had a friend, she’s just like him. Or her” (Interview, November 3, 2004).

*Ashley as Comedienne*

Ashley’s peers described her as “fun” and “funny” (Interviews, October 4, 21 [two interviewees], October 26 & 27; November 2 & 4, 2004). Ashley’s mother described a repertoire of practical jokes and humor. She said joking was “empowering” for Ashley.

She really has a sense of humor, or a teasing aspect in her. All of our family does. We’re all teasers. You will not think she even knows what’s going on. But you’ll have your coffee, a cup of coffee, up high, away from her reach. She can make a beeline and see that cup of coffee, and she’ll reach for it and hold onto it, and look over at you and just grin. I mean, we’ll all say, “Don’t touch the coffee!” and run towards her. And she’ll think that is so funny. And she’ll do that to this day. For a joke, we’ll put a cup and she’ll do that or she’ll look over at you, you know, with this little teasing look on her face, you know, “I’ve gotcha!” Because that gets a big rise out of everybody.
She’ll get her water glass, same thing, you know she won’t be into things (we call it “into” things) all day, walking around. Then she’ll find her water glass, or a water glass, and the next thing you come in, water’s everywhere. You wouldn’t think she would have had the strength to pick up the glass of water that day. But she does things like that, and I know she knows what she’s doing. . . . And of course the more that you’re looking at her, the more she reacts. (Interview, October 13, 2004)

Ashley’s sense of humor was observable in her interactions with paraeducators. On one occasion, when Ms. Hanna and Ms. Alice were trying to get Ashley to drink some water, she used a version of her water joke to great effect:

Ashley was at the lunch table. Ms. Alice and Ms. Hanna were hovering on either side of her, and both speaking at once: “You’d better drink this water!” “You need to drink this water!” Ms. Hanna kept swooping the cup of water up to Ashley’s lips, even though Ashley kept turning her head away. This went on for about three minutes. Finally, Ashley let Ms. Hanna put the cup up to her lips, as if she had been persuaded to drink. But when Ms. Hanna began to pour the water into Ashley’s mouth, she clamped her lips shut, and turned her head away so the water spilled on the floor. Ashley laughed. After a few seconds, the paraeducators laughed too. (Field Notes, October 18, 2004)

Ms. Hanna and Ms. Alice said Ashley also played jokes on them when they were brushing her teeth. (Ashley did not use a regular toothbrush. She used a “toothie,” a small, pink sponge on the end of a stick about the size of a lollipop stick.) Both paraeducators said Ashley would clamp her teeth down on the toothie and refuse to let
them brush her teeth. She would smile through her clenched teeth (Interviews, October 21 & 26, 2004). Like Ashley’s mother, Ms. Alice felt Ashley’s sense of humor was empowering (Interview, October 21, 2004).

She just held [the toothie] there in her mouth and just grinned at me. You know, like she was playin’ with me. Like, she was in control, you know. (Laughs) And she was! Like her way of getting her little control, you know. (Interview, October 21, 2004)

Ms. Hanna got Ashley to allow tooth brushing by making Ashley laugh.

She just gives me that smirk grin because she knows there’s no way I can get that toothie in there to clean her teeth. So all I can get are those two front teeth. So I’m cleaning those teeth, and I’m telling her the whole time, you know, “You better open your mouth.” You see she’s getting’ tickled and she’s laughing, so finally I’m gettin’ in there and I’m able to brush her teeth. Then she’ll clamp down on the toothbrush, on the little tooth thing, and make it so I’ve gotta get another one to clean her teeth some more. (Interview, October 21, 2004)

Ms. Hanna noted examples of Ashley’s sense of humor in classes, as well:

She’ll remember somethin’ like “Row, row, row your boat” like we always do, or she’ll remember somethin’ in the middle of a class . . . and they might be reading or whatever, and she’ll—I’ll look at her and she’ll look over at me, and she’ll remember that we just sang a song that made her laugh or played a game that made her laugh, and she’ll just bust out and she’ll start laughin’. But here we are tryin’ to read. But that’s OK. (Interview, October 21, 2004)
Ashley as Communicator

Ashley’s peers with and without disabilities (Interviews, September 23, October 4 & 26 [two interviewees], November 2 & 3, December 1, 2004), her life skills teacher (Interview, November 10, 2004), paraeducator Ms. Polly (Field Notes, August 18 & October 11, 2004), and her occupational therapist (Field Notes, August 17, 2004) made a concerted effort to understand her nonverbal communication. Ms. Hanna also made an effort, but believed she did not always understand what Ashley wanted or needed:

The way that her and I communicate—I had worked really hard, or tried to watch her eyes, her face, her hands—body language. ‘Cause that’s the only communication I have. . . . But, I think she responds and understands a lot more than what we give her credit for. . . . I think that she responds very well to what she wants and her needs. She, um, it’s just a matter of trial and error, you know, just have to keep tryin’ things, like a child, a smaller child, a baby, keep tryin’ and tryin’ and tryin’ ‘til you finally figure out what they want. This means she’s tired, or this means she’s hungry, or that’s her face for she’s thirsty, or, just, you know—like a baby—you just keep tryin’ and tryin’ until you finally get it right. (Interview, November 21, 2004)

Ashley’s general education science teacher also believed that Ashley understood more than people realized. When she saw Ashley smile about a conversation she was having with a paraeducator, she described it as:

A little epiphany . . . because I didn’t realize that she was that connected. . . . Ashley was just sitting there, kind of expressionless, and the paraeducator started to describe the way Ashley tricks her sometimes. And as soon as she started
talking about that, Ashley got the biggest smile on her face. And I realized, “Boy, she really does understand a lot!” [Another time], I noticed her eyeing my little bag full of rice cakes . . . so I took one out and broke some off, and as soon as I started it toward her mouth she went like this [imitates a hand gesture] telling me that she wanted it, she wanted to try it. So I put it in her mouth. (Interview, September 20, 2004)

Her science teacher felt that the children understood what Ashley was trying to say better than the adults. Some of Ashley’s classmates had observed her communication techniques, and were willing to translate them. They said they could tell a difference in the tone and volume of her voice, and that it communicated different feelings. Two of them stated that she had her own way of talking—“Ashley’s way” (Interviews, September 23, October 4 & November 3, 2004):

Sometimes she’ll rub her eyes; kinda like with her side of her hand [imitates Ashley rubbing her eyes]. That means she’s tired. . . . And when she’s like this—“aaaaaah”—she’s happy. . . . When she’s really moving and acting like she’s talking in Ashley’s way, her talk, her talk—that means she’s wide awake, happy, ‘n’ she’s glad to be here. . . . Yeah, she’ll go like this—“aaaah, aaah, aaah” . . . . “aaaaaah” – “aaah” – “aaaaaah”. That would be tired, and also sad. And, uh, and “aaaaah” kinda like a high pitched sound would be happy. . . . That’s her way of talking to people. (Interview, September 23, 2004)

You can tell when she’s really happy. She’ll be smiling and talking in her way. And when she’s sad she’ll get a frown, and sometimes be very quiet or sometimes be very loud. And sometimes, when she’s just, I guess, just being
Ashley—she’ll kind of pick up something and start banging it on the table. She really likes noise, I think. I think she really likes music because it has lots of noise and stuff. I think it’s because if everybody else is making lots of noise, why not make some noise too? . . . The louder they go, the louder she wants to go, and the quieter they go, the quieter she’ll be. And it’s just sometimes really funny.

Sometimes when the class is really quiet she’ll go ‘Yeahhh!’ I think she’s saying that she wants to be a part of everything, and not be left out, and sometimes I think she’s wishing that she were just a regular kid like everybody else, but sometimes I think she wants to stay the way she is. (Interview, October 4, 2004)

Another general education student noted:

When she’s laughing you can definitely tell a difference between if she’s trying to talk. If she’s trying to talk it’s more of a moan. If she’s laughing it’s higher, and kind of, not a straightforward, but a ragged – like it goes up and down. (Interview, November 3, 2004)

A life skills classmate noted that it was “hard to talk with people who don’t know how to talk. You really have to, like, try to know what she’s feeling or something” (Interview, November 2, 2004). Several other classmates said it took some time to figure Ashley out, and get to know her, and that this was an important thing to do (Interviews, September 23 & October 4, 2004).

A Circle of Friends volunteer sensitive to Ashley’s interactions described her communication this way:

I can tell she’s having a really good time and she feels like she’s a part of . . . this school. When she has a big smile and she’s happy, she’s just like,
well hanging out. She’s kinda, “Uh, oh well. Another day” (Interview, October 21, 2004)

A life skills classmate noted: “When she grabs, when she nods her head yes, nods her head rectangle-like, side-to-side, that means ‘yes’ and if she puts that like that [demonstrates reaching for something] that means she wants that. She’s gonna get it” (Interview, November 3, 2004).

Another life skills classmate noted that Ashley’s pinching was also a form of communication: “She either pinches herself like that [demonstrates], or she says, ‘mmmmm’ or she’s pulling her face and her hair. . . . I think one’s “sleepy” . . . and . . . she makes kinda like faces sometimes” (Interview, November 3, 2004).

*Ashley as Role Model*

Some of the children seemed to perceive Ashley as a role model. Many of these examples came from her life skills classmates, who expressed both admiration for, and imitation of, Ashley’s ordinary accomplishments:

It was the day before Ashley’s surgery, and the children were making gingerbread. Each one took a turn adding an ingredient, and Krystal helped Ashley hand-over-hand to add the butter. The electric mixer was connected to a “Big Mack,” a switch with about the size of a hamburger. The large surface area made it possible for Ashley to depress the switch and run the mixer.

Annabelle asked: “Ashley, can you do the switch?” The children hovered over Ashley and the mixer, which was emitting the fragrance of gingerbread. Annabelle repeated her question three times before Ashley was able to depress the switch. (Field Notes, December 8, 2004)
When she finally did, Katy yelled: “I can’t believe she did it by herself! Tell her mom!” The children translated Ashley’s thoughts, as she tried again to depress the switch, but seemed to be having trouble making her hands do what she wanted them to do.


When Ashley managed to push the Big Mack and stir the gingerbread some more, Annabelle said: “That’s so cool! She pushed it by herself! If I was like Ashley, I would do that!” Sammy said: “That’s awesome!” (Field Notes, December 8, 2004, emphasis added).

Katy said: “Pretend I’m a person that’s like Ashley is,” and depressed the Big Mack to run the mixer. Sammy said: “When Ashley comes back [from surgery] we should throw her a party. Ashley’s tough, right?” (Field Notes, December 8, 2004, emphasis added). Katy got the attention of the life skills teacher to announce: “I have small muscles like Ashley.” (Field Notes, 12/8/04, emphasis added).

Another example of Ashley as a role model came from an essay written by a general education classmate, for a national competition sponsored by the Parent Teacher Organization (See Appendix D for the complete essay.). The assigned topic was, “My Kind of Hero.” His first-place-winning essay was entitled “A Small, Frail Hero.” While he portrays Ashley as a hero, he does not require her to achieve “supercrip” feats. He celebrates and admires her quite ordinary heroics:
You think of a hero as a strong man or woman such as firefighters, police, and soldiers. All of who are big, strong and brave. Well some heroes like mine are small and not very strong.

My hero’s name is Ashley and she has Rett syndrome. If you looked at Ashley and me side by side you might be surprised that Ashley is the real hero. I am big and bulky for my age while Ashley is small and fragile but strong in her heart. . . .

When Ashley smiles at me it makes me feel good. I smile back. She smiles at someone else and makes them feel good and then the whole class feels good. She is not a firefighter, policeman, or soldier, but she is brave, strong and determined in her own way. . . .

Ashley is my hero because she can do outstanding things like being able to go from a wheel chair to walking and from having someone feed her to trying to do it herself. All these are simple for us to do but are very hard for her to learn how to do. I always thought my hero would be a major league baseball player, but I find my true hero is Ashley. . . . (Appendix D)

Through ordinary, but frequent opportunities to interact with Ashley in the setting of the school, new meanings of disability were created, as old meanings were transformed through *including interactions*. While a few of the adults saw Ashley as Other, most of the adults and nearly all of children saw her as Same. In her general education classes, it was the children who spontaneously modified the curriculum and included Ashley in instruction. It was adults—particularly Ms. Hanna, the paraeducator
who was assigned to Ashley for most of the day—who seemed to hold low expectations and limit Ashley’s social and academic roles.
CHAPTER V
INTERPRETATION AND IMPLICATIONS

In this chapter, I interpret the findings obtained through the grounded theory method of data analysis, and discuss their implications. I apply Foucauldian and symbolic interactionist lenses to the findings. I show that children’s instinctive interactions and meanings are in line with current thinking on some assessment and instructional strategies in special education. I unpack the various layers of symbolic inclusion and symbolic exclusion, and discuss their implications beyond special education. I explore the power and value of student voice as insurrected knowledge. I discuss delimitations of the study, and suggest approaches for further research. I suggest that symbolic inclusion is applicable to issues of school improvement and social justice not confined to special education.

Through a Foucauldian Lens

What Does Ashley Think?

Does she just give up—“Well, this is the way it’s gonna be. They’re gonna talk about me like I’m just this thing for the rest of my life.” You know, I always wonder, what does she think? (Interview with Ashley’s mother, October 13, 2004.)

If one’s soul is formed through the imposition of values, beliefs and self-identity (Prado, 2000, p. 61), if it is “born . . . of methods of punishment, supervision and
constraint” (Foucault, 1995/1975, p. 29), what does Ashley think? Does she internalize excluding interactions that portray her as an eternal child, a classroom disrupter, a medical Other, a “thing”? Does she swallow these limitations of her soul, along with the goldfish that are stuffed into her mouth to ensure that she will produce “no noise, no chatter, no waste of time” (Foucault, 1995/1975, p. 201)? In the “universal reign of the normative” (Foucault, 1995/1974, p. 304), have the limiting teacher-judge, the medically-othering physical therapist-judge, the rubber-gloved speech-therapist-judge, and the infantilizing paraeducator-judge sentenced her to low expectations and limited participation in school and in life? The findings here point to the significance and power of symbolic interaction. The cumulative impression of a few excluding interactions can create an image of Ashley—an image of disability—as that which we punish, [as] a way of saying that we wish to obtain a cure” (1995/1975, p. 22, emphasis added). The findings here also indicate that Ashley resisted the forces of normalization and control. At one point, she literally spit cold water on them (Field Notes, October 18, 2004).

Ashley’s empowering sense of humor (including the water joke), and her persistent non-traditional, non-verbal communication, indicate that her interactions provided “resistance, counterattack, appropriation and construction” (Scheurich and McKenzie, 2004, p. 23). Ashley’s mother, most of the adults in her school environment, and her peers saw Ashley as a maturing child with complex social roles: special education ambassador, friend, playmate, teacher, comedienne, role model, and even hero. Ashley and her including interaction partners were able to transcend enduring stereotypes and catalyze the creation of new meanings.
What do Adults Think?

I talk to [Ashley] like a regular fifth grader; because that’s the way her parents talk to her. That’s the way everyone else talks to her. And that’s what she understands. . . . I think she responds and understands a lot more than what we give her credit for. That’s how I feel. I really do. . . . It’s the most rewarding job in the whole – I mean there’s nothing like it. Ever. I would never think about doin’ anything else. I will follow her—if they’ll let me—all the way through high school. (Interview with paraeducator Ms. Hanna, October 21, 2004)

Ms. Hanna, like the other adults who agreed to participate in this study, made a concerted effort to understand Ashley. She sought out ways to include Ashley in classes and activities. She spoke of high expectations and declared her devotion. Even so, excluding interactions worked their way into the repertoire of Ms. Hanna and a few of the other adults who described their stance on inclusion as proactive, and their feelings for Ashley as loving and supportive. So how can I account for their excluding interactions? The answer lies in the space where Foucault (1980, 1995/1975) and the symbolic interactionists (Blumer, 1969; Hewitt, 2003; Mead, 1962/1934) diverge—the arena of intent.

The Importance of Intent

In Chapter III, I discussed the importance of intent as a factor in both symbolic interaction (Blumer, 1969; Mead, 1962/1934) and symbolic communication (Weatherby & Prizant, 1989). I noted that intent was the dividing point between Foucauldian concepts of power and knowledge (1980, 1984/1971, 1995/1975) and Blumer’s (1969) concept of symbolic interaction. For Foucault, habitual compliance to rules and laws led to
internalization of norms. This was a process of oppression, since norms were hierarchically imposed, and normality was defined by “truth[s] of power” (Foucault, 1980, p. 93) that were dictated by those in power over those who were subject to power.

For symbolic interactionists (Blumer, 1969; Hewitt, 2003; Mead, 1962/1934), each interaction—and each subsequent internalization of the reaction of one’s interaction partner—is conscious and intentional, rather than coerced and habitual. It is the actor’s conscious and intentional choice of what to internalize that plants within each interaction the seed of transformation—transformation of self, and transformation of society. Foucault (1988a), in his later work, became more intrigued with the possibility of intentional internalization of norms, as the individual turned himself or herself into a subject. If excluding interactions are performed—as they were in this study—by individuals whose self-proclaimed intent is to perform inclusive interactions, perhaps internalization of norms can subjugate intent.

Foucault (1980) claimed the force of normalization was strengthened by the constant interaction of the two forms of power: juridical and disciplinary. Since the two forces are incompatible—as equity and excellence, systemic inclusion and standards-based education reform, and general and special education now appear to be incompatible—some kind of arbitrating or normalizing discourse becomes necessary. The stronger the norms (education law and litigation, educational standards, practices, and policies, and school rules), the deeper they will be internalized. Perhaps the adults in this study who demonstrated excluding interactions had so thoroughly internalized the norms with which they were inculcated, that their intent was not strong enough to overcome
their subjugation. Perhaps, as Foucault (1995/1975) would have predicted, the norms have invaded their souls.

*The Physical Therapist, the Speech Therapist, and the Medical Model*

It may be that the physical therapist had so thoroughly internalized the medical model of disability as pathology, that she was completely focused on her goal of “curing” or “rehabilitating” Ashley’s abnormalities. It is possible that the physical therapist’s view of Ashley was not phenomenological. She may have seen Ashley only as a disabled body, rather than as a whole, complex child. On one occasion when I observed Ashley’s physical therapy, Foucault’s words seemed particularly relevant: “*We punish, but this is a way of saying that we wish to obtain a cure*” (1995/1975, p. 22, emphasis added). On this day, the physical therapist required Ashley to stand from a kneeling position, with help, several times. The first two times, Ashley whined and vocalized in a way that seemed to indicate extreme discomfort. The third time, when the physical therapist attempted to get Ashley to stand, Ashley refused. I told Ashley it was “very important” for her to stand, even though it might be painful. She then tried one more time. (The reason it was important, which I did not mention, was to strengthen her muscles as much as possible before her surgery, to help aid her recovery.) When Ashley stood I cheered and applauded, and she smiled. The paraeducator’s verbal interaction with Ashley that day was limited to providing instructions. Ms. Hanna’s verbal interaction consisted of baby talk. On this particular day, it is possible that the powerful combination of the medical and infantilizing models prevented these well-meaning adults from seeing Ashley as a child who was being asked to do something she did not understand, that caused her pain.
(Field Notes, October 26, 2004). When Ashley stood one more time, I—like her peers—saw her as a role model and a “small frail hero” (Appendix D).

It may be, as I mentioned in Chapter IV, that the speech therapist was wearing gloves to protect Ashley from some type of infection or open cut on her own hands that may have contained pathogens. But this is an unlikely explanation, since she handled Ashley’s instructional materials without the gloves, and then put them on to work with Ashley and a drinking cup.

I interpret the physical therapist’s and speech therapist’s excluding interactions as examples of powerful internalized norms regarding the pathology of disability. Such norms derive from the medical model. While a pathological view of disability did not prevent them from providing their services, how different, and how differently effective, might their services have been if they were working with the “whole child”?

Through a Symbolic Interactionist Lens

*What did Ashley’s Peers Think?*

“They’re just like you, except in a different way.”

(Interview with a Circle of Friends Volunteer, October 21, 2004)

Ashley’s peers with and without disabilities appeared to be creating a new set of norms. They saw Ashley as a whole child: Ashley as Self, friend, playmate, role model, and hero. They facilitated her agency and engaged her individuality. They allowed her behavior to shape their understanding, and influence their own behavior. (When Ethan learned that Ashley’s pinching was a form of communication, he asked: “Can she pinch me goodbye?” [Transcript, August 24, 2004]). Did these children, whose intentions overcame deep-seated norms, have *no* souls? Or did they have *new* souls? Foucault might
see the children’s interactions as formative truths subject to eventual oppression by the strength of reigning norms. But through the lens of symbolic interaction, Ashley’s peers were seen as capable of transforming deep-rooted meanings of disability, mental retardation, and inclusion.

**Unpacking Symbolic Inclusion**

As defined in Chapter II, *symbolic inclusion* is the intentional accommodation, assimilation, appreciation and engagement of one’s interaction partner. People engage in *symbolic inclusion* individually, and within their organized roles in society. The following definitions and examples explicate the concept of *symbolic inclusion*.

**Assimilation**

To *assimilate* is to incorporate, fit in, integrate, and understand (Encarta, 2005). Ashley’s peers with and without disabilities helped her fit in physically, academically and socially, through the *including interactions* described in Chapter IV. The children demonstrated intent to understand Ashley when they made an effort to interpret and attribute varied meanings to her limited and unconventional communication repertoire (Appendix E).

**Accommodation**

To *accommodate* is to have room for, to adjust, to become accustomed, to assist, to help, to be of service (Encarta, 2005). An example that illustrates the extent of Ashley’s accommodation by her peers is the statement by Annabelle (Interview, November 2, 2004), when asked how she would introduce Ashley to sixth-graders: “She can’t talk, and you’re going to get used to it.”
Appreciation

To appreciate is to welcome, to be pleased about, to value (Encarta, 2005). Ashley’s peers were pleased about her accomplishments. They valued her as a friend and a classmate. She inspired words of appreciation, such as “awesome” (Field Notes, December 8, 2004), and “hero” (Appendix D). Educators and peers appreciated the value of the lessons she taught them, the fun they had, and the smiles she shared.

Engagement

To engage is to connect, to take on, to absorb (Encarta, 2005). Ashley’s peers connected with her as a friend and classmate, by means of the including interactions described in Chapter IV, and others. They were willing to take her on—to communicate and interact with her as a whole child, to listen, to interpret, and encourage her communication. They absorbed her into their lives. In the social world of her peers who engaged in symbolic inclusion, Ashley was not Other, but Same (only in a different way).

Children in this study assimilated, accommodated, appreciated and engaged Ashley in a rich variety of social roles. They acknowledged her eventual adulthood, and troubled the discourse of low expectations (“What do you mean? What do you mean, not get married?” [Field Notes, August 24, 2004].) They expressed appreciation and admiration for her ordinary achievements—depressing a switch, smiling, and trying to feed herself (Field Notes, December 8, 2004; Appendix D).

When applied to the domain of special education, children’s intentional meanings and interactions of symbolic inclusion can be seen to be in line with current thinking on assessment and instructional strategies—strategies intended to include children with disabilities in communication, and in current and future environments.
Current Strategies in Special Education

Which are Compatible with Symbolic Inclusion

Dynamic Communication Assessment

Communication skills in children with severe disabilities are divided into two categories: receptive (understanding) and expressive (being understood) (Reichle, Beukelman, & Light, 2002). Receptive communication skills are difficult to assess with any certainty in a child who does not speak and has mental retardation (Westling & Fox, 2004). In a child with Rett syndrome, receptive communication has rarely been systematically assessed, and there is room for considerable individual variation (Von Tetzchner, 1997). Receptive vocabulary assessments may underestimate children’s receptive comprehension (Reichle, et al.). Snell (2002) recommended “dynamic assessment”—building on existing vocalizations, gestures and behaviors—to foster the growth of more complex communication. Dynamic assessment is appropriately conducted by: using familiar contexts for assessment, relying on information gathered over time and with people who know the learner, increasing communication output by manipulating the environment, and probing potential for learning rather than simply describing current performance.

Ashley’s peers assessed her communication within the familiar contexts presented by the school environment. They relied on information gathered over time (Interview, September 23, 2004) and actively discussed what she might be thinking or trying to achieve (Interviews, September 23 & October 4, 2004; Field Notes, December 8, 2004). An innovative example of manipulating the environment and probing potential for learning was provided by the presidential candidate in Ashley’s mock election group,
when he asked her to put her finger on the topics she wanted him to debate, and waited for her to process and direct the movement of her hands (Field Notes, October 18, 2004). Were her hand movements purposeful? How much of the interaction did she understand? If given choices of pictures, objects, or even a list whose content was verbally described by a communication partner, what would Ashley do? Her classmate’s spontaneous probe could serve as a model for assessments by trained practitioners.

Constructing a Communication Signal Inventory

As a tool for dynamic assessment, Reichle, et al. (2002, pp. 46-47) recommended constructing a “communication signal inventory” to help the communication partners of a non-verbal individual understand and respond to idiosyncratic vocalizations and gestures. The inventory serves as a guide for consistent and appropriate communication interactions with adults and peers. Observations, interviews, and field notes made it possible for me to construct a communication signal inventory for Ashley using information I obtained primarily from her mother and her peers. (See Appendix E for this Communication Signal Inventory, which also documents the sources of the information.)

Many of the communication signals in the inventory were perceived by Ashley’s peers, with no observed coaching from teachers or paraprofessionals. Peer signals were consistent from peer to peer, and over time. These data indicate that professional educators can solicit peer participation, and be guided by children’s keen observations, when constructing a communication signal inventory. How many teachers, paraeducators, and related service providers do this? How many of them do it consistently, over time? What part are students with and without disabilities allowed to play in creating and practicing symbolic communication that differs from the norm? When children with and
without disabilities communicate with each other, how firmly are they expected and
instructed to use traditional truths of power about communication; and how many
imposed limitations of pathology are they forced to accept?

Ecological Assessment

Ecological assessment, also referred to as functional- or environmentally-referenced assessment, focuses on assessing the support needs of a person with mental
dertardation/developmental disabilities in his or her current environment and culture
(Schalock, 1999). Academics are only one domain of this focus (Hamill & Everington, 2002). Ecological assessment is recommended for persons with mental
dertardation/developmental disabilities because of its reference to specific individuals and
environments, rather than to a standardized curriculum guide (Hamill & Everington, 2002).

Questions asked by Ashley’s peers comprised an instinctive and spontaneous
(though partial) ecological assessment of the skills needed to succeed in current and
future environments, with the academic domain as only one aspect of assessment:

“Can she walk?”; “Can she see?”; “Can she write?”; “Can she express her
feelings?”; “Can she cry?”; “Can she hear people?”; “Does she try to talk
back?”; “When something’s bothering her, how can you tell?”; “How do you
know if she’s mad?”; “How’s she gonna get married?”; “How’s she gonna
have a baby?”; “How’s she gonna earn money?”; and “Is she gonna be stuck
like that for the rest of her life?” (Field notes, August 23 & 24, 2004.)
The salience of the children’s questions, and their observed skill in recognizing functional environmental needs, illustrates the value and applicability of peer interaction and understanding to assessment and curriculum development.

Structured Overinterpretation

Von Tetzchner (1997) recommended the use of structured overinterpretation for girls and women with Rett syndrome, whose communicative behaviors were similar to Ashley’s (i.e., their eye contact with intended communication partners was inconsistent, brief, and difficult to determine as intentional). Structured overinterpretation is to be conducted by significant persons in the environment of the individual with Rett syndrome, such as Ashley’s peers. When utilizing structured overinterpretation, these significant persons interpret behaviors that indicate interests, needs and preferences as communicative strategies. Von Tetzchner concluded that even though these strategies might not lead to improved communication by an individual with Rett syndrome, they could contribute to a “responsive and predictable” environment (p. 33), and the set of strategies could be used by communication partners. Ashley’s peers developed a set of strategies for consistently interpreting her communication behaviors (Appendix E)—an instinctive form of structured overinterpretation.

Partial Participation

Partial participation in instruction is recommended for students with mental retardation and other developmental disabilities. The term does not refer to limiting their participation, but rather to increasing and enhancing it. Partial participation refers to being flexible about how these students participate in environments where they do not have and cannot master all of the skills the environment requires (Turnbull, Turnbull,
Shank & Smith, 2004). Inviting Ashley to participate in the mock election in social studies (Field Notes, October 18, 2004) is a clear example of partial participation initiated by her peers. Although she could not speak, and was not likely to be able to read a list of topics for the presidential candidate to discuss, she could indicate her choice of topics by pointing. In fact the presidential candidate let her make the initial selections, which were then approved by the rest of the committee through traditional, verbal discussion.

Ashley’s peers were spontaneously and instinctively flexible in their attempts to include her in instruction by partial participation, through the including interactions described in Chapter IV, and others.

**Transition Planning**

Ashley’s peers in life skills class troubled the discourse about her adult life in relation to marriage, driving a car, and employment (Field Notes, August 24, 2005). Their probing questions would be appropriate to the process of transition planning, which is traditionally conducted by a child’s special education transdisciplinary team (Hamill & Everington, 2002). (“How’s she gonna earn money?”; and “Is she gonna be stuck like that for the rest of her life?” [Field Notes, November 24 & 23, 2004]). In transdisciplinary planning, the special education team of professionals and related service providers prioritizes goals and objectives that will generalize across people, settings, time and materials. These goals and objectives are supported with curriculum, instruction, and opportunities for interaction with nondisabled peers in school and community. Ashley’s peers were skilled at recognizing some of these goals and objectives.
Person-centered Planning

Peer questions and comments related to Ashley’s Rett syndrome (Field Notes, August 23 & 24, 2004) were instinctively in line with a recommended instructional planning approach: the McGill Action Planning System or MAPS (Hamill & Everington, 2004). The steps of MAPS include asking and answering the following questions by a team comprised of family members, general and special education teachers, and peers:

1. What is (Ashley’s) history?
2. What are your dreams for (Ashley)?
3. What is your nightmare?
4. Who is (Ashley)?
5. What are (Ashley’s) strengths, gifts, and talents?
6. What are (Ashley’s) needs?
7. What would an ideal day at school look like and what must be done to make it happen? (Hamill & Everington, 2004, p. 117)

Ashley’s school did not use formal MAPS planning during this study. But information and questions exchanged by Ashley’s mother and peers (Field Notes, August 23 & 24, 2005) dealt with the MAPS questions—without the questions ever having been presented. Children’s instinctive interactions and meanings revealed a complex, comprehensive understanding of Ashley’s present and future needs. Ashley’s peers showed they were capable of making a significant contribution to her communication, curriculum, and instruction, and person-centered planning.
Unpacking Symbolic Exclusion

*Intent* is the common element that links *symbolic inclusion*, symbolic interaction and symbolic communication. Intentional interaction implies a choice of behavior, a conscious development of beliefs, and a conscious, constructed presentation of the self. Disability, physical appearance, race, age, language, religion, gender, and sexual orientation are biological characteristics; they are not forces which, by themselves, inhibit or prohibit *symbolic inclusion*.

Acts of symbolic inclusion—and its tacit binary *symbolic exclusion*—are *intentionally* chosen by the actors. Applying Foucault’s (1980, 1995/1975) to the construct of *symbolic exclusion*, it may be defined as *intentionally choosing not to* assimilate, accommodate, appreciate and engage one’s interaction partner, and instead to *intentionally other* them. In order for an interaction of *symbolic exclusion to be completed*, both interactions partners must choose to make it happen. One actor may choose to exclude, and the interaction partner—having internalized oppression—may intentionally allow himself or herself to be excluded, eventually becoming a “docile body” (Foucault, 1995/1975, p. 138) through habitual compliance to laws and rules created by those who exercise excluding power. If the interaction partner resists exclusion, and avoids habitual compliance, the norm is weakened and may not become ensouled (Foucault, 1988a, 1988b, 1995/1975). *Intentional* interactions—those interactions of which we remain conscious—allow the possibility of transformed meanings—in personal interactions, and in social order (Blumer, 1969; Foucault, 1988a, 1988b; Mead, 1962/1934).
Implications of Excluding Interactions

Excluding interactions were practiced primarily by some of the adults in this study. It is important to note once again that they were not practiced by all—or even many—of the adults who interacted with Ashley. The excluding interactions of some of the adults in this study derived their significance from the context in which they occurred. The excluding interactions examined as part of this study occurred in environments described by teachers, paraeducators, and administrators as intentionally inclusive. They were practiced by professional educators whose stated intentions were to facilitate Ashley’s inclusive education and social interaction. The existence of these excluding interactions reveals a need for careful scrutiny of, and reflection upon, the meanings and goals of professional educators and paraeducators engaged in self-described “inclusive” practices. They also serve as current examples of the power and persistence of existing meanings of disability, mental retardation and inclusion, as described in Chapter II. As Blumer (1969) pointed out, everyone communicates symbolically. But some people do it badly.

Excluding interactions within self-declared “inclusive” special education practices also reveal a need to explore and synchronize educator’s personal meanings of disability, mental retardation and inclusion. This may be achieved through reflection, collaboration, administrative support and professional development that recognizes, articulates, and facilitates symbolic inclusion.

Excluding Interactions Beyond Special Education

Blumer’s (1969) observation, supported by the excluding interactions that emerged from analysis of the data, indicates a need to scrutinize and synchronize our
individual meanings within the social order—not just in special education, but in the field of education as a whole, and in the practice of school improvement and systemic education reform. Are there excluding interactions within self-proclaimed inclusive practices? Are stakeholders in critical educational issues working from compatible meanings of key ideas? How would they answer Ethan’s challenge: “What do you mean?” What do you mean?” (Field Notes, August 24, 2004). What do educators, educational researchers, legislators, and parents mean by: no child left behind; highly qualified teachers; accountability; at-risk; scientifically-based research; multicultural education; equity; excellence; celebration of diversity? What do these constructs mean to the children who are subject to their meanings?

Implications of Including Interactions

Including Interactions Beyond Special Education

Including interactions by Ashley’s peers were shown to transform existing meanings of disability. They were not associated with enduring, negative stereotypes. They were compatible with current practices in special education. Including interactions were found in student voice. Within and beyond special education, student voice could be recognized as a force for the transformation of educational policies and practices, and incorporated as a valued component of systemic education reform. Educational researchers would be well advised to solicit and incorporate student voice in policies and practices of education in colleges and universities, and in public school classrooms—in general education, special education, and “self-contained” classrooms. Current practices in general, special and inclusive education might be enhanced and transformed, if student
voice were more actively solicited, and more actively incorporated. Why isn’t it happening?

**Student Voice as Insurrected Knowledge**

Foucault (1980, p. 87) might classify student voice as an “insurrection of knowledges against . . . institutions . . .” which Foucauldian genealogy seeks to “expose and specify.” How thoroughly (if at all) do educators, legislators, and their policies and practices ignore or stifle the insurrection of knowledges from student voice—from students with disabilities, from students at-risk for school failure, from students under pressure to compete and succeed in high-stakes tests—from students in our public schools and those in our colleges and universities? How intentionally and authentically do we attend, assimilate, accommodate, appreciate and engage student voice? Would an insurrection of student knowledges topple the structure of education in America? Would this be bad? In this study of fourth and fifth graders, the insurrection was a felicitous one.

*Ashley and Her Peers: A Gentle Insurrection*

The innate wisdom and transformational force of Ashley’s peers was an insurrection of new knowledges and new meanings. With the possible exception of allowing and engaging (rather than stifling) Ashley’s vocalizations in general education, the student voices in this study transformed new meanings without disrupting existing rules and policies. The norms of general and special education, and schoolwide discipline, were not totally destroyed; and yet they were transformed. *Symbolic inclusion* occurred with strong intent, but gentle insurrection. The power source of the children’s
questions was their intent to understand Ashley and symbolically include her in their world. In doing so they sought and created new knowledge.

In our scholarly endeavors to understand, explain, and reform education, we must resist the subjugation of student voice. Schools where the insurrection of knowledge through student voice is oppressed, rather than fostered, are schools that will fail. They will fail at fostering new generations who are “just like us, but in a different way.” The power of student voice can deconstruct the metanarratives of disability, inclusion, and education—as naturally as Ashley and her peers deconstructed the stereotypes and limitations imposed by some of the adults who were charged with her education. Ashley’s friends communicated the “unheard-of” (Derrida, 1997, p. 31): “I always thought my hero would be a major league baseball player. But I find my true hero is Ashley.” (Appendix D). They dreamed “undreamt-of possibilities” (Derrida, 1997, p. 31): “She’s gonna talk someday” (Transcript, September 24, 2004). Such possibilities may transform not just education, but the lived world.

Delimitations of this Study

This is a qualitative study of a single case. As such, the particular context, participants, and conditions that comprise this study are unique to the particular school in which the study was conducted. However, the findings in this study can be utilized to guide further research, as follows.

Implications for Further Research

Longitudinal Extension of the Existing Study

If Ashley’s experiences with inclusion were to be studied longitudinally, as she goes on to middle school and high school, the effects of increased maturity and academic
complexity could be explored, as they relate to the dynamic of excluding and including interactions, and symbolic inclusion. It is not likely that a longitudinal study of this particular case will occur. But there are other opportunities for further research on this topic.

Symbolic Interaction, Symbolic Inclusion and Symbolic Exclusion

Studies of symbolic interaction in inclusive classrooms could be conducted at various grade levels, and in schools where the socioeconomic status and diversity of the school population differ from Ashley’s school. Key participants could be selected from among students with other types of developmental disabilities. How would a student less attractive, less congenial, less gentle, less behaviorally appropriate than Ashley fare in inclusive situations? Would symbolic inclusion occur in a school where inclusion—however confusing in its meanings—was not a specified goal? Would excluding interactions occur in a school where meanings of inclusion were more explicitly defined? What are the interactions and meanings in other classrooms, beyond special education? Would acts of symbolic inclusion and symbolic exclusion be found in exploring other differences—racial, cultural, linguistic, gender-related? In such cases, would norms and truths of power override intent?

Genealogy and symbolic interaction are effective tools for exploring possible contradictions and contentions within the “truth[s] of power” (Foucault, 1980, p. 93), and the “endlessly repeated play of dominations” (Foucault, 1971/1984, p. 85) within the context of current education policies, prejudices, practices, and systemic reform efforts. Exploration and exposure of such meanings can lead to transformation (Blumer, 1969; Foucault, 1988a; Mead, 1962/1934), especially when transformation is a well-defined
and truly intentional goal. Within our schools, the constructs of *symbolic inclusion* and *symbolic exclusion* lend themselves to future studies that may expose deep-rooted stereotypes and oppressive norms, facilitate reflective educational practice, and contribute to the understanding and synchronize the goals of systemic, inclusive education reform.

Unpacking Power Relationships and Shifting the Balance: Implications For Educational Leadership

In the “endless play of dominations” (Foucault, 1984/1971, p. 85) among parents, educators, and paraeducators in this study, one particular imbalance of power to facilitate—or to be unable to prevent—*excluding interactions*: the play of power among Ms. Hanna, Ashley, and the life skills teacher. Ms. Hanna, a former school bus driver for the district, was hired by and reported to the assistant principal. The assistant principal scheduled her day, described her duties, and assigned her as Ashley’s primary service provider. Yet, when Ms. Hanna’s infantilizing interactions were noted by peers and teachers, it was the life skills teacher who assumed responsibility for teaching Ms. Hanna a more appropriate way to express her love for Ashley. When Ms. Hanna didn’t seem to “get it,” (Field Notes, December 17, 2004), the life skills teacher said she didn’t know what to do. It appeared to be a situation in which she would not, or could not, ask the Assistant Principal for help in resolving the problem. While a study of these power relationships is beyond the scope of this study, the dilemma of Ms. Hanna provides an intriguing illustration of power relationships in public schools that may be explored from a symbolic interactionist perspective, where individual interaction meets social order.
It is also intriguing to note the comment of the student in this study who was labeled as gifted and talented. He described Circle of Friends volunteers as “like teaching aides” (Interview, November 3, 2004). In typical peer-mediated interventions, the nondisabled peers are provided by adults with specific training that covers social interaction prompting techniques, teaching a student with disabilities to respond, adapting play activities, and using prompts to encourage untrained peers to interact with a target student (Westling & Fox, 2004). The majority of peer tutoring strategies focus on training nondisabled students to function as instructors of students with disabilities, by means of formal information presentation, modeling and instruction by the adult, usually a teacher (Westling & Fox, 2004). With the exception of the brief, one-time Circle of Friends discussions by the school psychologist and Ashley’s mother described in Chapter III, no regularly-scheduled, systematic training in peer mediation was observed at the research site. The training that was done followed the tradition of adults training children to interact with other children. Under what circumstances could the traditional trainer-trainee power relationship be reversed? Could adult observers trained in symbolic interaction, symbolic inclusion and symbolic exclusion create a description of peer interactions that served as the inclusion curriculum—children teaching adults how children interact, at the level of symbolic interaction? Could children with and without disabilities serve as models, consultants and instructors for professional educators? Could these instructional activities incorporate academic objectives, such as graphing, writing, oral presentation, sequencing, and others?

In Chapter II, the voice of the disability movement was shown to have transformed educational policy, inspiring the civil rights legislation that created special
education. Disability rights activists and other civil rights activists exercised their agency at through individual symbolic interactions such as high visibility in college and community, and within social order in mass protest demonstrations. In this study, a much gentler assertion of student voice and insurrected knowledge was shown to transform existing meanings of disability, mental retardation, and inclusion. At some level, an observable shift in the balance of power occurred—from adults deciding what children should know and be able to, to children demonstrating what children do know and are able to do.

In the present, standards-based educational paradigm, inclusion continues to be debated as a place and a percent. Success continues to be measured by test scores from which students like Ashley are excused. Students like Ashley do not “count” in the measures of success that are being counted by those educational leaders and policymakers whose power affects the future. Educational leaders define what is the “normal” purpose of schooling; and in the process create a tacit definition of what the normal purpose of schooling is not.

In the discourse of current truths of power, disability continues to be narrowly perceived as pathology; and special education continues to develop on a parallel path with “regular” (i.e., normal) education. Yet, in the phenomenological spaces where student voice—verbal and non-verbal—is asserted, acknowledged, and understood, in the places where inclusion is symbolic, children appear to be learning and teaching that students with mental retardation and other developmental disabilities are just like them, only in a different way.
If symbolic inclusion and symbolic interaction can be observed, explored, and allowed to influence the education to which our children are subjected—if the power of student voice and symbolic inclusion can be exercised in corridors where such power is not yet exercised—we may see the emergence of a new generation of student leaders, who play an influential role in transforming “special” education, “regular” education, school, community, and world.
APPENDIX A

OVERVIEW OF RETT SYNDROME

Recent Discovery and Diagnosis

Rett syndrome is a neurodevelopmental disorder first described by Dr. Andreas Rett in 1983. It is caused by a mutation of the MeCP2 gene, which is found on the X chromosome. Rett syndrome affects about 1 in 20,000 females. A few males have recently been diagnosed with Rett syndrome. The MeCP2 chromosome manufactures a methyl cytosine binding protein that controls gene function throughout the body. Current diagnostic techniques detect a structural alteration of the MeCP2 gene in 70-80% of girls diagnosed with Rett syndrome. The cause of Rett syndrome in the remaining 20-30% of girls is unknown; but it is hypothesized to be caused by partial gene deletions on MeCP2, or by genes that have not yet been identified. Less than 1% of Rett syndrome cases are inherited. Most cases occur randomly, in the father’s sperm cell. The mother’s egg cell may also carry the MECP2 mutation. However, since women have two x chromosomes in each cell, and only one x chromosome is “turned on” in each cell, the MECP2 mutated chromosome may not be activated. In boys, a defective X chromosome that carries Rett syndrome is usually lethal, because there is “back-up” copy. It is hypothesized that the faulty or absent synthesis of the methyl cytosine binding protein (MECP2) may cause other genes to be abnormally expressed; but this hypothesis has not yet been confirmed.
Essential Diagnostic Criteria for Rett Syndrome

1. A period of apparently normal development until 6-18 months

2. Normal head circumference at birth, followed by slowing of the rate of head growth (3 months-4 years)

3. Severely impaired expressive language and loss of purposeful hand skills, which combine to make assessment of intelligence and receptive language difficult

4. Repetitive hand movements, including one or more of the following: hand washing, hand wringing, hand clapping, hand mouthing, which may become constant while awake

5. Shakiness of the torso and limbs, particularly when agitated or upset

6. Unsteady, wide-based, or still-legged gait, toe walking, or inability to walk

How Rett Syndrome Affects the Brain

Brain weight and volume are reduced. Neurons (brain cells) are smaller. Many functions controlled by the brain (breathing, mood, language) are compromised.

Stages of Rett Syndrome

Stage One: Early Onset

The infant, between the age of 6 and 18 months, may show less eye contact, and have reduced interest in toys. There may be delays in gross motor skills such as sitting or crawling. Hand-wringing and decreasing head growth may occur, but may not be pronounced enough to draw attention.
Stage Two: Rapid Destructive

This stage usually begins between ages one and four. It may last for weeks, or months. Purposeful hand skills and spoken language are lost. Characteristic hand movements begin to emerge: washing, clapping, tapping, clasping behind head, held at the sides, random touching, grasping and releasing. These movements disappear during sleep. Breathing irregularities—apnea and hyperventilation—may occur. Some girls display loss of social interaction and communication. General irritability and sleep difficulties may be observed. Gait patterns are unsteady and reduced head growth is highly visible.

Stage Three: Plateau or Pseudo-Stationery

This stage begins between the ages of two and ten, and can last for years. Apraxia (inability to get one’s body to do what one wants it to do) and seizures are prevalent. Behavior may show less irritability and crying. Alertness, attention span, and communication skills may improve. This stage may last throughout the lives of individuals with Rett syndrome. (However, most girls diagnosed with Rett syndrome since its discovery are in their early twenties. Studies of the life span are limited. Causes of death from Rett syndrome are usually related to seizures or swallowing difficulties.)

Stage Four: Late Motor Deterioration

This stage is characterized by reduced mobility. Muscle weakness, stiffness, abnormal posturing of the trunk, and scoliosis (spine curvature) are prominent features. Girls who were previously able to walk may stop walking. Generally there is no decline in cognition, communication or hand skills. Repetitive hand movements may decrease, and eye gaze may improve. (http://www.rettsindrome.org)
APPENDIX B

OPEN-ENDED INTERVIEW GUIDE

FOR FOURTH AND FIFTH GRADE CHILDREN

1. What is a “friend?”

2. Tell me about Circle of Friends. (What is it for?)

3. On your first day at Circle of Friends, what did you expect? Any concerns?

4. Why did you/do you participate in Circle of Friends?

5. What do you like/dislike about Circle of Friends?

6. Do you know Ashley? (How) do you understand her without words?

7. One thing you could tell others about Ashley?

8. Your wish for Ashley?

9. Your life in middle school?

10. Ashley’s life in middle school?

11. What did you teach Ashley?

12. What did Ashley teach you?

13. Has knowing Ashley changed you? How?

14. If you were going to introduce Ashley over at the middle school, where no one knows her, what would you say?
Ironically enough, a day or two after a seizure she is actually better, more alert and happier than the time leading up to it. The cycle with Ashley, and there certainly is a cycle, is this:

1. One to four seizures
2. Parents give medication depending on length, duration, etc.
3. Ashley sleeps for a long time
4. Ashley is very drowsy for a day or two, not wanting to eat or drink, and is very quiet
5. Ashley gradually comes out of the effects of the seizures and the medication. She quite often begins to be very “vocal” as we call it but agitated and hyper is more like it. This can last from one to three days. During this time she can be attentive and alert. She does not sleep much.
6. She gradually gets back to “herself” and she is generally alert and receptive. Take advantage of this time; it’s a great time to work with her! This period may last a week or more but then gradually she starts slipping into the next stage.
7. The period before a seizure, in which she becomes more and more lethargic,
sometimes acting like she feels awful (which she might because of headaches, absence seizures or perhaps even an aura before a seizure). She will sometimes fall into deep sleep. This period can last anywhere from a week to several weeks. I hate to dwell on the seizures but they are such a big part of her life as well as ours that we must discuss them.
APPENDIX D

COMPLETE TEXT OF AN ESSAY ENTERED IN A
NATIONAL PARENT TEACHER ORGANIZATION COMPETITION
WRITTEN BY A FIFTH-GRADE, NONDISABLED PEER

My Kind of Hero

You think of a hero as a strong man or woman such as firefighters, police, and soldiers. All of who are big, strong, and brave. Well some heroes like mine are small and not very strong. If you think about it big, strong and brave heroes ride on big trucks with screaming sirens. They save people from burning buildings. A small frail hero like mine might only sit in a chair smiling and talking. If you had a small frail hero and they smiled at you, would you be happy? Well, that is what my hero does for me.

My hero’s name is Ashley and she has Rett Syndrome. The first year Ashley was in my class, her mom came and explained that Ashley had Rett Syndrome and it is a genetic developmental disorder which affects her motor ability and talking and it would get worse as Ashley got older. This syndrome is only found in girls.

If you looked at Ashley and me side by side you might be surprised that Ashley is the real hero. I am big and bulky for my age while Ashley is small and fragile but strong in her heart. I play baseball, catching 60-mph balls and hitting homeruns over the fence. She has to struggle just to get up out of her wheel chair which makes my accomplishments seem much smaller.
When Ashley smiles at me, it makes me feel good. I smile back. She smiles at someone else and makes them feel good and then the whole class feels good. She is not a firefighter, policeman, or soldier, but she is brave, strong, and determined in her own way.

Ashley is my hero because she can do outstanding things like being able to go from a wheel chair to walking and from having someone feed her to trying to do it herself. All of these are simple for us to do but are very hard for her to learn how to do. These are amazing acts for a true hero. I always thought my hero would be a major league baseball player, but I find my true hero is Ashley.
## APPENDIX E

**COMMUNICATION SIGNAL INVENTORY**

CONSTRUCTED PRIMARILY FROM INFORMATION PROVIDED BY ASHLEY’S MOTHER AND HER PEERS

<table>
<thead>
<tr>
<th>Signal: What Ashley does</th>
<th>What it means: What Ashley’s communication partner thinks the signal means</th>
<th>What do you do/say?: How partners should or could consistently react</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[Information provided by]</td>
<td>[For all signals, frequently describe the signal immediately after it is performed, and comment on its perceived meaning. Interact with appropriate response to the signal. “You are pulling on your hair. That tells me you are sleepy. You can lie down now.”]</td>
</tr>
<tr>
<td>Vocalizes</td>
<td>“I’m here!” (loud, with smile) [Mom, peers, participant observation]</td>
<td>*Greet Ashley; acknowledge her presence.</td>
</tr>
<tr>
<td></td>
<td>“I’m participating!” (Ashley’s volume and pitch matches volume and pitch of another speaker or group of speakers) [Peers, participant observation]</td>
<td>*Adult partners need to find and assess alternative, consistent reactions to replace stuffing food in Ashley’s mouth, covering her mouth with their hands, or removing her from class.</td>
</tr>
<tr>
<td>Behavior</td>
<td>Signal</td>
<td>Response</td>
</tr>
<tr>
<td>----------</td>
<td>--------</td>
<td>----------</td>
</tr>
<tr>
<td>Frowns and whines; cries with or without tears</td>
<td>“I hurt” [Mom, peers, participant observation]</td>
<td>Peers should alert teacher or paraeducator.</td>
</tr>
<tr>
<td></td>
<td>“I have to go to the bathroom” [Paraeducator]</td>
<td></td>
</tr>
<tr>
<td>Pulls on her hair</td>
<td>“I’m sleepy” [Peers]</td>
<td>*Adults should tell Ashley if/when she will be able to rest.</td>
</tr>
<tr>
<td>Walks toward a person or object and stands in front of it.</td>
<td>“I am interested in this person or object.” [Mom, peers]</td>
<td>*Allow, observe, and assess walking communication. Incorporate walking communication into instruction and social interaction.</td>
</tr>
<tr>
<td></td>
<td>“I want to interact with this person or object.”</td>
<td></td>
</tr>
<tr>
<td>Makes eye contact 3-5 seconds [Eye contact timed by researcher by counting: “One-thousand-one, one-thousand-two, . . .”]</td>
<td>“I am making purposeful eye contact with this person or object.” [Participant observation, Mom, peers]</td>
<td>*Interact with Ashley and/or the object of intent.</td>
</tr>
<tr>
<td>Behavior</td>
<td>Comment</td>
<td>Strategy</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Grasps and pulls an object toward herself, or reaches toward an object but cannot manage to grasp it.</td>
<td>&quot;I want to interact with this object.&quot; [Life skills teacher, Mom, peers, participant observation]</td>
<td>*Provide opportunities to interact with the object.</td>
</tr>
<tr>
<td>Grasps a person or pulls a person toward herself.</td>
<td>&quot;I want to interact with this person.&quot; [Mom, peers, occupational therapist, life skills teacher, participant observation]</td>
<td>*Provide opportunities to interact with this person.</td>
</tr>
<tr>
<td>When asked to choose, points to a picture or object with her nose (not touching object, but pointing her nose toward object and slightly moving her face toward it).</td>
<td>&quot;I can’t make my hands work, but I can choose by pointing with my nose.&quot; [Occupational therapist]</td>
<td>*On days when Ashley’s purposeful hand movement is the most limited, ask her to point with her nose (i.e., do not give up on communication on these days).</td>
</tr>
<tr>
<td>Pushes a person, food, drink, or object away from herself. Turns her head away from offered food or drink.</td>
<td>&quot;I don’t want to interact with this person or object.&quot; [Participant observation]</td>
<td>*Recognize protest behavior and do not force unwanted interaction with a person, food, drink, or object.</td>
</tr>
<tr>
<td>Smiles</td>
<td>&quot;I like this person or activity.&quot; [Mom, peers, life skills teacher, paraeducators, participant observation, occupational therapist, physical therapist]</td>
<td>*Recognize preferred persons and activities. Smile back.</td>
</tr>
</tbody>
</table>
| Jokes (spills water, laughs at a person, interaction, activity or conversation) | “I understand this person or interaction and I think it's funny”
“Gotcha!”
[Mom, peers, participant observation] | *Recognize the complex cognition and receptive communication skills involved in humor, and provide opportunities for Ashley to use these skills.

*Smile back. Acknowledge the joke. Greet and or interact with Ashley. |
REFERENCES


*Hearing on Education for All Handicapped Children Act of 1975, 94th Cong., 1st sess., p. 4, 1975*


Schools (pp. 43-76). Upper Saddle River, NJ: Pearson Merrill Prentice Hall.

http://www.bancroft.berkeley.edu/collections/drilm/introduction.html


