The Fallacy of Choice: The Story of Nelly

Maggie Bartlett and Nancy E. Rice

University of Wisconsin-Milwaukee, USA

Abstract

In this study, we explore the intersections of school choice and inclusive education through a "disability studies in education" (DSE) frame. Specifically, we examined the educational decision-making for a young child, Nelly, with significant multiple disabilities and complex medical needs through the lens of her mother, LaTina. (Note: All names are pseudonyms.) While this mother made the decision to send her daughter to a voucher ("choice") school, it required significant sacrifices in relation to the needs of her child. Throughout the mother's narrative, we see her struggle to find a school setting that would meet the most foundational needs of her child, guided by her perception of fear for the safety of her daughter. As she narrows her options between two schools - a public and voucher/private - we see her decision come down to a "choice" among not ideal settings, but two settings that illustrate the need for structural changes in how we provide education for children labeled with disabilities.

Keywords: Disability Studies in Education, Charter Schools, Early Education

Introduction History of School Choice in Wisconsin

The first school choice program in the United States, the Milwaukee Parental Choice Program (MPCP), began in 1990. MPCP provided low-income parents with a voucher that could be used for tuition at a participating non-religious private school ("School Choice," 2019). In the first year, 350 students attended 7 different choice schools (Pitrof & Borsuck, 2014). In 1998, the Wisconsin State Supreme Court upheld a lower court decision allowing religious schools to be part of MPCP. Following that ruling, the program experienced tremendous growth, reaching the enrollment cap of 22,500 in 2005 (https://www.chooseyourschoolwi.org/history/). The program was expanded to include the Racine Parental Choice Program (RPCP) in 2011 and the entire state in 2013 (School Choice Wisconsin, 2019). During the 2017-18 school year, the MCPC issued 27,857 vouchers to 126 different schools (Department of Public Instruction, (DPI), 2017a); the RPCP issued 2,916 vouchers (DPI, 2017b); and the WPCP issued 4,404 vouchers (DPI, 2017c).

In 1993, legislation was passed to allow charter schools in all of Wisconsin. Like voucher or choice schools, charter schools were established to allow parents an alternative to the public school system. The market reform ideas from the private sector influenced policy in the public educational arena in terms of more than just competition like vouchers did: charter schools were also free of government bureaucracy, and could thus implement innovative, creative and more efficient solutions to break the cycles of poor achievement results and inertia that were viewed as having a hold on public schooling. The idea was to have a small "lab school" in the form of a charter school, and once success was found, it could be brought back to the public schools and scaled up. This ideology, and the research behind it (see Witte, 2000), was used to justify the public funding of charter schools in Milwaukee, Wisconsin.

The success of charter schools in reforming public education is decidedly mixed. They have been found to be similar in achievement scores to traditional public schools, though wide variation by school has been shown (Denice, 2014). Charters are bound by the same federal laws that guide public schools; for example, they must serve students with disabilities.

During the 2015-16 school year, 242 charter schools enrolled 44,300 students in the State of Wisconsin (Kava, 2017). Nationally, the percentage of students who attend charter schools increased from 1% to 6% between 2000 and 2015 (https://nces.ed.gov/programs/

coe/indicator_cgb.asp). As of 2015, 43 states had legislation that introduced the development of charter schools. As of 2017, 15 states had voucher programs.

Clearly voucher and charter schools are changing the educational landscape for many students, while simultaneously providing choices for parents. As noted earlier, in Wisconsin, choice programs began in 1990 and the original rationale was to offer low-income families the opportunity to attend a private school paid for by tax dollars (Sandler, 2014). The most recent addition to Wisconsin's parental choice program is the Special Needs Scholarship Program (SNSP). This program provides funds to pay a private school for Wisconsin students with an Individual Education Plan (IEP) (Wisconsin Department of Public Instruction, n.d.). The state legislature approved this program in 2015. Importantly, this legislation was passed just after midnight, without any public discussion on the bill (Simpkins, 2017). Including Wisconsin, 10 states have a voucher program for students with disabilities. In 2017, 28 private schools enrolled 244 students via the SNSP (DPI, 2017d).

Similar to other school choice options, the SNSP was controversial, with parents of children with disabilities on both sides. Some parents felt that the quality of the education their child was receiving at the public school was lacking and supported the SNSP. Others were happy with their local school and concerned that the SNSP would siphon funds away from traditional public schools, causing existing programs to suffer (Ferguson, 2015). Like MPCP, the SNSP provides a voucher for families to send their child with a disability to a private school. Unlike charter schools, private schools are not bound by federal laws. That is, private schools are not required to provide some of the basic provisions of the Individuals with Disabilities Education Act (IDEA), such as: 1) Free and Appropriate Public Education (they can charge fees for books, materials and activities); and 2) implementation of Individualized Education Plans (IEP) (a legal document developed by the school and family that spells out a child's special education instruction, supports and services) (U.S. Department of Education, n.d.) This includes both specialized instruction and related services. If a child received specialized reading or math instruction, or speech, or physical or occupational therapy in the public school, but parents choose a private option for their child with a disability, including a school in the SNSP, the private school is not obligated to provide those services. The voucher initiatives are not the answer to providing education for children labeled with a disability, but merely illustrate that our public system needs to build capacity to serve the needs of all students.

Sifting through options for a school for children labeled with a disability may be daunting. Most often, parents use their social networks to learn about schooling options and help make decisions about school choice (Stewart & Wolf, 2012). As far as factors related to parental decisions, parents emphasize "values" of the school, academic factors, and educational quality as three primary factors. Other important factors include school size, class size, and safety (Howell & Peterson, 2006; Stewart & Wolf, 2012; Witte, 2000).

John Witte, who studied the MPCP for two decades, said, "Over and over again, the private schools were seen as safe and secure and disciplined, and with an adequate achievement level, so that they [the students] can graduate from high school and have a chance to go to college. If they don't get those two things satisfied, they will leave" (Pitrof, 2014, para 23). Fleming, Cowen, Witte and Wolf (2015) surveyed parents who participated in the MPCP and parents who had children in Milwaukee Public Schools (MPS). They found that there were not significant differences between the two groups: all parents were most interested in the quality of the teachers and schools, in student safety, and discipline in the schools. One main difference between the groups was that MPCP parents placed a greater emphasis on religious instruction. However, this was selected as the 10th characteristic of 14, so it may be that these parents are drawn to religious schools not because of religious instruction, but because they view these types of schools to be safer and to have better discipline.

Glenn-Applegate, Justice and Kaderavek (2016) surveyed caregivers of children with and without disabilities with regard to what factors they consider when choosing a preschool.

Among both groups of caregivers, they found that the two most important factors were interpersonal relationships between teachers and students, and safety. Further, their study looked at structural versus process characteristics. Structural characteristics are tangible and more objective, such as teacher education, class size, playground equipment, materials available, books, etc. Process characteristics are more intangible, things like quality of play, and quality of interactions between adults and students. Caregivers of children with disabilities were found to focus more on structural characteristics than caregivers of children without disabilities. Caregivers of children with disabilities, for example, considered physical space for access (e.g., ramps) if a child had a physical disability, whether speech therapy was offered if a child had a speech or language need, or whether the staff had the capacity to manage tube feeding, if a child should need that. The researchers wrote, "These elements are essential to caregivers of children with disabilities but may not even arise in the minds of caregivers whose children are developing typically" (p. 145).

Choice policies and the introduction of special needs voucher options in Wisconsin create an increasing array of educational possibilities for families and their children with special needs. The focus of this study is to examine how one mother approached the decision-making process presented by school choice for her child with significant disabilities. Her choice was between a public school, which was a more inclusive educational setting, and a private school using the MPCP, which solely served students with significant multiple disabilities and complex medical needs.

Theoretical Framework

The theoretical lens of this study is "disability studies" (DS). DS scholars view disability as a social, cultural, and political construct (contrasted to the medical or clinical perspective) and are interested in understanding the meanings and consequences of this construct in various social locations (Baglieri, Valle, Connor, & Gallagher, 2010; Connor, Gabel, Gallagher, & Morton, 2008). Disability studies scholars problematize traditional binaries of abled/disabled due to the privileging of one over the other. Thus, power issues that are always embedded in discussions of disability are foregrounded. Listening to disabled people is another important tenant of disability studies (Linton, 1998).

More specifically within disability studies is "disability studies in education" (DSE). While the tenants of the field are the same as DS, the theory "... is to deepen understandings of the daily experiences of people with disabilities in school" (Connor, et al., 2008, p. 441). The application of this frame to pedagogy and practice is aligned with inclusive education. While those terms are not synonymous, DSE work begins with a common understanding that all people are entitled to a quality education that is grounded in full access, full participation, and an honoring of all sources of differences and diversity (Baglieri, et al, 2010; Connor, et al, 2008). Using DSE as a frame for research is "a vehicle for voices so that they can tell their own stories and share their own goals, aspirations, and needs" (as cited in Baglieri et al.,2010, p. 273). DSE views inquiry from a multi/inter-disciplinary perspective (Gabel, 2009). Disability studies and DSE inform the methodology, analysis, and interpretation in this study, keeping notions of the self-determined needs and rights of disabled people in the center.

Methodology

Narrative inquiry as a research methodology seeks to make sense of experiences vis-a vis-stories and values narrative as a means of uncovering and making experiences tangible. "These lived and told stories and talk about those stories are ways we create meaning in our lives as well as ways we enlist each other's help in building our lives and communities" (Clandinin, 2006, p. 44). This qualitative study foregrounds the lived experiences of a mother LaTina, mother of a child with significant multiple disabilities and complex medical needs. This case study explores her efforts to choose a school that would best serve her daughter, Nelly.

Data Collection

Data were collected via two interviews, each lasting approximately 90 minutes. The interview method was based on Seidman's (2013) notion that the "root of in-depth interviewing is an interest in understanding the lived experience of other people and the meaning they make of that experiences" (p. 9). The first interview focused on three broad questions. The first question asked for a chronological history of Nelly, which included stories about Nelly's experiences at home and school. The second question sought to create a narrative portrait of a day in Nelly's life. The final question focused on sense-making, asking LaTina to elaborate on relevant points related to her aspirations and concerns regarding schooling for Nelly. After a preliminary review of the data, a follow-up interview was conducted. Questions honed-in on themes that emerged from the initial interview regarding decision making about her choice of schools for Nelly.

Analysis

This study focused the analysis on the content of what was spoken and culling out relevant themes. After interview data were transcribed, the data were reviewed for the "content of the speech" (Riessman, 2008, p. 58). This process first viewed the story holistically and began by isolating and ordering the lived experience into a chronological account. Next, initial coding was accomplished by "...identifying the underlying assumptions in each account and naming (coding) them" (Riessman, 2008, p. 57). In this case, assumptions presented by LaTina were related to her child, her needs, and the best way to meet her needs. After the initial coding, categories or theses that emerged in the initial analysis were used as the basis for a follow-up interview with Nelly's mother. Using additional data from the second interview, initial and newly emerging themes were viewed recursively and either confirmed or eliminated.

Participant and Subject

LaTina. LaTina is a 33-year-old African American woman who earned a master's degree in social work. She is a single mother and a social worker in a children's education center that serves under- resourced children and families. This family lives in an urban city situated in the Midwest. LaTina lives with her daughter, Nelly, age eight, and her sons, twin brothers, Ollie and Zach, age five. Nelly's sole caregiver is LaTina.

Prior to having children, LaTina pursued her dreams. She focused on her education first and then traveled. She explained, "I lived in Atlanta for five years and then came back to her home town.... so I just did everything at that time. [When I got pregnant,] I was ready for a baby so everything was great." LaTina had a strong circle of support during her pregnancy.

Nelly. LaTina's early pregnancy was fairly typical; however, at about four months gestation the doctors indicted that there was atypical brain development but were unable to determine the prognosis. After giving birth to Nelly, the first five to six months were fine. When Nelly was 6 months old, LaTina began to notice differences in how Nelly attended to communication and that she was not meeting her developmental milestones (sitting, crawling). She was found to have been having seizures and was diagnosed with epilepsy. However, it was later found that she has schizencephaly. LaTina explained.

Ok here we go [reading from a website], 'schizencephaly, developmental birth defect is characterized by abnormal slit or cleft in the hemisphere of the brain. People with these commonly have developmental delays, speech and language delays, seizure' so this is actually what she has.

Nelly uses a power wheelchair to navigate the world that is operated by whomever is providing care. Since the age of three, she has used a g-tube for feeding. She takes a combination of prescription medications daily to manage her seizures. These are dispensed on a schedule throughout the day. She communicates her happiness via vocalizations, especially during the

early mornings while her family is sleeping. Nelly enjoys playing in water and swimming, other sensory experiences, and chilling out at home with her brothers.

Findings

In this section, we provide a chronology of Nelly's schooling experiences. Following that, we present data regarding the process and factors that influenced LaTina's decisions related to schooling for her child, paying particular attention to what she considered important and how she prioritized and weighed her child's needs against the choices she had available to her. The final section analyzes sub-themes of safety/fear that framed and supported LaTina's final choice for Nelly's schooling.

School Chronology

To provide some context for understanding LaTina's decision-making, we first provide a chronology of Nelly's early childhood experiences and school history in Table 1, and some information about each school. LaTina left the paid workforce to stay home with Nelly from birth through nearly age three. Through birth-to-three services, Nelly received early intervention services at home.

Table 1.

| Location of education and | Type of provider | Age |
|---------------------------|-------------------------------|----------------------------|
| care | | |
| At home care | Care provided by mother | Birth to 2 years old |
| Summerfield School | Special care nursery | 2 years old |
| Randolph | Public school serving | 3 years old to 4 years old |
| School/Summerfield | children three years to 5th | |
| | grade in the morning/Special | |
| | care nursery in the afternoon | |
| Jewel Street Academy | Private choice school | 4 years old to present |

Summerfield School. When Nelly was nearly three, LaTina reported that she learned of a program, called Summerfield that offered appropriate services for Nelly. Summerfield is a children's center in an urban setting that serves children with and without disabilities from birth to age five. The school serves a total of 1400 of children per year; 800 of whom are receiving birth-to-three services. At this level, the majority of services are provided in the home. The focus of the center is on early learning experiences, wellness and health, and family services. Nelly was specifically placed in the Special Care Nursery, where her medical needs were attended to by nurses and nursing assistants. Additionally, special educators and related service providers are on staff to support academic learning and therapeutic needs. This is a center that required the family to privately pay for child care beyond the birth-to-three services.

Once Nelly turned three years old, her special education services were offered via the public school system, which is governed by Part B of the Individuals with Disabilities Education Act (IDEA). Part B of IDEA spells out the provisions for a free and appropriate education in the least restrictive setting for students with disabilities aged three through 21. In contrast, the rules which govern Part C, provides for children who are served from birth to age three. (Department of Education, n.d.)

Randolph School. Randolph is a public elementary school that serves children from age three to 5th grade. Services for three-year-old students are limited to children that have been labeled with a disability; education for all children begins at age four. The school is comprised of about 300 students of which 72% are Black, 16% are Asian, 8% are Hispanic and 4% are White. This urban school works with students and families that have low incomes; 94% of all children receive free/reduced lunch. It houses a class for children with significant multiple disabilities

and/or with complex medical needs. Nelly attended this class in Randolph School in the morning and was bused back to Summerfield for after school care until her mother could pick her up.

Jewel Street Academy. Around the time when Nelly turned four LaTina learned about Jewel Street Academy and the Milwaukee Parental Choice Program (MPCP). Since making the decision to send her daughter to Jewel Street Academy, Nelly has been attending this school full time. (LaTina switched to the SNSP once that became available, as the vouchers pay more per student than the MPCP). Jewel Street Academy is a private choice school that serves only children with significant multiple disabilities and/or with complex medical needs. In its one room school, located within a large agency servicing people with disabilities across the lifespan, two teachers serve approximately 18 students from age four to 21. Jewel Street has multiple nurses and nursing assistants that continuously provide vital medical care for the students.

Schooling Decisions

LaTina explained why she chose Summerfield, the children's center that serves children from birth to age five, with a Special Care Nursery, as Nelly's first experience being cared for outside of the home or with family:

By the time she was almost three, I found out about Summerfield for day care. I got her into Summerfield on a part-time basis because I was paying out of pocket obviously. I think they call it special care nursery or something. So, they watch children I think about zero to five with special needs. For me that was like a turning point cause you just don't want to put your child with special needs in any daycare, you know. Daycare isn't any better but they are not really qualified for take care of special needs so to have her in a place where they would do the things that she needed and take care of her medicine and then there were nurses, so they know we're good. But around three, that was a really rough, rough time. So, what happened was she was going to Summerfield and then because she had turned three with the [Individualize Educational Program] (IEP) right away, it was time to start her at school so at age three, she went to Randolph Elementary School.

LaTina was clear that she didn't want to leave Nelly "in any daycare." Summerfield had nurses who could attend to Nelly's medical needs. This reassured LaTina that Nelly would be safe. If something were to happen with Nelly, there would be staff on hand to handle any potential emergency that may arise. Unfortunately, though, as soon as LaTina was comfortable with this placement, the rules governing Individuals with Disabilities Education Act (IDEA) forced a change for Nelly once she turned three years of age.

On a child's third birthday, early intervention programs and their Individual Family Service Plan (IFSP) ended, and children with disabilities then proceeded to the public school sector for their needs. In public schools, the Individuals with Disabilities Education Act (IDEA), Part B, governs how children's needs are meet. IDEA mandates that each child have an Individual Education Plan (IEP) that spells out the needs of the students, sets goals and objectives, and explains how and where these will be met, and who will be responsible for helping the child meet his/her needs.

Randolph was a monumental change from Summerfield. Nelly's new placement was in a classroom for children with significant multiple disabilities and/or with complex medical needs, situated in a K-5 public elementary school with 300 students. The second half of her day was spent back at Summerfield for after school care until her mother could pick her up.

So, when you do the IEP, when you have a very detailed IEP with a lot of services, there's like maybe two public schools [in the area] that people shoot for. I was shooting for Jefferson because I heard about it when I was working for the state; I used to work with them. They said that Jefferson is too far from my home. So, they told me she needs to go to Randolph. The IEP team told me it was not possible to go to Jefferson. Even I am part of the 'team,' I

felt I had no say in this decision. So she was started going to Randolph three hours a day for K-3. She was going there for like 8 a.m. to 11 a.m. and then after Randolph, she would go from Randolph over to Summerfield daycare and she would stay there about three hours. From like 11 a.m. to 2 p.m. So, the more in depth her care was the more anxious I got about me being back in the workplace and then more importantly about her being at two different places during the day. Like the more places she is, the more exposed she was to different caregivers and like potential creeps. So, I was nervous cause she was catching a school bus to Randolph, then she was catching a school bus from Randolph to Summerfield and then from Summerfield I was picking her up. It just seems like a lot of movement around.

The decision to go to Randolph School was not LaTina's first choice, but she did not feel she had a choice within the public school system. Indeed, based on geography and district policy, she would likely have had a difficult time successfully getting Nelly placed at Jefferson. In addition, the transportation issue would have become more complicated as it was further from their home. In any case, LaTina was presented with a single option in the public school system while Nelly was three and four- years-old, and that option was Randolph School in the morning and Summerfield in the afternoon.

LaTina voiced concerns regarding the fact that Nelly was not in the same building the entire day. The risk involved in moving her from one location to another was a source of anxiety for LaTina, due both to Nelly's "in depth care" needs and to the potential exposure to "creeps." LaTina's concern about Nelly's "in depth care" is focused on her interest in having qualified individuals – nurses and nursing assistants – who can manage Nelly's medical needs.

Her concern about "creeps" goes beyond apprehensions about unqualified personnel. LaTina was anxious about Nelly being "out and about all day" with individuals who provide transportation, potentially without much or any oversight, and without a means to make her needs known or to communicate about any incidents, should they occur. As a social worker, LaTina was familiar with cases of child neglect and abuse. Her unease with Nelly's situation was something she voiced to co-workers.

So while Nelly was in those two schools, I kept talking to other advocates and most of us have like a social service background or research background and I was talking to a coworker. I was telling her it really bothers me and how I feel about her being out and about all day and her going to multiple places, and you know, she can't communicate, and a coworker told me about Jewel Street Academy. I think Nelly was like four.

Thus, when a co-worker suggested another option, LaTina was ready to listen. Jewel Street Academy is a private school that served only children with significant multiple disabilities and/or with complex medical needs. LaTina was able to use MPCP program to pay for this placement.

I went over there, talked to [the Director] and did [a] tour [of the facility]....I think what impacted me was I saw children there that I felt like their needs were greater than Nelly's....I was like if y'all can care for them, you know Nelly is gonna be a breeze.

LaTina was relieved to see an environment where Nelly's needs would not be viewed as atypical. She was secure in knowing that Nelly would be in an environment where the staff would know how to take care of Nelly. They had been trained to work with people who have medical conditions such as Nelly's. They understood how to position Nelly, how important it was to change her position frequently, and how to do this carefully and cautiously, given her needs. Another role of the nursing staff was to ensure that medications were dispensed on schedule for all 18 students. Feeding Nelly using a feeding tube was not viewed as atypical in this environment, and there were several people who had experience using feeding tubes. The risk of being vulnerable to a variety of people, being wheeled onto and off of a van, being secured (brakes on) and warm during each transition, and being transported from one school to

another throughout the day were not issues anymore because Nelly was in one setting all day with the people who are most qualified to manage her medical needs.

LaTina explained:

I trust them and I don't want her to ever leave there because I think that they're a safe place for her. So, I was willing to sacrifice some services. One bonus about the public school district is that they have to service her and they have to provide. She had an IEP with like, their physical therapy like four times a week, she had OT twice a week. Like she had all these therapies and they had to provide it. With me putting her there [Jewel Street Academy] I did give up on that because she doesn't have an IEP where she's at now. They have a plan and with that plan they're providing physical therapy but she's only getting it like once a week; they don't even provide the OT like some stuffs technically you don't pay for it and she's not getting it. I chose to make that sacrifice and now I realize it is because I felt she is safer and in better hands there, and I was willing to sacrifice some services that she could have got by her being in public school. So that was a loss that doesn't matter to me.

LaTina clearly identified her priority of safety as being the most important factor in deciding a placement for Nelly. In spite of the fact that Nelly was not getting important, necessary services such as occupational therapy, or was receiving severely reduced services (physical therapy), LaTina was not bothered by this. LaTina's clearly identified priority of safety for Nelly was being met, in her opinion, at Jewel Academy. Instead, of being concerned about Nelly not having occupational and physical therapy, LaTina was relieved about the daily care should did receive. This was a tremendous weight off of LaTina's mind.

Factors in LaTina's choice

Fear/Safety. As Nelly moved from Summerfield to Randolph/Summerfield and finally to Jewel Academy, LaTina was forced to make choices based on her fear of the unknown and, the opposite side of that coin, ensuring safety for her daughter. While LaTina acknowledged that Nelly "has never experienced any neglect that I am aware of," she nonetheless repeatedly and overtly expressed concerns related to her fears that Nelly would not be sufficiently taken care of or protected during the school day. Fear/safety were also underlying LaTina's decisions and thoughts about the following sub themes: 1) caregiving for Nelly; 2) interacting with siblings and peers; and 3) qualifications of professionals.

Caregiving for Nelly, given her (Perceived) Medical Needs. LaTina based her school placement decisions on her perception of the need for her daughter to be cared for in ways many children are not. Prior to attending Summerfield, LaTina had stopped working for a time to care for Nelly. She explained how she viewed her role and the role of her family in caregiving for Nelly:

The safest option is with me. It was easier when it was just her and me and I just decided to leave the work force all together. I didn't trust anyone and people were scared to watch her because of the seizures. They were scared they wouldn't know how to help.

LaTina explained that caregiving for Nelly was simplest when it was just the two of them and LaTina was a stay-at-home-parent. She learned Nelly's needs and could meet them. She had concerns that others may not know how to care for Nelly as well as she could, and some in her family shared her apprehension. Given this level of uneasiness, LaTina's choice was self-reliance. However, over time, things changed, as she explains:

It was just as I have become more realistic and I have other responsibilities and she can't have the safest options all the time, so I am looking for number two. Because I know that my family will never intentionally do anything to hurt her, but she's safer with me than with them. I don't have any friends or family who can keep Nelly for more than a three hour period.

Once she had her sons, she realized that she could not always be the one taking care of Nelly, so she needed to look for help, a "number two." As Nelly got older, and as LaTina realized she needed help, she still believed Nelly was safest with her. Her family did take Nelly for short stretches of time.

After she had been at Jewel Academy for a couple of months, she found out that they offer skilled nursing care on Saturdays for the students.

[E]ventually I found out about the Saturday thing and I was like are you kidding me?! And so Saturday became like a staple for my boys because I do feel in some way they are disadvantaged. They develop a lot of empathy and they are developing social skills. That's great for them, they are having a sister with special needs, but then sometimes I felt like they're not able to get up and go as quickly as the other children. Like we are not at the museum on Wednesday. It's just too difficult for us. But like Saturday, I commit to them on a date every Saturday. Our families know, everybody knows, Saturday LaTina and the boys are doing something off the chain, and I felt like they deserve that because somedays they have to make sacrifices because all of my attention is on her. So, [Saturdays] are a form of rescue for me. They have skilled nursing all day and I can drop her off.

LaTina was able to utilize the school resources on Saturdays to help with caregiving for Nelly. Given her primary concerns of fear and safety, it was essential for LaTina to find this respite in order to have some predictable routines for everyone in the family. This allowed LaTina to have time for herself and her sons and it allowed Nelly to have some rest and relaxation time as well.

Interacting with Siblings/Peers. Another way LaTina voiced concern for Nelly's safety had to do with ways that adults and children interact with her, in unintentionally harmful ways. This is something LaTina worried about both at home and at school. Speaking about her twin sons, LaTina said,

They're very, very busy, so I have to really teach them boundaries like the way they are playing, wrestle with each other or climbing over her, we can all be there watching a movie, they like to climb and roll, one of them likes to cuddle around her, but they have to be careful. [All of a sudden, I see] her tubing is hanging out.

The natural roughhousing of toddler boys that happens in many homes became a source of anxiety for LaTina in her home. She was in the position of needing to shield Nelly from any unintentional harm that might arise from an otherwise playful situation.

In the school setting, LaTina also had concerns related to Nelly's classmates. At Summerfield, Nelly was in a Special Care Nursery with children who had significant medical needs; and Jewel Academy has a similar population of students with a wide age range. At Randolph School, Nelly was in a classroom with children who had "multiple disability" labels and/or who had significant medical needs. This classroom was a mix of students who had a wide variety of needs, and a range of ages. LaTina explained her concerns about Nelly being part of this classroom:

...at school, it freaks me out that a child who's medically fragile [is] being [placed] in a room with a child who is defiant or ADHDⁱⁱ. To have a room that mixes kids with different disabilities...because he doesn't listen and then this kid is here because he's not obeying rules and he punches her...It's just scary for me when you said inclusive because you're mixing different types of needs together because she's' non-verbal and I never wanted a kid to punch her, knock her wheelchair down.... I was always fearful [about that].

It is clear that LaTina is concerned for Nelly's safety in this classroom. Similar to her sons, she worried that Nelly could get caught in the "crossfire" and become unintentionally physically harmed by activities going on around her.

At the same time, it is difficult to know the basis of these fears. Had there been actual incidents of children becoming harmed or who were in harm's way? Or were these potential fears, based on cultural constructions of "explosive" children with labels of "emotionally or behaviorally" disordered? Whether actual or potential, LaTina's fears for Nelly were real from her perspective. Randolph School was the setting where Nelly received the most services (Occupational Therapy, Physical Therapy, Speech Therapy), yet she was willing to give up those services for her daughter to be physically safe. LaTina preferred a setting for Nelly where she was with peers who were more similar.

In addition, LaTina did not view the academics as being as important for Nelly; nor did she believe that having students with such dissimilar needs was actually meeting the needs of either group:

She is not gonna learn one plus one this year. She's not gonna learn what blue is. I understand the least restricted and most restricted room [referring to the least restrictive environment (LRE) principle]ⁱⁱⁱ, so I understand in those rooms you have a child who's there, like Nelly, who has a health impairment. You also have a kid in that room who is defiant or ADHD, who was seen as he needs a smaller environment. But they have different sets of needs so the mixed environment of the classroom, that concerns me.

At Jewel Academy, LaTina worried less about issues with peers because she felt the students at Jewel Academy were more similar to Nelly, in that they were less mobile than students in her class at Randolph School and thus less likely to unintentionally harm Nelly. Keeping Nelly safe from peers was a priority for LaTina, as evidenced by the fact that she moved Nelly out of Randolph School as soon as she found what she viewed as a better option, Jewel Academy.

Trust in/Expectations of Professionals

Once Nelly began attending Jewel Academy, LaTina was able to relax. Her fears regarding Nelly's medical needs were being take care of and issues with potential problems with peers were resolved. The primary reason she felt more comfortable, as we have seen, was due to the fact that Nelly was with professionals who understood and could manage Nelly's needs. The qualifications of the professionals were the foundation of LaTina's ability to feel somewhat secure in Nelly's placement.

We heard from LaTina earlier that she did not like the fact that Nelly was bused back and forth and she didn't like Nelly's exposure to the bus drivers. She explained,

[T]o me, the bus company isn't the same as like the teachers. You know, you're just bus driving. I don't mean anything negative, but you ain't got the job because you got a license and you're just a driver and sometimes you might drive a route full of normally developed children and then if you're lucky, [you] might have a route that has special need kids on it, and I don't know if you're skilled or qualified for that. So, I was really uncomfortable about the fact that she was riding that yellow school bus. It's just a contracted company and she was riding that bus twice a day. There and back. I also didn't like that she was going multiple places [multiple stops].

The issue LaTina raises here with regard to the bus drivers is their lack of skill and qualifications regarding young children with disabilities. The fact that four-year-old Nelly was being transported several times throughout the day was one concern. Another worry for LaTina was that if something were to happen, what would the bus driver be able to do? She clearly did not have confidence in a system that contracts a private company solely to drive the bus but does not have an aide or another qualified person (even someone who knows CPR) to ride with the children. LaTina had several issues with Nelly riding the bus: 1) the risk of being out of the building; 2) the risk of being transported and moved so frequently during the week; and 3)

concerns that Nelly was spending so much time in the "care" of unqualified personnel. This is reminiscent of LaTina's concerns about even her family not being able to provide adequate caregiving for Nelly.

Fortunately, Jewel Academy did provide qualified nursing and educational staff. Once Nelly's basic needs were taken care of, LaTina began to consider the emotional climate where Nelly spent her days:

I feel like if you work at the public school and you are a teacher and you have to be in the special ed classroom, you might be interested in the special ed children. You might a have a passion but the aides and staff who are there, their passion was education and they're there to teach. Whereas somewhere like Jewel Academy, the people are there because of a health background. They intentionally took a job where they know every kid in the room will probably be really, really different. ...I want her in a place where everyone who comes to work knows they come to work with medically fragile children and shouldn't be frustrated or fatigued or lack compassion and I want her to be in a place where a lot of the children have similar types of issues. In MPS I felt like someone was just babysitting my daughter so I could go to work whereas now I feel like...someone is taking care of her to make her better.

Moving beyond security issues, LaTina was able now to consider what more she was looking for from a school. She wanted quality teachers and staff; people who were committed to being there and to helping her child learn. This is similar to what many parents of choice schools consider to be important (Stewart & Wolf, 2012).

Once Nelly began attending Jewel Academy, LaTina started to get to know the staff. LaTina explained how her trust and their relationship grew:

Nelly has this thing in her chest that can stop her from seizing and I was nervous about them taking it out, but I talked to Jewel Academy about it the day before the surgery. They mentioned to me how a couple other kids had it and they already knew how to use the remote. I needed to be trained on it but it felt good knowing the place I was sending her to, they knew how to use it better than me. Sometimes they will give me questions to ask my doctors about or they tell me stuff to follow up so I felt like I'm part of the team. Sometimes I felt like they have a more helpful prognosis for her than I do.

Given LaTina's history, where she felt she had no option but to be self-reliant in terms of Nelly's care, since she was in an environment where there are professionals who know more than she does felt like a luxury. She was in a position where she did not have to know all of the answers; in fact, others did not expect her to since they learned from both training and experience, and they understood that LaTina was inexperienced in many areas regarding Nelly's care. Moreover, they were more than willing to work with LaTina as a partner in Nelly's education. LaTina could rest a little more easily, knowing that she did not have to fear for Nelly's safety while she was at Jewel Academy.

In terms of Nelly's education, LaTina talked about her initial expectations and desires:

At one point it was for her to be awake during the day, like more alert and awoke...Now I just kinda want her to get to a point where she can communicate different things. Right now, she communicates happiness and sadness...I wish there was a way she could communicate more than just happy or sad. Like maybe when she's hungry, maybe when she wants a hug or if you do something and she wants you to do it again. I want her to sit up independently.

The teachers and nurses at Jewell Academy have been working on this with Nelly:

Well, they use the switch every day at Jewell Academy when they say hello. "Hello, good morning, Ms. Nelly, nice to see you." When they serenade, she's supposed to hit the switch

[push the button on the switch device-which is for communication]. So, she uses her arms, but there's no intention of meaningful use. But they expect her to participate and use the switch.

Working with Nelly on communication skills keeps the expectations high for her and signals to LaTina that she should do the same.

Finally, the quality of experiences provided to Nelly at Jewel by the teachers impressed LaTina:

They sing a lot of songs. She gets read to by the volunteers and the teachers. Whatever arts project they do, she does hands on. So likes she puts her hands in the shaving cream or she's putting her hands on the dirt when they're planting; they have the dogs that come visit so she tends to pet the dog. They go swimming in the summer. So, she's getting in the pool. They have a fiber optic light room that they take her in because she has the visual impairment so she's laying down in there. She's stands in the stander, some day for like two hours, someday 45 minutes. I like that, they try everything with her no matter they think she's participating actively or not.

Inclusive Education. In looking at factors that are most important in making a decision about school choice, it is not uncommon to find some priorities in conflict. Unless and until one is faced with specific circumstances, those conflicts may not surface. In LaTina's case, she considered the pros and cons of inclusive schooling, specifically with Nelly in mind.

It's so funny, when I went to school for all this stuff, when I was single and had no child, never imagining you know, this would apply to me. So, I would say on one hand I felt like it's never cool to kinda just give up and just think she has no chance even if she may not have a chance at certain things but then the parent side of me sometimes just worries about safety. There's a level of inclusion that isn't best practice because she's nonverbal. It's stuff like that I worry about.

It's just scary for me when you said "inclusive" because you're mixing different types of needs together because she's non-verbal and I never wanted a kid to punch her, knock her wheelchair down...but that I was always fearful...but I'd also like her to be included because you never know what melody is gonna spark her.

In theory, LaTina might say she would support inclusive schooling as a best practice. However, given the circumstance of considering the needs of her child within the context of inclusive schooling, LaTina clearly supports having a continuum of placements for students with disability labels.

Discussion

This study sought to understand the decision-making process of one mother for her daughter labeled with significant intellectual disabilities and complex medical needs as they traversed the educational landscape. The factors that dominated LaTina's discourse were around safety and fear. Elements that were mediated by those factors were issues of Nelly's health, siblings/peers, and the qualifications of caregivers and professionals.

In this section, we discuss three issues brought to the forefront by LaTina: 1) important considerations of parents with a child with complex medical needs; 2) authenticity of choice; and 3) considerations of school choice for parents of children with disability labels.

A central theme evident in LaTina's responses was about the unique questions and concerns influencing decision-making for parents of children with significant multiple disabilities and complex medical needs when weighing options for their child's education. LaTina had concerns that influenced her decisions in layered ways. Its foundation was safety. Can the

professionals/care givers give her the medication properly and timely? Will they get her up in her stander [a frame that allows a person that uses a wheelchair to stand upright for mobility and standing]? Will they feed her on time and clean her up afterwards? Layered upon safety was LaTina's desire to have professionals and care givers that truly cared about her daughter: people that knew they would be working with children with unique circumstances and embraced that work and the children in the classroom. Finally, LaTina was concerned with Nelly's experiences throughout the day. She spoke of Nelly enjoying pet therapy, art projects, and music therapy.

We noted earlier that parents of students who participated in the Milwaukee Parental Choice Program (MPCP) (these are parents of typically developing children) were also concerned about quality of teachers, safety, discipline and quality of the education (Fleming, Cowen, et al., 2015). We also saw that parents of children with disabilities were more concerned with structural than process concerns, though both groups of parents valued quality interactions between teachers and children, and safety (Glenn-Applegate, et al., 2016). LaTina's concerns were very much in line with these findings: her primary concerns were structural, specifically, ensuring that Nelly's medical needs would be met by qualified professionals; and secondly, that her physical safety was not at risk from rowdy classmates. She also expressed the importance of the quality of interactions and experiences that Nelly had during the day. Thus, while LaTina's concerns about schooling were similar to what the majority of parents consider when choosing a school for their child, the specifics differed, due to Nelly's needs.

Second, LaTina's experiences help to sharpen the focus on the authenticity of choice. School choice, as proposed by advocates, is a way to empower parents (Pattillo, 2015). Certainly, LaTina had two schooling options for Nelly. However, from LaTina's perspective, a school that met all of Nelly's needs did not exist. This is not unusual to hear. According to Pitre (2014), often school choice is not even a realistic option because in some cases the child labeled with a disability can be denied the opportunity to attend a charter school or denied services in many choice schools. The public school provided more related services (e.g., occupational therapy, physical therapy, speech therapy); while the choice school required Nelly to sacrifice these services for a setting that LaTina perceived as the safest. As the term "safe" was used by LaTina, it was really a proxy for what was needed for Nelly to function (e.g. feeding, seizure control, medicine dispensing, etc.) in addition to ensuring that she was not being neglected and/or abused. LaTina had two choices: 1) keep Nelly in a situation that she perceived as unsafe; or 2) send her to a choice school where Nelly would be safe but surrender important related services. Nether seemed ideal. LaTina did not have a choice that would meet Nelly's needs in terms of related services and interactions with same age nondisabled peers. Although LaTina is satisfied with Nelly's care and education at Jewel Academy, Nelly deserves to be at a school that meets all her needs.

Third, LaTina's decision-making process illustrated conflicts that can arise for parents who are forced to make a choice, given the dilemma of two less than desirable options. Advocates for choice schools may say that this is exactly why school choice exists: to provide families with options, while sending a message to the public school to do better if they want to earn their return business. However, choice advocates do not address the notion of state responsibility to provide access to a quality education, not to mention a Free and Appropriate Public Education (FAPE) as described in the Individuals with Disabilities Act (IDEA). Instead, this study offers a critique of both public schools and voucher schools, as well as a critique of a public policy that favors private choice.

A central tenet of inclusive education, and disability studies in education (DSE) for that matter, is that all students should be able to attend their neighborhood school, along with siblings and neighbors. Parents can get to know teachers within their community and have a voice in decisions made by local school boards. Further, attending neighborhood schools a creates natural proportions of students with and without disabilities in that school. When public schools "cluster" students in certain schools, as was the case at Randolph school, a higher percentage of "students with disability labels" exists at certain schools. It also moves people out of their

neighborhood base, separating siblings and communities. When voucher schools offer only certain services and cater to only students with disabilities, as in the case of Jewel Academy, parents may experience relief that their child will be safe. They are looking at the here and now, and not considering whether and how their child will be included in society in the future.

The Special Needs Scholarship Program (SNSP) in Milwaukee has been given increased funding since the program began in 2015. "Lawmakers also lifted the \$12,207 cap for special needs students in the private schools, agreeing to pay up to 90% of any costs incurred" (Johnson, 2018, para 23). This has angered public school advocates who have been fighting for increased funding for special education for many years. While the public school did not provide a schooling option that LaTina found to be acceptable, the SNSP is also not providing a schooling option that provides Nelly with any interaction with typically developing peers of any age.

Given that public resources are being provided to meet the needs of students, both with and without disabilities, there should be some public discussion of the types of schools that parents want for their children. LaTina spoke about having to choose between safety and including her child with typically developing peers. She said, "It's just scary for me when you said inclusive because you're mixing different types of needs together because she's non-verbal...I was always fearful...but I'd also like her to be included because you never know what melody is gonna spark her."

So, while LaTina "chose" a private voucher school for Nelly, it was not an ideal choice. It was the best choice she could make, given the options. This study highlights the fact that more public resources are available for students with and without disabilities than have been provided to public schools in the past. In Wisconsin, these resources are being spent by some parents without public discussion regarding intended outcomes. While public schools may interpret "free and appropriate public education" variously and imperfectly, there is still an expectation that students with and without disabilities will be educated together. Further, in public schools, parents and students are afforded due process if the right to FAPE is infringed upon.

While the rhetoric of choice is powerful, the question remains: Are parents truly empowered if their only schooling option for their child is to choose "safety" over necessary social and educational experiences and related services? Public monies must be spent giving all families and children schooling choices that include quality teachers, quality interactions between teachers and students, natural proportions of students with and without disability labels, access to school spaces frequented by students with and without disability labels, services needed by all students, and a sense of security. When parents are provided with schools that include these elements, only then we will be able to say that parents are truly being provided with "choice" schools.

References

- Baglieri, S., Valle, J., Connor, D. & Gallagher, D. (2010). Disability Studies in Education: The Need for a Plurality of Perspectives on Disability. *Remedial and Special Education* REM SPEC EDUC. 31. 10.1177/0741932510362200.
- Clandinin, D. J. (2006). Narrative Inquiry: A Methodology for Studying Lived Experience. *Research Studies in Music Education*,27(1), 44-54. doi:10.1177/1321103x060270010301
- Connor, D., Gabel, S., Gallagher, D., & Morton, M. (2009). Disability studies and inclusive education — implications for theory, research, and practice. International Journal of Inclusive Education. 12. 10.1080/13603110802377482.c
- Denice, P. (2014). Are charter schools working? A review of the evidence. Center on Reinventing Public Education. Retrieved from https://www.crpe.org/sites/default/files/CRPE_Are-charter-schools-working brief.pdf

- Department of Education (n.d.). Sections of the IDEA Statute. Retrieved from https://sites.ed.gov/idea/statuteregulations/
- Department of Public Instruction (2017a). Milwaukee Parental Choice Program Facts and Figures. Retrieved from https://dpi.wi.gov/sites/default/files/imce/sms/Choice/Data_and_Reports/2017-18/2017-18 MPCP Facts and Figures.pdf
- Department of Public Instruction (2017b). Racine Parental Choice Program Facts and Figures. Retrieved from https://dpi.wi.gov/sites/default/files/imce/sms/Choice/Data_and_Reports/2017-18/2017-18 RPCP Facts and Figures.pdf
- Department of Public Instruction (2017c). Wisconsin Parental Choice Program (WPCP/Statewide) Facts and Figures. Retrieved from https://dpi.wi.gov/sites/default/files/imce/sms/Choice/Data_and_Reports/2017-18/2017-18 WPCP Facts and Figures.pdf
- Department of Public Instruction (2017d). Special Needs Scholarship Program Facts and Figures. Retrieved from https://dpi.wi.gov/sites/default/files/imce/sms/SNSP/SNSP%20Facts%20and%20Fig ures%20for%202017-18.pdf
- Ferguson, D. (2015, May 20). Special needs vouchers outrage disability advocates. *Green Bay Press Gazette*. Retrieved from https://www.greenbaypressgazette.com/story/news/education/2015/05/20/special-needs-vouchers-outrage-disability-advocates/27645439/
- Fleming, D.J., Cowen, J.M., Witte, J.F., & Wolf, P.J. (2015). Similar students, different choices: Who uses a school voucher in an otherwise similar population of students? *Education and Urban Society*, 47(7), 785-812.
- Glenn-Applegate, K., Justice, L.M., Kaderavek, J. (2016). How do caregivers select preschools?

 A study of children with and without disabilities. *Child Youth Care Forum*, 45,123-153.
- Howell, W. G. & Peterson, P.E. (with Wolf, P.J. & Campbell, D.E.). (2006). *The education gap: Vouchers and urban schools*. Washington, DC: Brookings Institution Press.
- Kava, R. (2017). Charter schools. Madison, WI: Wisconsin Legislative Fiscal Bureau. Retrieved from https://docs.legis.wisconsin.gov/misc/lfb/informational_papers/january_2017/0027_c harter schools informational paper 27.pdf
- Linton, S. (1998). Disability studies/not disability studies. *Disability & Society*, 13(4), 525-539. Pattillo, M. (2015). Everyday politics of school choice in the black community. *Du Bois Review: Social Science Research on Race*, 12(1), 41-71. doi:10.1017/S1742058X15000016
- Pitre, S.A. (May 13, 2014). 'School choice'-As long as your child doesn't have a disability. Retrieved from: http://www.huffingtonpost.com/shayna-a-pitre/school-choicetrue-choice- b 5318677.html
- Pitrof, M. (2014). Milwaukee voucher program turns 25: The history. Retrieved from (http://wwwm.com/post/milwaukee-voucher-program-turns-25-history#stream/0)
- Pitrof, M. & Borsuck, A. (2014). Milwaukee voucher program turns 25: What it has taught. Retrieved from http://wwwm.com/post/milwaukee-voucher-program-turns-25-what-it-has-taught#stream/
- Riessman, C.K. (2008). Narrative methods for the human sciences. Los Angeles. Sage.
- Sandler, L. (December 2014). What is the Milwaukee k-12 school system? Milwaukee, WI. Public Policy Forum.
- School choice Wisconsin. (2019). Retrieved from https://www.chooseyourschoolwi.org/wp-content/uploads/School-Choice-101.pdf
- School choice: Wisconsin-Milwaukee parental choice program. (2019). Retrieved from https://www.edchoice.org/school-choice/programs/wisconsin-milwaukee-parental-choice-program/
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences.* NY: Teachers College Press.

- Simpkins, K. (2017). Special needs voucher expansion proposal once again tells families of students with disabilities your voices don't matter. Retrieved from www.thewheelerreport.com/wheeler docs/files/0907ssnv.pdf
- Stewart, T. & Wolf, P.J. (2012). *Understanding school shoppers in Detroit*. Detroit: Michigan Future Inc. Retrieved from http://www.uark.edu/ua/der/SCDP/Detroit/Detroit Shoppers Report-Final.pdf
- (n.d.) United States Department of Education IDEA. Retrieved from https://sites.ed.gov/idea/about-idea/ Wisconsin Department of Public Instruction (n.d.) Special needs scholarship program (SNSP). Retrieved from https://dpi.wi.gov/sms/special-needs-scholarship/student-applications/18-19
- Witte, J.F. (2000). The market approach to education: An analysis of America's first voucher program. Princeton, NJ: Princeton University Press.

Biography

Maggie Bartlett is an Associate Professor at the University of Wisconsin-Milwaukee in Teaching and Learning. She is the program chair for Early Childhood Exceptional Education. Dr. Bartlett has ten years of teaching experience working with children with disabilities and their families within the United States and over two years of working with teachers, families, and children in Namibia and Tanzania. She earned her Ph.D. at Arizona State University. Currently she is teaching courses that relate to working with families of young children with disabilities in urban settings and language and literacy for young children. Dr. Bartlett's research and writing focus on the cultural practices and complexities as it intersects with the education for children with disabilities and their families. She uses critical, decolonizing, social justice, and comparative lens in her work both nationally and in Namibia and Tanzania. She is currently working on understanding the impact that mandated aligned of Common Core State Standards has on IEP goal development and teacher efficacy.

Nancy Rice is an Associate Professor of Teaching and Learning at the University of Wisconsin-Milwaukee. Nancy Rice teaches and does research related to cultural representations of disability, qualitative research, inclusive education, and teacher education. Her research focuses on how people with disabilities and educational policy are represented in teacher education textbooks and what this means in terms of attitudes toward students with disabilities among preand in-service teachers. She earned her Ph.D. in cultural foundations of education from Syracuse University.

¹ IDEA is a federal law that mandates a free and appropriate education for children with disabilities while providing special education and related services to the child.

ii ADHA means Attention Deficit/Hyperactivity Disorder

iii Least restrictive environment is when children with disabilities are educated with their non-disabled peers to the maximum extent appropriate.