

Slowly and deliberately she slid her right hand forward, hesitated for a moment and then shuffled her right knee behind it. As she sensed her body out of balance, with her right side pushed ahead of her left, she quickly picked up her other hand and moved it forward, the left knee following instinctively. After an unsteady pause on all fours, she repeated the maneuver: right hand forward, left knee, left hand, right knee. With each successive round, her movements became more fluid, though still somewhat tentative. Arcing slightly to the left, she crawled across the living room floor, across the silly cow blanket, right to where I was sitting.

As she moved, my heart quickened. By the time she arrived in my arms, a warm elation was washing over me.

"You crawled," I sang out, "you crawled right to me!"

She could sense my happiness, and smiled and clapped in return. I quickly turned her around and scurried to the other side of the room, encouraging her to repeat her performance in the other direction, which she did at once. I hooted and hollered with joy. I had never seen a child discover mobility.

When Maureen came home, at about midnight, Margaret was already in bed asleep. Before she could put down her bag, I was breathlessly recounting Margaret's triumph. We hugged and laughed and cried and cried.

From: Aidan's Way (2003)

6.

The Human Realm

The three pennies clattered down on the table before me: heads, heads, heads; nine, a pure yang line. The next toss yielded tails, tails, and heads, which added up to seven, another yang line, though not pure this time; then, another seven. The fourth toss was an eight, followed by two sixes, both pure yin lines. The image thus created was "Peace," or "Tranquillity," the eleventh hexagram of the *Book of Changes*.

The question was: how would Aidan fare in his move to pre-kindergarten at the local elementary school? He was just turning three years old, eight months past the terrible *status* and two months before the first of the chronic pneumonias that would lead to the g-j tube. And his fortune was decidedly mixed.

The sense conveyed by "Tranquillity" was one of balance and harmony. The great primal forces—yin and yang—were equally poised in the hexagram: three solid yang lines on the bottom and three broken yin lines on top. At a moment of such complementarity of light and dark, strength and submission, good things were bound to happen;

hence, the oracle stated: *the small departs / the great approaches*. Good fortune was the general prediction. I had images of a happy group of children surrounding Aidan with friendship and fun; he would be the yin to their yang. But when I looked more carefully at the commentaries associated with the pure yang and yin lines, something more troubling appeared. While the first two—the first yang and the fifth yin—reinforced the overall positive message, the last, the sixth yin, issued a warning. Rather vaguely, the text read:

The wall falls back into the moat.

Use no army now.

Make your commands known within your own town.

Perseverance brings humiliation.

The harmony of the present moment was bound to slip away as time unfolded and change occurred. The solid wall of good fortune that now surrounded us would decay and tumble into a moat of stress and strain. The martial metaphors suggested avoiding bold action and sweeping expectations; they implied that we should keep our own counsel and not try to fight when things went wrong. I knew that Maureen was not likely to follow this advice. When things went badly for Aidan, when people were not doing for him what she thought they should, she would fight back resolutely. I would just have to follow along and watch to see if such perseverance did, indeed, bring us humiliation. So, while there was much good to be found in these passages

from the *Book of Changes*, it was with a certain foreboding that I accompanied Aidan and Maureen to his first day of preschool.

The classroom was a good size, filled with furniture and toys. Two long, low shelves—one filled with books, the other with blocks—partially divided the space; a wide gap between them allowed for movement from one end of the room to the other. Half of the floor was covered with dark gray institutional carpeting, the other half with pale yellow linoleum. All of the chairs and tables were low to the ground, perfect for a three- or four-year-old, a long way down for an adult. The walls were adorned with instructive artwork and pictures: a train, with each car noting the birthday of a child in the class; an oversized calendar, to help the preschoolers keep track of time and weather and holidays. The doorways were rather narrow and we were not sure if Aidan's wheelchair would fit. Indeed, our worries ran much deeper, to how well Aidan would fit into the commotion of public school.

We recognized some of the parents, dropping off their little ones on the first day, and some of the kids, who had crossed paths with Aidan at one public event or another. There were about fifteen children there. Two others had "issues"—Attention Deficit Disorder and the like—and one child's disability was similar to Aidan's: he could not see, talk, or walk, and was significantly mentally retarded. The rest of the class, the majority, was made up of typical children, bouncy and bright three- and four-year-olds. This

pre-kindergarten, named "Side-by-Side," was specifically designed to integrate kids with disabilities, whether mild or severe, with their average peers. The teacher was certified in special education. She knew how to create an environment that included all the children together. Aidan would be part of the class. He had his own place marker on the carpet for circle time, when they sang and shared stories and news. It seemed a supportive and harmonious setting.

Aidan had been in social services programs before. By law, all children with diagnosed disabilities are entitled to therapies and care that will maximize their developmental potential. From birth to age three, these sorts of benefits are usually provided through Early Intervention agencies. This had been the channel that brought Linda, the African-American physical therapist, to Aidan's aid. Other specialists had also been assigned to our case: an occupational therapist, who concentrated on Aidan's fine motor development, especially his fingers and hands; a vision therapist, with an extraordinary bag of visual tricks; developmental educators, who engaged him cognitively and socially. Many of these encounters happened in the security of our home. When Aidan was about a year old, we enrolled him in a day program in a nearby town. Instead of many different therapists working individually in many separate houses, all of the various services were centralized in a single location. Children congregated together, adding a social dimension to their treatments; therapists moved efficiently from child to child; and we met parents in similar circumstances. It was all very flexible and cooperative.

In Massachusetts, when a disabled child turns three, responsibility for therapy and care shifts to the local school district, a completely different world. However welcoming the teacher was that first day, she was embedded in a more structured bureaucracy. Unlike Early Intervention, which was created especially for children with developmental delays, the elementary school served the interests of the entire community, the most gifted students along with the most severely disabled, the average and the extraordinary. The Side by Side pre-kindergarten was somewhat sheltered from the raucous competition for resources and attention that pervaded all public education: it paid for itself through tuition charged to the typical children who attended. But we had already felt the sharp edge of financial constraint.

At our first meeting with the school administration to create an Individualized Educational Plan (IEP), the official document that defined what kinds of therapies Aidan would receive, the superintendent, who doubled as director of Special Education, revealed his budgetary concerns. When the physical therapist suggested that she work with him "two or three" hours a week, the superintendent was quick in response:

"Good, we'll do two hours a week, then."

He straightaway went for the minimum. No one tried to counter him. Maureen and I did not know what was possible or usual, so we too kept quiet. We had grown to trust the Early Intervention administrators, who seemed driven primarily by what would be best for Aidan. The cash-strapped

public education system would be more of a struggle, however. Aidan would be just one more line item vying for scarce expenditures. We would have to negotiate and wrangle for his best interests.

Despite the difficulty, there were also new and comforting surprises in Side by Side. The children in the class took to Aidan immediately. At first, there was an explosion of questions:

“Why can’t he walk?”

“How come he can’t see?”

“Why doesn’t he talk?”

However abrupt, this grilling did not grate on us. With their questions, the kids were not trying to place Aidan in a social category, to classify, differentiate, and interpret; they just wanted to know why he could not walk or see or talk. When we answered with something like, “He’s just made that way, some people can walk and others can’t,” they quietly accepted this new information and went about their play. They might ask about other facets of Aidan’s life, prefaced by “why”—something we asked ourselves all the time—but straightforward answers, without too much medical detail, sated their curiosity. After a couple of weeks of regular contact, they no longer questioned Aidan’s disabilities. He became a given element of their social scene, a classmate, a friend, someone to invite to birthday parties or to share secrets.

School thus provided Aidan with a new social life. It was there that he was surrounded by his peers and given a place

in line. At home we could love him and care for him, but we could not, by ourselves, construct a full and rich public identity for him. We could not make him all that he could be without a broader community. And he seemed to sense this, for it was at school where he was most attentive, brightening his eyes at the clamor of his classmates. The other children were quite happy to be around him. Their abilities were magnified in the mirror of his limitations, so they were pleased to congregate around him. They greeted him in the morning, sometimes bringing over their favorite stuffed animal for him to feel; they sat with him at story time or helped him swirl his hands in finger paint. They made for him a world of sensations and relationships.

It was at school, too, that Aidan had the greatest effect on people around him. In his first year, one of his classmates had a pronounced speech impediment. Ricky’s words were often unintelligible, drawing quizzical looks, and sometimes giggles, from his peers. As a result he shied away from speaking, a reaction that could worsen his problem. The teachers and therapists did a good job of engaging him and supporting his efforts to shape his mouth and tongue to produce recognizable English. But he was very much aware of his idiosyncrasy and uncomfortable with it. In Aidan, however, he had a friend, one who did not strain to understand his words or laugh when they came out garbled. Aidan did not judge or correct. He just sat silently, varying little in his countenance whatever Ricky might say. On more than one occasion when I was in the classroom, I noticed Ricky close to Aidan, happily

chatting away, gaining the practice he needed to clarify his speech, sustained by the presence of an uncritical buddy. Aidan was yin to his yang, and was able to help.

Chuang Tzu tells a story of a man who had his foot cut off, most likely as punishment for some crime. This in itself is an eye-catching image in Chinese literature: an incomplete man, a deformed body. For Confucius, the great ancient Chinese upholder of filial duty and social hierarchy and proper ritual, physical wholeness was of the utmost importance. From a Confucian perspective, it would be terribly offensive to one's ancestors to die with a deficient or desecrated body. Chuang Tzu thus takes aim squarely at Confucian rectitude when he turns the tables in this short fable, and puts Confucius himself in the position of praising the one-footed misfit.

It seems that one of Confucius's disciples comes to him one day to report that the mangled man has taken up teaching and is attracting as many adherents as the venerable philosopher himself. To this, Confucius surprisingly—this is Chuang Tzu's mischief at work, after all—responds that, clearly, this man is a “master, a sage.” The disciple is puzzled; how can it be that this obviously imperfect man commands the respect of the upright and wise, and physically whole, Confucius?

The key to the man's insight, Confucius says, is his transcendence of worldly concerns. The mutilated one does not let life or death affect his outlook and takes unforeseen surprises in stride. His teaching is literally wordless: he does

not say anything to the multitude surrounding him but simply radiates a certain wisdom. Seeing the integrity of each thing unto itself—even those things that appear imperfect and damaged—he does not have to make distinctions and judgments but can perceive the totality of the Way, where all things move as one and the same.

Seen in terms of sameness, the ten thousand things are all one. If you understand this, you forget how eye and ear could love this and hate that. Then the mind wanders the accord of Integrity. And if you see the identity of things, you see there can be no loss. So it is that he saw nothing more in a lost foot than a clump of dirt tossed aside.

With the serenity that comes from knowing there can be no loss, the hobbled man becomes a sought-after teacher. People flock around him to learn how they, too, can detach themselves from their desires and escape from their frustrations. It is his tranquillity that draws their attention. We are hopelessly battered by the daily tumult of our responsibilities, pushed and pulled to such an extent that we lose track of who we are. So, we look to the calm and collected man, seemingly disabled, who is at peace with his world and himself. And we look to him because:

A man... cannot see himself in running water, but in still water. For only what is itself still can instill stillness into others.

7. The Form of this Body

His second year in Side-by-Side moved along and melted into summer, only to resume again for a third year the next fall, and we fell into a steady routine. Aidan and I were usually the first ones into the pre-kindergarten room in the morning. I liked to get there a bit early, earlier than the teacher wanted, to avoid the rush at the door and in the hallway. We parked by the rear entrance next to where the van pulled in and off-loaded the kids in wheelchairs, the “handicaps” as the older typical kids called them, riding in the “handicap van.” We never used the van. When we had first seen it, there was no one other than the driver to look after the children. What if Aidan had an apnea seizure and the driver was unaware of it? To avoid this question, I drove him instead.

We were consistent in our habits. As we pulled up to the door, Aidan, now five years old, was safely strapped in his extra-large car seat, a blue cloth-covered cushion around his neck to hold his head upright. I hopped out of the station wagon and quickly moved around to the rear hatch, pulling

out his collapsible wheelchair. It took a minute or two to open up the frame and slide the seat into place, but I was well-versed in the mechanics of the chair—the springs and knobs and levers—and was never too long in getting it ready. Pivoting back to where Aidan sat, I unsnapped his seatbelt and slid my right hand behind him and curled my left under his knees, gently lifting him up and out of the car and into the wheelchair.

The building was awkwardly designed. It had originally been three separate buildings, near one another but disconnected. When the town rejected the idea, and expense, of a new building in the late 1970s, a second-best renovation plan knit the three structures together by way of a long corridor and a new gymnasium. Our parking spot was behind the western-most building and Aidan's classroom was in the middle section of the E-shaped edifice. We wheeled our way down the long hallway, lined with large uninsulated windows and always chilly in the cold months. Squeezing through a door and a narrow stairwell, past the library, we turned right, through large double-doors and down the locker-lined corridor of the middle building. The walls were festooned with artwork from the preschool and kindergarten classes: happy blue cows dancing with ragged red lions on yellow lawns and purple mountains. Aidan was confined to the first floor of this part of the school, as there was no elevator to allow him access upstairs.

I stopped by his locker and, when he was bundled up against the weather, slipped off his coat and hat and stowed

them behind the narrow metal door marked "Aidan," written in both standard letters and in Braille. His backpack, containing a change of clothes, diapers, and emergency seizure medicine, also went into the locker. The medicine was always close by him, in case danger erupted.

His teacher was usually there when we arrived, though some days we entered the room alone. I sat quietly with him, not wanting to disturb the teacher's morning rituals of preparation, and waited for his aide to arrive. For a child as medically involved as Aidan, the school district was required to provide a teacher's aide, a "one-on-one" in the local parlance, to work exclusively with him. The classroom teacher still ruled the roost, overseeing the general curriculum and daily flow of activities, but the aide had the most sustained and intimate contact with Aidan. We had been careful to request that Aidan's aide have a medical background, a person who would be able to assess and respond to his multiform seizures, someone who could tell the difference between everyday neurological flare-ups and strange new brain dysfunctions. Karen got the assignment and she entered the classroom at precisely the same time every morning.

Karen was a meticulous and careful woman. Trained as a nurse, she had found her way into the elementary school for a less time-consuming job. For all of the emotions that Aidan could inspire, she never let his seizures or crying or fussing shatter her professional calm. Her countenance was always even and unruffled. In the four years she worked with him, I never heard her raise her voice.

When Karen arrived in the morning, we first exchanged small talk, and then I would relay any important bit of information: how Aidan slept the night before; what his seizures were like since he awoke; whether he had a doctor's appointment or other reason to leave school early that day. She always listened to me intently, asking a follow-up question here or there. When I was done but before I left, she turned to the daily journal that she and Maureen kept, writing back and forth to each other on the details of Aidan's days and nights. Karen knew that Maureen followed everything more closely than I; she knew that the mother-nurse at home kept a much more intense focus on her baby than the father-teacher rushing off to work. Only after Karen had reviewed Maureen's notes, and questioned me on whatever might be written there, was I free to leave.

Some days, I lingered awhile and watched Aidan's classmates come trickling into the room. This year, his third in Side-by-Side, Katherine was his alter ego. The bossiest child in the class, Katherine lived up to her regal name by self-assuredly informing all and sundry of what needed to be done. She oversaw morning dress-up, when the children pulled various costumes out of a trunk and modeled for one another; she reminded everyone of their daily duties: who was to lead the line down the hallway, who was to help straighten up the toys, who was to report on the weather. Katherine went about her self-appointed duties with a certain world-weariness, as if she had seen it all before but just had to go through it one more time to make sure the others got it right.

With a heavy sigh, she entered the room, clutching her favorite stuffed animal under her elbow. She proceeded straight to Aidan, greeting him in a loud and clear voice, then taking his hand and running it over the soft fur of her toy tiger, knowing that tactile stimulation was one of the best ways of relating to him. She helped push his wheelchair over to the costume trunk and decide whether he would wear the purple hat or the grass skirt. Or she brought over the toy pizza and played at serving him his favorite flavor. As the teacher called the children into a circle for the day's first organized activity, Katherine would intermittently interject her thoughts on Aidan's preferences:

"Aidan likes to feel the sponge at the water table."

"Aidan should sit with us at lunch."

She knew him well and had knit him snugly into her classroom routine.

At recess, Katherine was right in the thick of the other students as they brought sticks and rocks and grass for Aidan to feel. Some days, after school, I would find all sorts of tiny debris fallen down the sides of his seat cushion, evidence of the children's activity. In the classroom, if Aidan had a seizure and his head fell forward, Katherine, when seated next to him, would calmly and gently push his head upright and continue on with the task at hand, unfazed by the neurological interruption. If he burst out in a laughing seizure, she would roll her eyes knowingly. If he drooled onto the bandanna draped around his neck, she would carefully wipe

his chin, without disgust or criticism. This was his normal, and it was her normal, too.

Katherine, and most other classmates, were accustomed to his physical configuration. His body, its limitations and abnormalities, were familiar and unthreatening to her. She did not think twice about the centrality of Aidan to her school life. It was a completely accepting sort of thoughtlessness: her attachment to him did not need explanation. He was, without thought or question, without hesitation or doubt, her friend.

A sage inquires into realms beyond time and space, but never talks about them. A sage talks about realms within time and space but never explains. In the Spring and Autumn Annals, where it tells about the ancient emperors, it says the sage explains but never divides. Hence, in difference there's no difference, and in division there is no division. You may ask how this can be. The sage embraces it all. Everyone else divides things, and uses one to reveal the other. Therefore, I say: "Those who divide things cannot see."

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Chuang Tzu would like the pre-kindergarten. He would see the sagely wisdom of Katherine simply going about her business, in no need of explanation or analytic distinctions. It is only as we age that we learn how to create difference, how

to separate out the normal from the abnormal, the pretty from the ugly, the smart from the dumb. We weave intricate webs of personal understanding and public policy from the threads of difference and division. But, however useful this kind of categorization might be for science and business and warfare, we miss something when we divide, we miss the whole, we miss the Way.

For Aidan, school simultaneously divides and combines. He is defined as a "severe needs special education" child, a designation that brings certain prerogatives. He is entitled to inclusion in the Side-by-Side program; he is entitled to a one-on-one aide; he is entitled to transportation to school; he is entitled to physical and occupational and vision therapies. It is only the state's prior division of disabled from abled that secures these services for him. In his case, the differences are made strikingly obvious by his wheelchair and his seizures and his speechlessness. But once in the classroom and surrounded by the other children, there is no difference in his difference. Katherine and the other children embrace it all; they do not divide Aidan off into a category of his own and then use that distinction to reveal themselves. They can see Aidan's place in the class, his social value, because they do not divide.

Aidan has a similar effect on the adults that are with him on a daily basis. Karen, through her close daily contact with him, is able to read his moods and desires. She knows his different cries and moans, what he sounds like when he needs a nap or when he is uncomfortable in his wheelchair. And, being a mother herself, as well as a nurse, she knows how to

respond when a child, any child, calls out. While she is, no doubt, still steeped in the pervasive categorizing that fuels modern adult life, for brief moments at least, her time with Aidan allows her to see the limits of social distinctions. Aidan brings her closer to the Way, for, as Chuang Tzu says elsewhere: *Where there is Way, boundaries haven't yet begun being.*

The classroom teacher reports much the same effect:

Aidan contributes very much to the fabric of the class. His quiet ways have enabled his classmates to relate to him and accept him for whom he is. When his peers interact with him, they do so because they are doing something with and for him, not his aide. He has assisted many children in learning to appreciate each other's differences and to understand disabilities.

Thank you for letting me share Aidan's year.

~~Looking back on it, the crying started in July, in the summer between his third and fourth year in Side-by-Side, when he was three months short of six years old. It was a different sort of cry, not a cry of fatigue or mild discomfort, but a cry of deep and real pain, a cry with tears and writhing. It did not dominate our attention at that time because it was brief. He cried for ten or fifteen minutes, shaking us and making us mentally review what might be wrong—stomach reflux, post-seizure headache, ear infection—but then it subsided on its own accord. It did not return for a couple of weeks.~~