

What's Behind the Curtain? A Family's Search for an Inclusive Oz  
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**Abstract:** Families are moving at ever increasing numbers. Relocating a family is challenging under any circumstance, but transitioning a child with a disability between schools, especially to new states or countries can be particularly difficult. When families seek full inclusion, the situation becomes more complex. This paper describes one American family's journey through the moving process and how that process brought to the surface ways in which disability is socially and culturally constructed. Despite federal legislation in some countries regarding special education and the involvement of families, practices differ geographically, sometimes significantly, when determining eligibility, communicating with parents, and discussing how support services will be provided. The author - a parent, educational researcher, and instructor of pre-service teachers - asks questions throughout the family's relocation and examines people's "storylines" or habits of conversation (Gee, 1999) to get at underlying assumptions. Related research and implications for improving educational practices are discussed.

**Keywords:** disability, narrative, special education

Seeking an Inclusive Land of Oz

While sitting at my kitchen table in rural Iowa, a Midwestern American state, I phoned one of the schools on my list. "What's your child's IQ<sup>1</sup>?" asked the special education teacher on the other end of the phone. She continued, "If he's below 70, we have a great Life Skills program<sup>2</sup>..." I was researching schools in a different state within commuter distance of where I was soon to begin my new job, trying to find an inclusive community where my two sons would be welcomed. When I first asked the Middle School teacher about their special education services for my eleven-year old, she sought his diagnosis, but I did not answer her question, instead choosing to explain "Iowa is a non-categorical state," meaning the label from the American Psychological Association's diagnostic manual was not included in my son's Individual Education Plan document. "Okay, but what is his disabling condition?" she asked, to which I responded, "He has difficulty with expressive communication. It's hard to understand his speech and because of his fine motor delays, he has trouble writing so we're working on typing..." She did not appear to be interested in hearing the details of my son's educational support needs. Instead, she persisted in asking for a label, something which I felt she would use to categorize him and strip away his individual human qualities. I was trying to figure out from the phone conversation what my son's educational experience might be in her school. I was seeking something similar to what we had in a rural farming community school where there were no Life Skills programs because there were too few children with disabilities to justify any "clustering" of those with similar diagnostic labels, or because the small town neighborhood school did not fall victim to external, top-down programming structures that some other districts, even those not more than an hour's drive away, seemed to embrace.

In the end, I gave the teacher an answer close to what she wanted: "Trisomy 21," I told her, choosing to emphasize the medical diagnosis in lieu of the more commonly used term "Down syndrome" in a weak effort to disrupt the typical discourse around students with this

label who are often referred to as “Down’s kids” implying they are the children of Langdon Down, the British physician who first described what he called “Mongolian idiocy.” I ignored the teacher’s subsequent reiteration of the question about IQ score, not because I did not know the answer, but because I wanted to share what I thought was relevant: “He’s been fully included throughout his schooling. I have current curriculum-based assessment results, work samples illustrating how teachers adapted lessons for him this year in 5<sup>th</sup> grade, and results from standardized testing. He loves to read and enjoys school, especially his friends.” Rather than engaging in this conversation with me, she said, “When you come, we’ll begin by testing him and determining his IQ.” I thanked her for her time, hung up the phone, and crossed out the school’s name on my list. I felt as though she, and many others with whom I talked on the phone, could not share the vision my family had of a successfully inclusive schooling experience for our son. I wondered if this teacher thought I was unrealistic, that I was like the disillusioned girl named Dorothy from the American children’s novel *The Wonderful Wizard of Oz* (Baum, 1900) who was swept away from the comforts of her rural Kansas life in a tornado, and who became lost in a land of poppies and faced many barriers to find the Wizard who would return her home. Although I was not disillusioned, it seemed as though I was lost in a list of schools in an unfamiliar state seeking some kind of Inclusive Land of Oz, but instead of finding the humane Tin Man, the courageous Lion, or the insightful Scarecrow, I was running into Wicked Witches who stood in my way.

Through a combination of auto-ethnography (Ellis & Bochner, 2003) and narrative (Connelly & Clandinin, 2006), I tell the story of our family’s move across the United States using the classic tale of the Wizard of Oz as metaphor. This blurring of lines between researcher and “subject” is intentional in auto-ethnographic work, offering a resistance to jargon and instead presents a narrative of daily interactions (Ellis & Bochner, 2003). In the Baum (1900) story, Dorothy was in a foreign land in search of a way back home just as we sought a place we could call “home” in an unfamiliar context. I found the prospect of thinking critically about and reflecting upon our decisions as they related to other research might be valuable to others who work with families on the move or who themselves might be moving. As such, it was useful to use narrative methodology “to adopt a particular view of experience as phenomenon under study” (Connelly & Clandinin, 2006, p. 375) and to analyze my personal experience through a social-cultural lens (Ellis & Bochner, 2003).

Families are moving at ever increasing numbers and many of these families include a child with a disability (Center for Global Development, 2010; McLachlan, 2008). In a British study of families moving internationally, McLachlan (2008) described significant disruptions to families that had been previously unreported. She emphasizes the importance of schools and families working together to mitigate the stress children experience. Relocating a family can be a challenge under any circumstance, and my husband and I were especially concerned about how we could support our children through the transition. We moved from the upper Midwest to the American West, from a rural community to a city. At the time, we had an 11 year old with an Individualized Education Program (IEP) and a 9 year old who qualified for a Gifted and Talented Program; we sought an inclusive community for both of them. By this we meant more than a placement option in the “least restrictive environment,” but rather a philosophical understanding of the naturally occurring diversity within our humanity where interdependence is valued and

impairments or disabilities are not stigmatized. We sought a community where neither child would be segregated but both would be welcomed as equal individual members.

As educators my husband and I knew services differed, sometimes significantly, between states and districts (Carlson, Brauen, Klein, Schroll, Willing, & Westat, 2002; Kluth, Biklen, English-Sand, & Smukler, 2007). We also knew interpretations of the Least Restrictive Environment (LRE) principle of the Individuals with Disabilities Education Act (IDEA) differed by category classification (Beratan, 2006; Downing, 2008; Grove & Fisher, 1999; U.S. Department of Education, 2006; Smith, 2010). We also found a paucity of research about the impact of moving on families that included a child with a disability with only a guide by the National Dissemination Center for Children with Disabilities and a few studies that I discuss in the following section. General information about transitioning students with disabilities tend to focus on young children as they enter public schooling and young adults' transition from the public schools to post-secondary school or employment. So, we anticipated a lengthy road ahead of us as we set out to find an inclusive school and community.

Two months following the relocation, our efforts to find an inclusive school were largely successful, not the land of inclusive Oz, but a fairly good "fit," that captured what Hansen describes as positive spaces of respect, acceptance, and support (2005, p. 34). This paper describes some of what we thought were preventative actions we took that seem to have made a significant positive impact for both of our children, and how the process of moving highlighted the social and cultural construction of disability. In a way similar to what Dorothy found when she looked behind the Wizard's curtain, we found some troubling realities based in human fear and prejudice. Like Dorothy who "dared to question the Great and Powerful Oz," we took extra time to more closely examine several schools' practices and underlying philosophies, to look "behind the curtain" of how schools purport inclusive mission statements, but who might otherwise practice socially isolating acts under the guise of special education.

I must acknowledge that my education, social class, and White ethnicity afforded me a more powerful opportunity to question school personnel than other families who might not have this social or financial capital at their disposal. In fact, I found the role of privilege in the special education process disturbing and consequently examined this issue in a separate paper (Sauer & Albanesi, 2012). Therefore, I understand the limitations of this narrative because of that privilege and I do not want to suggest that the choices my family had are the same as others and should not be used by the system as a weapon upon families with perhaps fewer choices. Such capital in fact has been argued to work against systemic change in what is for many discriminatory (see Skrtic & McCall, 2011). In any case, regardless of our cultural capital, there were some things we did not do as well as we might have and I share these insights as well.

### Home in Kansas, No Iowa – Clarifying Vision and Understanding Rights

The birth of our first child set in motion a frequent challenge to our inclusive beliefs that we had always espoused, that education and the pursuit of happiness for all is a civil rights issue. Over the years my husband and I engaged in many discussions about our vision and priorities for our children. We became increasingly informed about the importance of legal rights and knew that relocating our family would involve researching legal precedence in the place where we

planned to move. In their guide, *Moving to a New Location*, the National Dissemination Center for Children with Disabilities (NICHCY, 2009) advises parents to begin by familiarizing themselves with federal legislation. Before our son was born I was a practicing special education teacher and therefore familiar with the principles of Public Law 94-142, better known as the Individuals with Disabilities Education Act (IDEA). Since his birth and the confirmation of an extra twenty-first chromosome from a blood test, I (re)entered the world of special education, but this time from the parent perspective.

My husband and I felt the medical model that seemed to permeate most of the early childhood intervention programs conflicted with our inclination to approach our son as a complete person and include him in all aspects of family life. Despite his successes, we repeatedly we found ourselves having to defend our son's inclusive education referring to the process of negotiation as "the fragility of inclusion" (Sauer, 2007). We referred to and exercised our rights to direct involvement in our son's Individualized Education Program (IEP) and although on occasion we involved parent advocates, we never exercised our Due Process Rights (though we felt empowered knowing we could). So, we knew our rights and we knew we wanted an inclusive educational community. In an effort to find the best "fit" and minimize surprises, it seemed important to learn as much about prospective schools options as possible, to help in making the decision of where to move more specifically.

### The Cyclone Hits! Chaos and Questioning

In spite of our professional knowledge and sense of certainty about what we sought, we felt unsettled emotionally. Was the move a selfish ploy to advance my career? What would be the unintended consequences? Despite the frustration we had on occasion with our Iowa lives, would we ever find the same comfort that came with familiarity and local understanding (Kliwer & Biklen, 2007)? After I was offered the new position out of state, my husband and I entered into a discussion about the possible negative consequences of moving for our children. We found little written about this topic regarding families including a child with a disability other than the NICHCY piece and a national study about twelve families who moved in search of a more inclusive school for their children (Kluth, Biklen, English-Sand, & Smukler, 2007). The NICHCY paper begins:

Moving to a new location disrupts your life! For any family this can be a time of chaos. There is the adventure of newness but also a maddening confusion. Everything and everyone is certainly somewhere, but where? You have to find new grocery stores, new roads, new schools and new doctors. You have to unpack and reorganize your home and your daily routine. You have to make new friends, meet new neighbors and establish new systems of support and help. For a family with a child who has special needs, the confusion can be particularly stressful. (NICHCY, 2009)

The NICHCY paper goes on to outline a series of "To Dos" to make the IEP, assessments and medical files current, and to research the particular state's structures, entitlement procedures, and differences in local school practices, but it does little to address the social-emotional aspects to moving for families.

On the other hand, Kluth and her colleagues (2007) conducted in-depth interviews with families who moved and thus, in addition to the logistical and financial challenges, their article described many of the families' feelings of guilt, frustration, and disappointment throughout the relocation process. Although these researchers purposefully excluded families like ours who were moving for professional reasons in their study, we found the issues parents described personally relevant. For instance, they refer to parents' anticipating the inevitable "price to pay" for moving that could have negative implications for siblings as well. When we first told our children about our possible move, our younger son explicitly stated that he did not want to move and he proceeded to cry, a cry that would resurface unexpectedly and repeatedly throughout the move. Families described "finding inclusion was different than finding a place; it was more an idea than a location" (Kluth et al., 2007, p. 52). We agree with this sentiment and feel that inclusion is a belief and moral value about accepting the range of human experiences. Our search for an inclusive community was one where we wanted *both* of our children to feel welcome and benefit from an engaging education. We sought a community where coming from a different place was not stigmatizing – something my husband and I had always felt as adults in our rural Midwestern town since we moved there from another state 13 years prior – and one where our older son's differences would not be devalued and our younger son would not be made to feel embarrassment of his brother's disability such as the experiences reported by other siblings (Meyer, 2005). With both boys showing interest and talents in the arts, we also hoped to find a place where they might have a greater range of artistic instructional opportunities.

Our eldest son was soon to turn 12 years old and he had genuine reciprocal friendships with classmates with whom he had socialized since childhood in school, soccer and the local library's reading and music groups. Would a new community and school be as accepting? Would he make new friends? These of course are questions many parents ask themselves, but we were also familiar with research that showed the additional barriers that existed for students with disabilities in the attitudes and resulting practices of teachers and students without disabilities (Hansen, 2005; Palmer, 2002; Siperstein, Parker, Bardon, & Widaman, 2007). Additionally, our boys were close in age and the older son, the more social of the two, had always been there supporting his younger brother - yes, the one with the so-called disability was often the one leading the way in social contexts. The move, however, would mean they would no longer be in the same school, not because of the disability, but because of their chronological ages. We learned that the area where we were going had adopted the middle school philosophy<sup>3</sup> and since the boys would be entering into grades 6<sup>th</sup> and 5<sup>th</sup> respectively, they would not be attending the same school. Furthermore, the move would mean an overall financial hardship on our family, undoubtedly something that would add to family tensions.

Though we kept all of these concerns in mind, we opted to focus on the positive aspects of the move. First, the children would have greater exposure to culturally diverse people and experiences in a city than they had in the rural community of 200, mostly farming families, where they were born and raised. In Iowa our combined daily commutes to and from work totaled 120 miles and moving meant we could live closer to work and save both time and money. Ready access to a city provided both children with greater opportunities for employment when they came of age and public transportation would be available should either of them not get driver's licenses.

We learned to take stock in what we knew and felt. We were comfortable researching specific legal protections or court cases involving families and schools in the communities where we considered relocating. But we found we needed more time to assess and discuss our family members' feelings and to clarify our priorities. These sometimes awkward conversations seemed to provide us with greater clarity regarding our family's values about justice and equality.

### Follow the Yellow Brick Road

Immediately upon deciding to move, we began researching schools located close to my new place of employment. Ours was not a literal road like the one of yellow bricks that led Dorothy through forests and deadly poppy fields, but a metaphoric one representing similar challenges along a journey. To get a general sense of educational options in the area, we used the internet to explore school districts' homepages, reading their strategic plans, school board minutes, and current newsletters. One district provided the results of a recent survey they had conducted on parents' experiences with their schools' IEP processes. We also read local newspapers where we learned there was an impending redistricting plan. Additionally, both boys explored school websites alongside us, asking questions about the school's lunch options and schedules. Their questions and perspectives expanded our original set of research questions and it brought them into the act in a meaningful way. Our younger son's question, "Is it normal to bring your lunch from home?" led us to further discussions about 'What is normal?' and reaffirmed our family unit as a team, something more important, we insisted, than being accepted by others. This initial research phase provided us with information about the huge variability in the sizes of schools, teacher to pupil ratio, achievement results and the general financial state of education in the region. While sometimes people will also examine real estate to get an idea of "preferred schools" based upon the socio-economic status of the local families, it is more difficult to use numbers to understand the underlying beliefs that drive daily school practices.

Having worked in schools for nearly twenty years, teaching, supervising student teachers, collaborating with teachers, and conducting research, I knew that a school's outward appearance as viewed through their mission or official statements does not always accurately reflect the inner workings, beliefs, or daily decisions of a school. How could we find out what was being done in schools every day? How did the teachers, the other adults in the schools, and the children talk about or engage with diversity issues? We wanted to know what the daily interactions might be like, but we did not have the opportunity to visit the schools, and even if we did, would the people giving us a tour speak freely and wouldn't the teachers and children be "on their best behavior" for the visitors? From my professional background knowledge about discourse analysis, I had become sensitive to the way in which language, whether written, spoken, or expressed non-verbally, serves "to support human affiliation within cultures, social groups, and institutions" (Gee, 2005, p.1). In other words, although this was a lived experience and not a study, we began to reflect upon the words people used to describe their schools, students, and communities to see if they might reveal underlying assumptions and beliefs. For example, I began the piece quoting the teacher who asked for my son's IQ score, a clear indication that she thought this number was the most important information she needed to make decisions about what my son needed in order to learn despite extensive literature questioning the validity of these scores and their supposed predictive qualities concerning intelligence

(Borthwick, 1996; Donnellan, 1999; Gardner, 1983; Gould, 1981; Plucker, 2003). On the other hand, when school websites touted the virtue of the people who worked in the schools and echoed the use of the word “relationships” as symbolizing their communities, they reflected a different, more inclusive discourse.

### Looking “Behind the Curtain”

In the children’s story, after a long and terrible journey the young girl, Dorothy, is finally given an audience with the Wonderful Wizard of Oz. When the Wizard does not agree to fulfill her request to be sent home, Dorothy’s dog pulls aside a large curtain behind which is a little old “common” man, who she discovers had no magical powers at all. In our journey we used the phone and email to contact educational administrators directly asking both general questions (e.g. “Tell me about your school”) and specific questions about their special education services (e.g. “How do you educate your students who might need special education support?”). In our effort to find the inclusive “fit” we sought, we needed to look more closely, to look *behind the curtain*, to listen more deeply and think about the meaning behind the words. We were looking for an inclusive philosophy to be actualized through action; we sought specific examples of inclusive practices that reflected inclusive beliefs. The opening scene provides an example of one conversation where once I provided the teacher with our son’s diagnosis, we quickly learned he would be tracked based on his results of a battery of intelligence tests given to him by a complete stranger immediately upon moving to a new state and home. By contrast, a special education administrator in another district began by asking about our son’s achievements, his skills with various academic and social demands. After conversing at length, I told the administrator about the previous district’s request for an immediate IQ test to which she responded dismissively, “Oh, we don’t do that anymore.” Her response suggested a more closely aligned philosophy to ours.

Administrators can significantly influence a school’s culture, but occasionally they move on and schools return to entrenched practices. Sometimes the support staff, who are less likely to leave their positions, more accurately reflect a school’s culture. Therefore, we frequently engaged administrative assistants in conversations which informed our developing pictures of various schools. For weeks we continued making phone calls and exchanging emails with school personnel in an effort to narrow our search. We also identified parent support groups such as the “Parent to Parent” organizations (P2P) and advocates via the internet and sought their input. One advocate described her experience with a local district this way: “They are pretty good. I don’t get lots of complaints about them.” In hindsight it is interesting to realize we had not engaged one general education teacher in our research; we think one reason was their general inaccessibility, or they need not be further “burdened” by potential parents, or that we, too, had engaged in what Gee (1999) refers to as “storylines” or habits of conversation. Regardless of the reason, the irony did not escape us, that they are the very people whose philosophies about and practices with educating their students with disabilities are exactly the people who can have the greatest direct impact on our children’s education (Interstate New Teacher Assessment and Support Consortium, 2001).

We engaged in two facets of research. The first was practical and meant updating the current IEP and seeking advice and involvement from the originating home school. The second

involved examining the underlying meaning behind what people said. In our relationships with all of the players back at the originating home and while developing relationships with people in the various possible future home sites, we found it valuable to ask probing questions of as many people as we could and carefully consider *how* they engaged us. Also, we sought out specific examples to support claims made about the procedures and practices of school support teams. Although we felt we had gathered a great deal of information from a distance, we knew we would need to make a trip and walk the halls and neighborhoods of the prospective schools in order to get a better sense of each school community.

### The Reconnaissance Trip: A Split in the Road

With a copy of our son's new IEP and a folder of his work samples in hand, we went out West. We had scheduled appointments to visit two school districts which we felt best met our priorities for inclusive school communities and affordable housing, based upon the information we had collected thus far. From afar the two districts were similar, providing housing that was within close proximity to the schools and that offered our family small enough schools and neighborhoods that it would not be such a dramatic change from our rural Iowa community. The school principals and other personnel were all friendly on the phones and willing to meet with us and give us tours. They indicated it was the last week of the school calendar so we should not expect typical school days. I reminded them that both my husband and I had been school teachers and would not be surprised to find disturbed routines.

The obvious differences between the two districts were how they had chosen to structure the schooling for their 6-8<sup>th</sup> graders. In what I will hereafter refer to as District A, they had a Junior High (JH) for grades 7-8, because, as one principal put it, "The students need to be prepared for High School." "We are not a Middle School," she clarified, distinguishing her district from District B. Their newly-built JH was impressive but equally imposing I thought as I entered the large, modern, entranceway. It drew students from several elementary schools, three of which I visited. We visited schools by day and houses by night. In the "off time," we examined the district maps we had received from the realtor trying to match the houses we had visited with their respective schools. District B had chosen the Middle School model where grades 6-8<sup>th</sup> were educated in one building; they drew their students from three small elementary schools. There were houses in both districts we could afford and which offered comparable advantages, so the decision essentially came down to the schools.

In addition to meeting principals, for the greater part of a week we engaged janitorial and office staff, teachers, parents dropping off and picking up their children, and the children themselves. We took note of the location and support service structures for the enrichment and special education programs. We were disappointed to see separate "resource" classrooms for students in both schools and to learn the state used categories to determine eligibility for special education. Both schools touted teaching all children but there were subtle ways in which we began to see markedly different foci between the two districts. Though both districts reported similar achievement data, our conversations with people in District A repeatedly focused on students' standardized test scores, whereas our conversations with people in District B centered on relationships. With a laugh one principal from District A shared how a parent of a kindergartener already had pegged his daughter as a future graduate of the prestigious Yale



University, suggesting a tone of presumed class privilege. Her comment was one of many in which we became concerned about what seemed like an inordinate pressure on students' test performance. Our younger son, whose standardized scores qualified him for the Gifted and Talented Program, had expressed heightened anxiety regarding any tests. We shared this concern with the elementary principal in District A, who then assured us she was familiar with students like our son and she gave us her home phone number offering to let our son talk with her on the phone before the move. We were comforted somewhat by her comments but we wondered how the atmosphere might negatively impact both of our boys.

The principal from District A interacted kindly with the children who lined up in the hall, but it was nothing like the enthusiastic greeting a principal in District B received from the children who hugged him and begged him to listen to their stories they had written about their community. The principal from District B had said, "We welcome *all* kinds of kids here," emphasizing "all" with his tone of voice. Furthermore, we observed a powerful spontaneous interaction between the Special Education Director in District B and a student who used an augmentative alternative communication device which suggested to us that students with significant disabilities were included in the natural hallway discourse of the Middle School. The reconnaissance trip reminded us of the importance of doing our logistical homework and reevaluating the underlying meaning behind what and how support services for students with disabilities are enacted. In hindsight, it's become abundantly clear that we benefitted from our cultural and economic privileges in this process and the inequities weighed on my conscience creating a tension between advocating for my son and the possibility that my efforts inadvertently contributed to the perpetuation of systemic discrimination against families of color or those with less capital (Sauer & Albanesi, 2012).

### Not Quite the Inclusive Land of Oz but a New Home

Upon returning to Iowa, we discussed our decision to move to District B. The children gathered their friends' addresses, emails, and phone numbers during a going-away party put on by their teachers. School ended and we decided before the actual move, we would camp near our new neighborhood, and visit the schools there. The camping trip helped demystify the changes ahead and provided our family with time to reaffirm our interdependency and, with fewer distractions, the reasons behind our decision to move.

Despite all of our best efforts, once we moved, the children still exhibited some anxiety about starting at a new school asking us a series of questions about when their Iowa friends would visit and they sought assurances that we could move back to Iowa if we did not come to like it. "We haven't sold our Iowa house anyway, so we can just move back, right?" queried our younger son. In the end, however, our children seem rooted in a shared value regarding inclusion. When the new elementary school offered him "GATE" (for the Gifted and Talented) services in a pull-out model, our younger son scowled and said he would prefer to stay in the general education classroom. And during a day in honor of Martin Luther King, Jr. when this son witnessed his older brother's social exclusion during an activity, he immediately brought it to our attention noting the irony of the situation.

The new Middle School held a welcome dinner for the students and their families the Friday before school was to start where they had intended to pass out the schedules but with a new principal these were not yet complete. Therefore our eldest son, thought to have significant intellectual disabilities, began his first day in his new school without knowing where to go first. “Don’t worry, none of the 6<sup>th</sup> graders will know where to go,” one teacher assured me. Needless to say I *did* worry but our son insisted he wanted to enter the school on his own. Pointing to the car as he climbed out of the back seat, he said “you stay.” He managed the change and adapted to the more complex schedule where he had seven class periods in different classrooms with different teachers.

One of our most poignant affirmations that we had made a good decision in choosing District B was when our elder son spontaneously said, “I like this school better.” We think one reason for his happiness was the welcoming attitude from one of the general education teachers who told us, “I feel it's a great privilege for me to have (son's name) in my class this year.” Her prior personal experiences with people with disabilities proved to be a comfort for her and she agreed to help identify possible budding peer friendships for our son using the Circle of Friends (Falvey, Forest, Pearpoint, & Rosenberg, 1994). However, I would be remiss if I did not acknowledge that conflicting interpretations of assessments and approaches to decision-making occurred with the new educational team, making it difficult at times for developing trusting relationships. What we found resonated with other researchers who suggest shared understanding and trusting relationships are often localized and temporary in the sense that each time new teachers became involved we needed to start anew, renegotiating power and local understanding (Kliewer & Biklen, 2007). Local understanding, according to Kliewer and Biklen (2007) holds that an individual's membership, regardless of impairment, is unquestioned in responsive and respectful contexts. The importance of this local understanding became increasingly apparent during our times of change in personnel as well as environment.

### Conclusion

Moving a family that includes a child with a disability proved challenging in many ways, and although we cannot call the new school and community The Land of (Inclusive) Oz, our family seems to be making the adjustments for a good ideological ‘fit.’ Nearly three decades have passed since Hamre-Nietupski and Nietupski (1981) developed a detailed list of suggestions for the “integral involvement” of students considered to have significant disabilities when they were moved from segregated schools to their neighborhood schools. In current literature, there is much written about transitioning students from early childhood special education programs to regular elementary schools and from high schools to work, but little is written about moving a family that includes a child with a disability, particularly articles that invoke questions about why there are such stark differences in the ways in which students with disabilities and their families are supported in their search for inclusive schooling experiences. This paper attempts to encourage the discussion about what Kliewer and Biklen (1996) describe as examining “how we come to understand what those differences mean” (p. 91). The process our family went through seemed to illustrate what the United Nations Convention on the Rights of Persons with Disabilities (2007) describes as the disabling impact resulting from attitudinal barriers. It was similar in many ways to Mercer's (1973) study about children who were successfully included in their families and communities and only “retarded” [sic] during their time spent in schools. For

our son it seemed, the implications for where he went to school would mean whether or not he was to be understood as an equal member in the school community, or forever an outsider. In other words, this experience for us illustrated how disability was socially constructed by the people and their practices in educational contexts.

Although every American public school must provide parents with information outlining their rights and states offer parent resource centers or support groups, these are insufficient in addressing the complex needs of students with disabilities and their IEP team especially in light of the numbers of families relocating to different parts of the country and abroad (McLachlan, 2008). As parents of children considered atypical, we found little guidance or ready systems of support. We relied upon our knowledge and experience gained from our professions as educators and as privileged parents within the American educational system to ask important questions, to seek out information, and to negotiate inclusion. This story leads one to ask questions about the role of privilege in the process of advocacy. What about families who are moving between countries that speak languages and have cultures that differ from those where they are relocating to? What disadvantages drive decisions for families that jeopardize their children's access to inclusive schooling? It would be helpful for researchers to examine the experiences of parents who have no or little educational background or "training" in special education, and the experiences and opportunities for teachers in the field to expand their knowledge and examine their practices in helping to support their students with disabilities and their families in their relocation process.

Although personal cultural interpretations of disability experiences from around the world increasingly appear in the literature, only recently have we begun to consider these types of questions regarding the movement of families with children with disabilities and the social and cultural intersections from a disability studies framework. One example is a special issue of *Disability Studies Quarterly* that included a collection of manuscripts resulting from a disability rights workshop in Kenya in 2007. Ressa's (2009) transcribed interview, for instance, provides insight into the complexities involved when lived experiences of disability are examined through a social-historical and political lens. Other more recent articles published in the *Review of Disability Studies: An International Journal* have also illustrated issues involved when families move. One example is described in a study about wheelchair users in Sweden (Krantz, Edberg, & Persson, 2011) regarding the required change of assistive devices when someone moves between municipalities. A more nuanced example in the same issue examines discrimination against women from within the disability movement in Ghana (Naami & Hayashi, 2011). According to the Migration Information Source (Terrazas, 2009), "The number of African immigrants in the United States grew 40-fold between 1960 and 2007, from 35,355 to 1.4 million. Most of this growth has taken place since 1990 and includes many women who tend to be the parent in charge of their children's education. As people increasingly cross geographic and social borders, it becomes important for us to continue to examine how mobility highlights the ways in which those with impairment become disabled upon confronting changes in social-cultural constructs.

<sup>1</sup> Intelligence quotients (IQ) are readily used in American special education as objective and stable measures of a child's level of understanding, with a score 95-110 being considered "average." IQ cutoff scores have been used to determine whether or not and the degree to which a child is mentally retarded [sic] (Kliwer & Biklen, 1996).

<sup>2</sup> According to one U.S. school district website, “Life Skills” means “Mental Disability;” These terms are presented as synonymous and defined as “Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects an individual’s educational performance. In practice, “Life Skills” is used to describe an educational curricular program where students are taught skills determined necessary for functioning in daily life such as window-washing or cooking.

<sup>3</sup> The Association for Middle Level Education, which includes members worldwide, ascribes to a philosophy focusing on the unique characteristics and behaviors of young adolescents 10 to 14 years of age.

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