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Beyond the IEP meeting: parents' perceptions of music education for individuals with exceptionalities

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BOSTON UNIVERSITY
COLLEGE OF FINE ARTS

Dissertation

**BEYOND THE IEP MEETING:
PARENTS' PERCEPTIONS OF MUSIC EDUCATION
FOR INDIVIDUALS WITH EXCEPTIONALITIES**

by

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DEDICATION

This dissertation is dedicated to Amy and to Amy's parents. Decades later, I still feel honored to have had the opportunity to work with a child in the early days of inclusion as I finished a master's degree in music education. Additionally, I dedicate this dissertation to the six mothers who came forward to participate in this research. Their fortitude and visions, hopes and dreams, unwavering passion and dedication, as well as their actions, are noble and significant. I also dedicate this to all the parents who have fought the long battles and who could never take *No* for answers even before they had opportunities to formulate questions. I also dedicate this to their amazing children. I will be eternally grateful for my friends' and family's patience and unwavering love, and for my advisor, Dr. James Imhoff.

When you play with these cats who have been out there, you learn a lot of street stuff which, a lot of time', they don't teach you in school. How to survive musically, and just survive, just how to get along with a lot of these kinds of cats. Because a lot of times, it's not about being able to play as much as it is about being able to learn how to live and get along with people and do what you've got to do to get by, to get on stage. Music is an art form... (Arnold, 2017, p. 22).

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ABSTRACT

In this phenomenographical study I documented and analyzed the perspectives of six mothers whose sons attended a postsecondary music academy in the northeast to discern the essence of parental experience and the meanings they attributed to music education. Education for students with exceptionalities arose from parental advocacy and legal battles; however, a review of the literature indicated that research had not documented the essence of parental experience and the meanings parents made of music education. Public Law 94-142 (1975) mandated parental involvement in the education for children with exceptionalities in a system that required parents' presences at Individualized Education Program (IEP) meetings and, as amended, is still in effect today. This law protects educational rights of individuals with exceptionalities and is designed to enhance their education, while insuring the rights and involvement of parents in educational planning. I explored the relationships between perceived experience and social capital, and documented the actions six mothers took based upon the meanings they made of music education. Parents whose offspring with exceptionalities have pursued music education beyond the American public school system offered insights

about their experience and the meanings they ascribed to music education for their children. Bracketing, intuiting, analyzing, and describing were used to document data collected from interviews, blogs, and journals. A theoretical relationship was considered between perceived experience and social capital.

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CHAPTER 1

EXCEPTIONALITIES AND THE PUBLIC SCHOOL: A HISTORY

The purpose of this qualitative phenomenographical study was to document and analyze the perspectives of six parents of adult individuals with exceptionalities at a post-secondary music academy in the northeastern United States, discerning the essence of experience and meanings they attributed to music education. Parents have continually advocated for and influenced change in the education of children with exceptionalities in the U.S. since the early 19th century. As a result of parents' advocacy and legal battles, children with exceptionalities were included in school systems across the U.S. by the mid-to-late 20th century (Giordano, 2007). A drastic change in the dynamics and status of parental involvement occurred once parents were federally mandated to participate in Individual Education Program (IEP) meetings (Osgood, 2005).

In this dissertation I sought answers to these questions:

- What perceptions of experience do parents (of individuals with exceptionalities who are pursuing postsecondary music education) have?
- What meanings do these parents make of music education?

Music educators are often not present at the meetings (Scott, Jellison, Chappell, & Standridge, 2007). Therefore, parents may not always be able to convey their perspectives regarding music education for their children at the IEP meetings.

Furthermore, mandated family involvement in education may not represent the culture of all parents (Baquedano-Lopez, Alexander, & Hernandez, 2013).

Parental Involvement

The inclusion of children with exceptionalities in classrooms across the U.S. took place after a long history that included parental and educator debate as well as federal mandates (Osgood, 2005; Taylor, 2000). In some—mostly urban—locations, as early as the 1920s, education became available for children with exceptionalities in separate classes or schools. By the 1960s teachers were receiving degrees in special education, although most children with exceptionalities were not yet enrolled in schools (Cruickshank, Morse, & Grant, 1993).

During the 1960s “parents sought an increased involvement in the education of their children; they encouraged school boards to provide programs for their children or banded together to begin their own programs” (Winzer, 1993, p. 379). Parents were involved in the creation of organizations including the National Association of Parents and Friends of Mentally Retarded Children (presently known as The Arc), United Cerebral Palsy Association, National Society for Autistic Children (now known as the Autism Society of America), the National Association for Down syndrome, the Association for Children with Learning Disabilities, and the Federation of Families for Children’s Mental Health (Turnbull & Turnbull, 1997). The actions of these organizations and other parent-originated advocacy groups confirm the vital role of parental involvement in the education of children with exceptionalities.

Legislation developed to ensure educational rights. Following the language and concepts of the Civil Rights Act of 1964 that protected gender and racial rights, the Rehabilitation Act of 1973 first mentioned, in a small paragraph, the protection of public

education for individuals with disabilities (Ong-Dean, 2009). The passing of Public Law 94-142 in 1975, known as the Education for All Handicapped Children Act (EAHCA), mandated the inclusion of children with exceptionalities in public schools. EAHCA was established after decades of parental advocacy, and the time leading up to this legislation was marked by interest in meeting the needs of children with exceptionalities in a period of struggle to define needs, services, and rights (Osgood, 2008). The Improving America's Schools Act (IASA) of 1994 stressed the importance of family involvement in school partnerships to promote the "social, emotional, and academic growth of children" (U.S. Department of Education, 1994).

Legislation of parental involvement. The Elementary and Secondary Education Act of 1965 (Public Law 89-10) and addendum P.L. 93-380 of 1974 established parental involvement. Public Law 94-142 of 1975 (EAHCA) and addendum P.L. 105-17 of 1994 mandated additional parental participation at Individualized Education Program (IEP) meetings. In addition to creating the IEP and the IEP plan, this legislation offered protection regarding the rights and individual needs of children previously excluded from public schools. Public Law 94-142 (EAHCA), which is still in effect today, requires parents' presences at IEP meetings; P.L. 93-380 allows for a parent surrogate to be used if the parents cannot be found or are unavailable; and P.L. 105-17 specifies that parents participate in planning and implementing the IEP (Taylor, 2000). This series of legislation assured parental involvement in the education of children with exceptionalities.

Public Law 94-142 (EAHC) transformed into IDEA and IDEIA. The Individuals with Disabilities Education Act (IDEA) of 1997 and Individuals with Disabilities Education Improvement Act (IDEIA, also known as IDEA) of 2004, legislated 29 years after EAHCA, are also known as Public Law 94-142. Identifying inequalities in the legislation, IDEA (2004) offered clarity and refinement to the original law and called for increased educational opportunities for children with exceptionalities. IDEA (2004) included, in Section 3(B), “strengthening the role and responsibility of parents and ensuring that families of such children [with exceptionalities] have meaningful opportunities to participate in the education of their children at school and at home” (IDEA, 2004. sec. 3). The IDEIA of 2004 offered amendments to IDEA (1997) and refined the roles and rights of parents allowing IEPs to be amended without a committee meeting.

Parents and the Individualized Education Program. IEP meetings are attended by at least one regular education teacher, one special education teacher, a public agency representative, an evaluation result interpreter (who may also be one of the other representatives), the child, when appropriate, and the parents as required by the law. Additionally, IDEA specifies that “other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate” may be present “at the discretion of the parent or the agency” (U.S. Department of Education, 2006, section 1). The attendance of specialists such as music educators is not mandatory. Parents may not interpret the IEP meeting as the most conducive setting to reveal the meanings they ascribe to music education without a music educator present, although

Cruickshank et al. (1993) asserted that too many people present at IEP meetings may actually confuse parents. According to the law, parents can request the attendance of music educators at IEP meetings.

Push for Active Parental Involvement

Although P.L. 94–142 established that students with exceptionalities should be placed in the *least restrictive environment*, Cruickshank et al. (1993) pointed out that children possess “inevitable individual differences” (p. 13), and the decision to mainstream should ultimately be the decision of parents and the children. In a 2002 U.S. Department of Education report, the President’s Commission on Excellence in Special Education stated, “The commission views parental empowerment as essential to excellence in special education. Increasing parental empowerment coupled with public accountability for results will create better results for children and schools” (p. 38). According to the report, “commissioners and expert witnesses have repeatedly stressed that parents are the key to success for students with disabilities” (p. 38) and that parents must be provided more choices in educational services and settings (2002). Yet, the U.S. Department of Education report (2002) noted, adversarial encounters with parents regarding the IEP process were not uncommon, and interactions between parents and school systems were affected by parents’ “growing threats of litigation” (p. 40). Active parent involvement occurred within the frame work of societal interaction best understood in the context of theory.

Social capital theory in relation to cultural capital. Social capital theory may be particularly applied to mothers of individuals with exceptionalities as they functioned

within a changing social world, within a state of social transformation. Although Gorski (2013) described Bourdieu as a “theorist of social transformation” (p. 2), Gorski noted that midcareer writings have tended to mark Bourdieu as a social reproduction theorist. Laslett and Brenner (1989) asserted that social reproduction includes “various kinds of work—mental, manual, and emotional—aimed at providing the historically and socially, as well as biologically, defined care necessary to maintain existing life and to reproduce the next generation (p. 383).

Bourdieu (1986) identified capital in three forms: economic, cultural, and social. In reference to those merely embracing capital from an economic stance, which is often the case, Bourdieu explained:

Because they neglect to relate scholastic investment strategies to the whole set of educational strategies and to the system of reproduction strategies, they inevitably, by a necessary paradox, let slip the best hidden and socially most determinant educational investment, namely, the domestic transmission of cultural capital (p. 243).

Conceiving of agents within society both psychologically and sociologically, Bourdieu later (1989) asserted:

Indeed there exists a correspondence between social structures and mental structures, between the objective divisions of the social world—especially the divisions into dominant and dominated in the different fields—and the principles of vision and division that agents apply to them (p. 1).

Cultural capital and the educational institution: Parents as agents within society. Two of Bourdieu’s (1986) three identified states of cultural capital, the *embodied* and the *objectified* may be easily understood. These two states can be conceived as being embodied in “long-lasting dispositions of the mind and body” and objectified in “the form of cultural goods (pictures, books, dictionaries, instruments, machines, etc.)” (p.

17). Bourdieu's third identified state of cultural capital, the *institutionalized* state, is more complex. Referring to the educational institution, Bourdieu (1989) suggested:

If the educational institution resembles something like an immense cognitive machine which continually redistributes students submitted to its examination according to their previous positions in the system of distributions, its classificatory action is in reality only the outcome of thousands of actions and effects produced by agents who themselves act like so many independent, yet objectively orchestrated, cognitive machines. Conversely the analysis of the acts of construction performed by agents, in their representation as much as in their practices, can only become fully meaningful if it also sets itself the task of grasping the social genesis of the cognitive structures that agents implement in them. (pp. 1–2)

Embracing the *social capital theory*, Warren, Hong, Rubin, and Uy (2009)

suggested that understanding and appreciating parents' cultures and promoting parental leadership may be key in fostering family involvement. Additionally, community-based organizations may help bridge the gap between families and schools. However, Warren et al. (2009) stated that "authentic collaboration will require efforts to address the imbalance in knowledge and power between teachers and less educated parents" (p. 2213). Ong-Dean (2009) asserted that although the EAHCA of 1975, i.e., Public Law 94-142, was set up as an act of social reform to integrate and include children and to enable parents to become part of the educational decision-making process, not all parents are equally equipped. There may be wide margins of difference between disadvantaged, privileged, and minority parents that in turn affect parental involvement and advocacy. Bourdieu (1986) pointed out that economists categorize *margins of difference* from a human capital stance, a view of "rates of profit on educational benefit" (p. 243).

Parents may be conceived as agents functioning within what Bourdieu (1989) described as *fields*: "social microcosms characteristic of differentiated societies" (p. 132).

Additionally, Bourdieu (1985) asserted that the only control individuals have of the social world is an understanding of what it is and the position they hold within it. He believed that “the social world is, to a large extent, what the agents make of it, at each moment” (Bourdieu, 1985, p. 734).

Contrasting parental roles: Functioning as a system. Societal views of parental roles have undergone a significant dynamic change throughout the history of education for children with exceptionalities. These roles are not necessarily defined and specified but seem to exist and evolve within the frame of social capital affected by systems within institutional states. Turnbull, Turnbull, Erwin, and Soodak. (2006), highlighting the ways parents have been perceived throughout this history, identified nine major parental roles: “(1) the source of their child’s disability, (2) organization members, (3) service developers, (4) recipients of professionals’ decisions, (5) teachers, (6) political advocates, (7) educational decision makers, (8) family members, and (9) collaborators” (p. 102), encompassing decades of blame coinciding with changing social, educational, and medical models. Turnbull et al. asserted that families actually function within a system, a *whole entity*, one in which children with exceptionalities impact subsystems negatively or positively.

A shift to state control creates loss of parental and local authority. Thomas (2012) described a shift that occurred in the early 21st century from local and parental authority to state control, which resulted in “loss of control and sense of responsibility for schools at the local level for all persons involved in the school, but especially parents” (p. 207). As legislation evolved ensuring parental involvement, parents’ roles within the

educational system, the very system parents helped to develop, may have undergone major changes. This role change is revealed in parental perceptions of how they believe they are perceived and/or valued by educators. Additionally, the role change, itself, may be a source of stress and challenges for families of children with exceptionalities.

Atterbury (1990) mentioned that parents were “among the strongest backers of P.L. 94-142” (p. 16), but she did not include parents as a resource for music educators to *find out* about their students with exceptionalities. She did, however, recommend that music educators consult students’ files (which should include parents’ input through the IEP). Parents of children with exceptionalities were basically left out as a resource for music educators in Atterbury’s thorough outline of the realities and challenges for music educators in classrooms that include students with exceptionalities.

The Participants

At a New England postsecondary academy, students with exceptionalities such as autism, Williams syndrome, and Down syndrome, among others, continue their postsecondary education with music as a focal point in their lives. Six mothers whose sons attend or attended this music academy participated in the study. They shared stories with me in interviews, journal entries, and as they engaged with peer participants while interacting on a private blog. I kept a journal filled with my own experiences as I was embedded in the research. In transcriptions, I documented their words, and their beliefs and meanings were offered to me to preserve forever their very personal accounts. These are not stories, but rather very real accounts of their own experiences from their own frames of reference within what would emerge as four systems: medical, educational,

community, and family.

The mothers each functioned within what emerged as three psychological and behavioral postures: *perceiving and intuiting*; *researching and critiquing*; and *reacting and acting*. This dissertation documents all three postures of the experiential perceptions of those whom I would describe as six fascinating and brilliant women, women whose lives very much changed when it became known to them that their offspring would face challenges in a world that seemingly was only beginning to know and accept their sons' exceptional features.

All six children have received additional labels other than *son*, ascribed to them in a world making sense of what it still calls "dis-ability." These three labels include one used for a participant's son who was literally *cognitively disabled* in a childbirth gone horribly wrong at a premier U.S. medical institution. Two of the participants' sons have been assigned the *autism spectrum* label. Autism continues to be a condition that perplexes the medical system and tries the educational system; additionally, there is the potential for fear and anger regarding the diagnosis as well as hope within the family system. One participant's son diagnosed on the spectrum came into the world from a very difficult pregnancy and was born into a mother's love that enveloped him despite all odds; he now functions as a musical savant on the spectrum. Additionally, three participants' sons were born with *Williams syndrome*.

Down syndrome occurs when individuals possess three copies of chromosome 21 instead of the typical two copies ("Chromosomes," 2015). Individuals with Williams syndrome (WS), in contrast, have an alteration, specifically a hemi-deletion, of around

1.5 megabase pairs (MB) to chromosome 7 (Nickerson, Greenburg, Keating, McCaskill, & Shaffer, 1995). It is estimated to occur in the range of one in 20,000–50,000 individuals (Greenburg, 1990). One effect of this syndrome is an alteration of the elastin (ELN) gene, which may or may not contribute to what some describe as the typical WS phenotype, or physical characteristics. Often individuals with WS are born with heart problems, specifically supravalvular aortic stenosis (SVAS), and individuals have other cognitive, physical, and behavioral effects of the chromosomal variance, as well. Individuals with WS are highly social, and parents note that that can be both an asset and a detriment, as their offspring, at any age, are more susceptible to negative societal impacts from strangers who could take advantage of this personality trait.

Propensity for music in WS individuals. Some of the parents reported during this study that they were the first to discover musical propensity in individuals with WS and to bring it to the attention of the medical community. In connecting with a neuroscientist who was also a parent of an individual with WS, they worked together to establish a camp and later a music academy for individuals with WS. This music academy now accepts individuals with other exceptionalities, and all six mothers in this study have offspring who attend or attended this academy.

Three Behavioral and Psychological Postures of All Participants

Parents have had to not only react to what they perceive and what they have discovered; they also have had to act in creative fashions that may be classified as actions rather than reactions. The three postures I allocated to the mothers, *perceiving and intuiting*, *researching and critiquing*, and *reacting and acting*, are not three neat

compartments. They are, in fact, intertwined, dynamic, fluid states demonstrated by a simplistic Venn diagram (see Appendix A).

While the mothers in this study have perceived and intuited all of their lives, they felt the need to adopt a research and critique posture as they found themselves and their sons thrust into a world that did not seem to understand them or their children. These mothers indicated that they believed they had to delve deeper because it had become apparent to them that the systems in which they functioned required not only their own research and critique of what was available, but their own actions and reactions. The reactions the mothers had were to the exceptionality itself and to the ways in which the world around them reacted or failed to react to the exceptionality, a system that seemed to fail at best serving their most cherished and loved beings—their sons.

It is apparent that the participants will continue these postures for the rest of their own lives. Their actions go beyond what I ever imagined in a world in the field of music education. This study serves as an analysis of the essence of their experiences and the meanings the six mothers each made of the systems in which they and their sons functioned.

CHAPTER 2

REVIEW OF LITERATURE

Historical Perspectives

The use, importance, dynamics, and consciousness of language are at the forefront in a phenomenographical approach. Research, like education, is fluid and evolving, a morphing of cultural acceptances and beliefs based on perspectives. An advocate of eugenics, Henry Herbert Goddard (1916), in language that would be unacceptable today, studied Deborah Kallikak, a young girl he labeled “feeble-minded” in his research from 1912, in which he blamed members of the family for the child’s malady. Serving as an example that research may expose more than the intended research purpose, Goddard’s research is a preservation of the historic, cultural, and social norms of the period and philosophies, paradigms, and language of those who conducted research at the time, as well as a documentation of research findings.

Emerging Themes in Mainstreaming Research

Parental perspectives of mainstreaming and inclusion. As parents advocated for their children’s rights in a time of change, thus the themes that emerged from research inquiries reflect relevant interests within periods of educational reform. By the mid-1990s, a primary theme within the field of research developed: *parental perspectives of inclusion*. Identifying that parents found positive changes in education, communication skills, social skills and interactions, behavior, and attitudes following their children’s inclusion, Ryndak, Downing, Jacqueline, and Morrison (1995) noted, “This study represents one small effort to listen to the participants” i.e., the parents (p. 156).

Children's integration into classrooms had initiated parents' fears and concerns as well as satisfaction (Green & Shinn, 1994; Hanline & Halvorsen, 1989; Ryndak et al., 1995). It is unknown whether feelings of "disempowerment, anxiety, and uncertainty among parents" (Osgood, 2008, p. 78) from the early stages of special education were factors in early collaboration attempts. While the research in the field of parental perceptions is quite limited, that which exists reflects researchers' queries about mainstreaming and inclusion. These concepts are now decades old.

Dynamics of parental perspectives. Early studies conducted by Hanline and Halvorsen (1989) and Ferguson, Ferguson, and Jones (1988) suggested that parents had very descriptive and dynamic ideas and concepts about the education their children received, particularly as their children were integrated into regular classrooms and transitioned out of those classrooms. Hanline and Halvorsen concluded that "a structured plan for integration that parents help develop and that is disseminated to parents before the IEP transition can be useful in reducing parent concerns regarding the district's commitment and the program quality" (p. 487). This early research study suggested not only the value in mitigating parental concerns, but the reported value of parental involvement.

Parents as multidimensional. Palmer, Borthwick-Duffy, and Widaman (1998) pointed out that in the early stages of mainstreaming during the 1980s, several researchers (Davis, 1989; Fuchs & Fuchs, 1994; Kauffman, 1989; Lieberman, 1985) noted that "the movement appears to be led by a small number of disillusioned special educators who may be ignoring input from many of those who are affected by the

implementation of such programs” (p. 272). Palmer et al. (1998) addressed parents’ perceptions of social benefits and the quality of inclusion for their children with severe cognitive disabilities. Although parents were apprehensive about the quality of education their children received in the inclusion classroom, they reported satisfaction with “social benefits, acceptance, and the treatment of their children” (p. 271). The researchers also noted the existence of a *multidimensionality* of parent attitudes, indicating a need to assess individual parental values regarding the role of education and curricula.

Parental desire to participate meets resistance from professionals: Advocacy. In DeLuke’s (1995) dissertation, 21 out of 22 parent participants expressed satisfaction in inclusion settings for their children. While they stressed the importance of teacher accessibility and the need to challenge their children, two distinct concepts emerged from the data: Parents wanted to fully participate in all aspects of their children’s lives including the education of their children, and parents wanted to fully participate in decisions made in their children’s lives although they often encountered what was described as resistance. In addition, DeLuke discovered that parents wanted classroom support for their children. The assistance parents wanted were the following: (a) consultant teachers, (b) special education and therapies delivered in the regular classrooms, (c) paraprofessionals, and (d) supports for social, behavioral, and academic needs (p. 107).

Parents trust communicative educators who are nonjudgmental. Some parents reported a genuine trust and rapport with educators particularly when parents sensed that those educators authentically cared, when education professionals communicated, and

when they were knowledgeable about the exceptionality (Angell, Stoner, & Sheldon, 2009). In addition, parents reported enhanced levels of trust when they perceived that “education professionals were nonjudgmental of the parents” (Angell et al., 2009, p. 169). Angell et al. noted that parents perceived that teachers were nonjudgmental when teachers “attempted to understand the struggles parents experienced, and when they [teachers] focused on children’s successes” (p. 169).

Parental Perspectives: Integration and Transition

In the late 1980s, the following research theme emerged: parental perspectives of children’s integration and transition into adulthood. Ferguson et al. (1988) explored parents’ perceptions of parent-professional relationships and parents’ perceptions of their children’s postsecondary transition. While the research topics from the period reflected current concerns, even more was gleaned from parental perspectives.

The research by Ferguson et al. (1988) revealed that many parents perceived and identified the existence of three separate transitions during their children’s transition into adulthood: bureaucratic, family life, and adult status. These parents perceived that a bureaucratic transition occurred in which involvement with agencies and professionals shifted from representing the special education system to representing the adult services system. In addition, as children transitioned into adulthood, a family life transition occurred. Parents believed that their children’s adult status transition was impacted by perceived roles of control between service-providing professionals and families who were handling the situation.

Non-Music Educators' Perceptions of Mainstreaming and Inclusion

Three non-music educator research themes emerged in the 1980s and 1990s: (a) non-music educators' perceptions of and reactions to mainstreaming research (Lombardi, Nuzzo, Kennedy, & Foshay, 1994; Smaller, 1989); (b) perceptions of preparation for education (Blocker, 1980; Floden & Klinzing, 1990), and (c) teachers' perceptions of the benefits of inclusion and mainstreaming (Luseno, 2001; Theilbar, 1995). Also, research regarding teachers' perceptions of parents' rights and legal implications regarding and school choice was carried out in the early stages of federal mandates (Sugarman, 1974; Wong, 1993). Research topics in studies of regular educators coincided with the development of mainstreaming and inclusion.

Floden and Klinzing (1990) defended the value of research that documents teachers' perceptions, stressing that it could benefit teacher education and policy formation and serve as a way for teachers to share best practices. Lombardi et al. (1994) found that special education teachers were significantly more sure of the value of inclusion for students with exceptionalities than regular teachers were. Parents and teachers completed evaluations to disclose perceptions of training sessions and integration (Lombardi et al., 1994).

Music Teacher Perceptions of Mainstreaming

Research of music educators' perceptions for those with exceptionalities is quite limited. Dated as well as more recent studies in this area provide a consideration of the trends in research topics. The first music teacher perception research focused on mainstreaming (Atterbury, 1986; Darrow & Gfeller, 1991; Frisque, Niebur, &

Humphreys, 1994; Gfeller, Darrow, & Hedden, 1990; Hawkins, 1991; Shehan, 1977; Shepard, 1993; White, 1981). Stuart and Gilbert (1977) found that preservice music educators felt unprepared to work with mainstreamed individuals. Shehan's (1977) early survey of 25 music supervisors revealed that students with exceptionalities in Ohio were moving out of self-contained classrooms, yet only 6% were fully mainstreamed. As education for children with exceptionalities became mandated, new research emerged that documented teachers' perceptions of this change regarding the adaptation new laws; Atterbury's (1990) research addressed the realities and challenges music teachers faced in mainstreaming, while providing information for teachers about learning styles associated with various exceptionalities.

Music teachers report need for techniques and methods. In a seminal study, Gilbert and Asmus (1981) surveyed 789 general music, instrumental, and vocal teachers' perspectives regarding their experience, knowledge of legislation, and needs for teaching students with disabilities. Sixty-three percent of the respondents had been affected by federal mandates and were experiencing the inclusion of students with exceptionalities in their music classrooms. Although Gilbert and Asmus found that most music teachers wanted to meet the educational needs of individuals, were familiar with legislation regarding students with disabilities, and wanted to avoid causing psychological harm to students with disabilities, the music teachers surveyed felt they needed more training so they could teach exceptional learners effectively. Six years after its inception, one third of the respondents remained unfamiliar with P.L. 94-142 (1975), and only 23.8% were involved in IEP development.

Teacher attitudes about effectiveness of mainstreaming. Gfeller et al. (1990) mailed 350 questionnaires to music teachers in Iowa and Kansas. These two states were characterized by comparable urban and rural population profiles and the employment of music specialists in public schools. The purpose of the research was to identify types of mainstreaming experiences, primary educational objectives, levels of available instructional support, and perceived stress resulting from mainstreaming. The results indicated a lack of consensus among respondents (half of whom had been teaching less than 10 years) in response to effectiveness of mainstreaming. Half of the respondents felt the needs of children with disabilities would be better met in a separate class (Gfeller et al., 1990).

Shift in Research: Teaching, Preservice, and Preparation

Decades after the inception of EAHCA in 1975, a shift occurred in music teacher perception research in the 21st century. Instead of documenting attitudes toward the concept of mainstreaming, research now reflected music educators' perceptions of teaching students with exceptionalities (Boumpani, 2005; Nabb & Balcetis, 2010; Salvador, 2015; Scott et al., 2007). Eventually the foci of research studies became preparation for parental involvement (Hiatt-Michael, 2001), and music teacher preparation (Salvador, 2010), and preservice music educators' perceptions (Hammel, 2001a, 2001b; Hourigan, 2007, 2009; VanWeelden & Whipple, 2005, 2007a, 2007b; Whipple & VanWeelden, 2005, 2012).

Boumpani (2005) compared music teachers' awareness, understanding, attitudes, and approaches to their years of experience in music classrooms. The results of the

research indicated that years of teaching experience was not a factor in awareness.

However, experience was a factor in the variation of instructional approaches. Results suggested a lack of understanding of effective instructional approaches, but an improvement in preservice teacher preparation within the 4 years prior to the research.

Scott et al. (2007) noted the historical development of music education research and distinguished “social problems of acceptance” as the first topic of studies following the passage of EAHCA (p. 39). This concern led to research regarding teacher attitudes in special education and psychology. Scott et al. reported that all high school band and orchestra teachers had had contact with parents, usually initiated by the parents, and 76% of elementary music educators had had contact with parents, usually initiated by the music educators. The authors reported that “only a few comments from elementary teachers indicated that they learned something from parents” and “most comments focused on learning about the parents’ emotions, getting new information about the child’s disability, and becoming aware of what parents expected for their child in the inclusive settings” (p. 46). Scott et al. noted that “there is no substantive set of data on IEP participation on the part of music teachers,” although most music educators in their sample did not attend the meetings (p. 49). Among other topics, Scott et al. considered that without contact with music teachers, parents may not receive vital information regarding “their child’s music abilities and the possibilities for their child continuing in music at the secondary levels and ultimately, throughout life” (p. 50). Scott et al. also pointed out that “the issue of parent contact is particularly critical and deserving of in-depth study given the importance of parental support to a child’s development” (p. 50), a

call for future research.

In the three decades prior to their research, Jellison and Taylor (2007) located only 32 experimental and descriptive music research studies “with a specific or implied purpose related to the study of attitudes, inclusion, and persons with disabilities” (p. 10). Jellison and Taylor disclosed that in those 32 studies “children with disabilities were participants in only two studies” (p. 11). They added that “absent from all studies were measures of attitudes of parents, siblings, professionals other than music teachers/therapists, administrators, and adults with disabilities.... Also absent from the attitude research are studies with parents as participants.” (p. 11). This led me to believe there is a gap in the research that my study may fulfill.

Parental Perspectives Regarding Music for Children With Exceptionalities

In a case study, Frick (2000) sought to discover how a “musically rich” preschool special education classroom affected communication development in children with a variety of special needs. Parents assisted with data collection at home. Frick, who acted in dual roles as researcher and preschool teacher, concluded through data analysis, interview transcriptions, and journal communication that there was carryover of the use of music from classroom to home. In addition, music had positively enhanced communication in preschool students with exceptionalities.

Houtaling (2003) conducted a survey to parents of females between the ages of 2 and 57 to inquire how their children, diagnosed with Rett syndrome, applied music to their lives. (Rett syndrome is a pervasive disorder affecting brainstem function.) In a later study, Bergström-Isacsson (2011) found that individuals with Rett syndrome

demonstrated varying facial expressions in response to music and that interpretations of facial responses were complex. She noted that parents shared the importance of music in the lives of their children, and that parents likened music to a “drug... when nothing else seemed to help, in situations of anxiety, self-destructiveness, anger, fear and sadness” (p. 127). Fang (2010) explored how music was helpful in the development of learning skills of two children on the autism spectrum. Music enriched the children’s lives in areas of enjoyment and functionality. Fang credited the parents of the children for recognizing the value of and for providing music in their children’s lives.

Parental involvement in and perceptions of musical development. Koops (2011) interviewed five parents who were asked to describe their current and desired role in their children’s early musical development. The parents reported satisfaction in working with their children, and they liked having their children see them in roles other than caregiver; however, parents did not have a desire to plan or lead the class. Some parents wanted “more information about [their] children’s musical development and the teaching method used in the class” (p. 13).

Fidler and Lawson (2003) explored 90 parents’ perceptions about the education of their children who had one of the following chromosome genetic syndromes: Down syndrome, Prader-Willi syndrome, or Williams syndrome (WS). The researchers noted that “parents of children in the three groups overall tended to bring up issues that were related to the educationally relevant features of their child’s syndrome” (p. 202). They found “that parents may support the tailoring of educational programming to meet the syndrome-specific needs of the child in terms of classroom instruction and services

received” (p. 203). Parents of children diagnosed with WS desired an increase in and modification of music services for their children. Other studies have indicated parents’ desire for increased services in areas in which their children naturally excel such as music; these same parents also requested more aides in classrooms (Fidler & Lawson, 2003).

Parental Perceptions of Music Education for Children With Exceptionalities

In order to discover significance of the musical home environment as well as parents’ priorities of music-specific activities in the music curriculum, Addison (1990) conducted a survey using a Likert scale in which parents could check responses such as *often, sometimes, never* or *agree, not sure, disagree*. Addison asked one question with an open-ended response at the conclusion of the survey: “Have you any other comments?” (p. 135). Ninety-six parents, a total of one in 12, added responses that ranged in opinions of what type of music to teach, who should teach music, and how and why music should be taught. Addison’s research, designed to gather specific teacher-driven data, was designed during a time when teachers were becoming aware of parents’ rights. The open-ended, qualitative question at the end of the survey enabled Addison to document parent-generated perspectives beyond the scope of the questionnaire and led me to believe that a qualitative approach may enable parents to disclose the essence of their experiences and the meanings they make of music education.

Colon-Leon (2018) cited “schools’ values [sic] and practices; parents’ motivational beliefs; and parents’ impressions about music” (p. 139) as the primary reasons parents of elementary and middle school-aged children with exceptionalities

became involved at four schools across the eastern U.S. Parents who participated expressed a desire to receive more communication from music teachers. It was noted that the greater the severity of exceptionality, the more parents participated.

Parents as Resources of Information

Addison (1990) concluded in his survey that teaching methods should be attractive and accessible. The first sentence in the report is worth noting:

In these days when parents' rights, expectations and responsibilities are in most teachers' minds, and are a part of government thinking, and when the National Curriculum is being hammered into shape both outside and inside the classrooms, it perhaps behooves teachers with an interest in music to find out something of what parents think about music's place in the curriculum. (p. 133)

According to Dai and Schader (2002), parents initially pursue music education for their children to help them acquire general musical knowledge; however, once the child becomes more advanced, many parents perceive that they (i.e., the parents) face dilemmas and choices. What effects do parents have on their child's musical endeavors and concepts of success? Are perceptions of musical achievement attributed to internal or external loci? How much do gifted students (i.e., those who perceive themselves or are perceived by others to be successful) attribute their success to be affected by parental "beliefs and by dominant social expectations" (Evans, Bickel, & Pendarvis, 2000, p. 81)? Evans et al. addressed these research questions, and questioned whether students, parents, and teachers attributed students' musical success in similar ways.

The researchers reported being surprised by the self-serving nature of the results of their work: Parents perceived that their children's musical accomplishments were related to the encouragement and opportunities parents provided their children.

Conversely, musically accomplished students reported feeling discouraged by family and friends as they developed in music. Teachers discounted family and friends' influences on musical development in talented children, and, instead, regarded the work done in school, including in-school rewards, as the primary influence in the development of "talented children's musical ability" (Evans et al., 2000, p. 89).

Parental Perceptions of the IEP Process

Barclift (2010) examined perceptions of parents with children on the autism spectrum. Parents described their life experiences and perceptions regarding the language teachers used to communicate with them during IEP meetings. Barclift advocated on behalf of parental advocacy and expressed the need for partnerships between parents and educators and also noted that research on parental perceptions in the field of autism is scant.

Childre and Chambers (2005) documented family perspectives on the IEP process using a student centered approach using Childre's previously developed Student Centered Individualized Education Planning (SCIEP) tool. Parents reported perceptions of increased credibility and involvement in the IEP process when working with educators and therapists, allowing for future goal development for their middle school-aged children as never before. The SCIEP approach was developed for use during an IEP meeting "to address legal requirements while incorporating person centered techniques" (p. 218). Childre and Chambers (2005) reported that "several themes arose as parents discussed difficulties that they had encountered in educational planning: noncollaborative actions, failure to understand family perspective, service provision problems, and

networking breakdowns” (p. 223). The themes that were revealed in this study led me to believe that my own study could offer valuable insights.

After conducting interviews with 20 fathers who regularly attended their children’s IEP meetings, Mueller and Buckley (2014) reported that these men had very clear conceptions of the IEP process set forth by the concepts of IDEA. The fathers described the meeting process as “overwhelming and insufficient,” and their visions of the meetings did not materialize (p. 124). In fact, the fathers characterized the meetings with the words, “overwhelming, daunting, challenging, and confusing,” as well as painful and emotional (p. 125). One father noted the irony of harboring the perception of the IEP meetings as “impersonal” when they are constructed to be individualized (p. 125).

By exploring the perceptions of five teachers and four parents regarding parental participation during the IEP development process for students with significant intellectual exceptionalities, Dodge (2018) noted a recurring theme: the value of collaboration. However, teacher perception descriptions were focused on setting-related experiences, and parent perception descriptions were focused on interaction-related experiences. Dodge stated that “setting-related experiences refer to the aspects of experiences that are affected by factors in the environment in which the IEP development process takes place” (p. 150), and “interaction-related experiences are those experiences characterized by the qualities of interpersonal interactions between parents and teachers” (p. 150).

After examining 88 IEPs of students with intellectual and developmental exceptionalities, Kurth et al. (2019) revealed that 33% of parent concerns were not addressed in IEP goals and supplementary aids and services. Furthermore, the wording on

IEPs suggested that teachers often excluded parents; for instance, teachers indicated that parents were *consulted* by the team. The term “consulted” suggests that parents were not considered part of the team. Additional findings suggested that student participation in IEP meetings was limited and that general education teachers were absent from IEP meetings 10% of the time. Recent research studies confirm systems of professional-dominated decision-making and/or lack of shared decision-making involving families (Elbaum, Blatz, & Rodriguez, 2016; Hancock, Beneke, & Cheatham, 2017; Love, Zagona, Kurth, & Miller, 2017; Ruppert & Gaffney, 2011; Tucker & Schwartz, 2013). These studies, including the aforementioned Childre and Chambers’s (2005) qualitative inquiry into parental perspectives of the IEP process, are examples of family involvement research. The research confirmed for me that it is important to conduct research that documents parents’ perceptions of family involvement in the IEP process and that relevant themes may emerge in my own study.

Family Involvement

Family involvement research has come to the forefront of importance in education for children as exemplified in the research conducted within the Harvard Family Research Project (HFRP) at the Harvard Graduate School of Education. The HFRP compiled a bibliography of research, which is not presented as an exhaustive bibliography, but is a notable documentation of research including journal articles, dissertations, papers, and books. HFRP is now the Global Family Research Project, a separate entity from Harvard.

McPherson’s (2008) research documents the role of parental influence and

emotional climate of the family upon music education for their children. He noted that very few studies exist in the field of family involvement in music, although family involvement is often researched in other academic areas. This supports the premise that there is a need for this type of research in this field of music.

Gap in the Literature in Music Education

A gap exists in the literature in the field of music education, regarding research about children with exceptionalities. In particular, there is scant research that documents the perceptions of parents regarding educational practice. The literature reviewed confirmed that parents have made historic progress regarding the education of their children with exceptionalities, in particular the ways and setting where children are taught.

This study has been conducted to develop an understanding of the perceived experiential consciousness of parents who have offspring with exceptionalities who are pursuing music education beyond the public-school system. Legislation stipulates that parents be part of collaborative education teams and that parents should attend meetings and have opportunities for involvement, yet the perceptions of parents' experiences remain undocumented. Gascoigne (1995) pointed out that it is the parent who provides a constant link in a multifaceted collaboration of specialists, with the potential to "fully inform" members of the partnership (p. 45). If parents are understood and have a voice in the IEP process, students may benefit.

My reading led me to believe that if parents have avenues, other than advocacy, to have their perceptions of music education revealed and documented, the path and

development of music education may take on new dimensions; also, if educational planning were more proactive than reactive, policy could be positively affected. Research could enhance Epstein's (1995) concept of school, family, and community partnerships, Taylor's (2000) concepts of collaboration and teamwork, and Creech and Hallam's (2009) concept of learning partnerships based on interpersonal interactions between parents and teachers, ultimately promoting enhanced learning for the students. Then teachers could be better prepared to teach diverse classrooms.

Research that discloses parents' experience and perspectives of music education for students with disabilities was conducted to help fill a gap that exists in the literature in music education enabling this important resource (i.e. parental perceptions) to be disclosed and documented. Following Westbury's (2002) lead, my interest in what parents imagine about music education, what they believe they understand it is and does for their child, and what their dispositions are, led me to this research. I wondered whether these parents had the opportunities to share these insights at IEP meetings in the past, whether they found other avenues or methods to develop discourses with teachers, and what reasons they attribute as to why their children continue to pursue music education into adulthood.

CHAPTER 3

METHOD

Researching Lived Experience

The purpose of this qualitative, phenomenographical study was to document and analyze the perspectives of six parents of students with exceptionalities at a postsecondary music academy in the northeastern United States to discern the essence of the parents' experience and the meanings they attribute to music education. This inquiry was guided by two research questions:

- What perceptions of experience do parents (of individuals with exceptionalities who are pursuing postsecondary music education) have?
- What meanings do these parents make of music education?

To answer these research questions, I employed a phenomenographical approach in a second-order perspective of describing others' experiences (Marton, 1981). How does one discover the essence and consciousness of lived experience? Phenomenography goes beyond merely seeking out the participant's self-expressed philosophical experience, as in phenomenology, to a phenomenographical grasping at and potential conceptualization of the meaning behind the experience (Marton & Booth, 1997). Marton and Booth pointed to qualitative differences in the purpose of phenomenology and phenomenography. Where phenomenologists seek to discover how the participant "experiences their world" from a first-order perspective, phenomenographers might ask "What are the critical aspects of ways of experiencing the world that make people able to handle it in more or less efficient ways?" (p. 117). Phenomenographic researchers study

the ways others experience the world in a second-order perspective. Marton and Booth differentiated the terms:

When we say “qualitative differences” here, we are implying qualitative differences in the way things are experienced (understood, conceptualized, apprehended, etc.)—as phenomena, situations, or learning itself. The question that now becomes interesting is that of what it means and what it takes to experience something in a particular way, and it is this question that we now address: “What does it take to experience something in a certain way?” (p. 86).

Creswell (2007) asserted that choosing a particular qualitative approach is dependent upon the researcher’s stance regarding five assumptions: ontological (or nature of reality), epistemological (knowledge), axiological (values), rhetorical (language), and methodological (process). My personal paradigm (worldview) prompted my choice to conduct descriptive research. Additionally, my view of the world affected not just the choice of the phenomenographical methodology, but the ways in which I framed the voices of the participants: from gleaning participants’ ontology (using quotations of their views of reality), gaining knowledge from the field based on participants’ values in relationship to my own, and using narrative in a process of deduction.

I chose phenomenography because I sought a way to map “the qualitatively different ways in which people experience or think about various phenomena” (Marton, 1986, p. 31). Marton pointed out, however, that phenomenography is not “concerned with perception and thought as *abstract* phenomena” but rather “with the *relations* that exist between human beings and the world around them” (p. 31). I embraced Bowden and Walsh’s (2000) concept that phenomenography is developmental and contextual in nature and can serve to expose individuals’ experiences. Phenomenography allowed me to delve into the meanings participants held in relationship to their experience.

Three methods of data collection were utilized to provide triangulation (Merriam, 2002): Participants were interviewed, interacted on a blog, and kept journals. According to Tesch (1990), phenomenologist researchers must study their own consciousness of experience in order to understand others. Likewise, it is important that the researcher exposes personal experience with the phenomenon being studied (Creswell, 2007) in phenomenography. *Bracketing*, which Merriam (2002) describes as “the process of epoche, allows the experience of the phenomenon to be explained in terms of its own intrinsic system of meaning, not one imposed on it from without” (p. 94). Gearing (2004) identifies several types of bracketing including ideal bracketing. In this form of bracketing, the researcher suspends “internal beliefs, ego, experiences, understandings, biases, culture, judgments, and assumptions” (p. 1436) and then, following the temporally suspended stage of data collection, “unbrackets,” and reintegrates into the research. Phenomenological techniques of bracketing, intuiting, analyzing, and describing were used in documenting data collected from interviews, blogs, and journals of six parents from which “intensive and exhaustive” (Tesch, 1990, p. 68) descriptions and themes emerged, leading to a general structure of the phenomenon (Tesch, p. 68).

Ashworth and Lucas (2000) warn researchers about the possibility of losing restraint and moving too quickly to establish structured data. In addition to bracketing, researchers must also embrace *empathy*, in which there exists “a detachment from the researcher’s lifeworld and a [sic] opening up to the lifeworld of the [participant]” (p. 299). The interview is an opportunity for reflection and therapeutic introspection, and is a place where a theme is presented and reflection on the theme is allowed, mindful always

of the relationship between the interviewee and interviewer (Marton & Booth, 1997, p. 130). One cannot generalize to a larger population from such a small sample, but my study documents a small group of parents' perspectives and engages in what Jorgensen (2006) describes as a conversation that needs to take place on local, regional, and international levels "from our differing philosophical perspectives" (p. 20). It may have pertinence and potential permanence in the field of music education as it relates to some views held in society (today) in the U.S.

Criteria in Recruitment of Participants

Six participants were selected using the following purposive criteria: *Parent* was defined as a person of any gender who has parented or reared a child with exceptionalities, including biological, adoptive, or foster parent regardless of gender or sexual orientation. *Exceptionality* was used instead of *disability* to reflect that all individuals have ability. Parents who experienced the school IEP process were defined as parents who attended at least one IEP meeting where their child was enrolled in a public or private school. The first six participants who met the criteria were selected.

Interview Methods

I began by disclosing the context of my experience and interest in the phenomenon, a practice suggested by Merriam (2002). I followed the constant comparative method, defined by Merriam as "continually comparing one unit of data with another in order to derive conceptual elements of the theory," without actually developing theory (p. 8). The interviews, which were transcribed and coded, varied in length. Creswell (2007), who wrote that the phenomenological data analysis strategy

includes analyses for “significant statements, meaning units, textural and structural description, [and] description of the *essence*” (p. 79), served as my guide.

Data Analysis

Using Creswell’s (2007) strategy as a guide (pp. 60–62), the following analysis steps took place:

- I wrote “about the combination of objective reality and individual experiences” in an attempt to *bracket out* my own experiences.
- Data collection took place in the form of “in-depth” and “multiple interviews” including data collected from blog and journal entries.
- I asked two broad questions of my six participants: “What have you experienced in terms of the phenomenon?” and “What contexts or situations have typically influenced or affected your experiences of the phenomenon?” (Creswell, p. 61).

Since Creswell (2007) suggests that more open-ended questions may emerge, these two broad questions were the primary focus of initiating the interviews, leading to a “textural description and a structural description of the experiences, and [to] ultimately provide an understanding of the common experiences of the participants” (p. 62).

Recruitment of Parent Participants

I felt I had access to possible participants for this study at a postsecondary music academy for individuals with exceptionalities in the northeast. After attending two student performance nights there, I contacted and met with the director of the academy to describe my research intent. Following our meeting, the director sent an email to all parents of students at the school regarding the opportunity to participate in this research.

Three parents contacted me directly via email and indicated that they were interested in the study. I asked the director to remind parents regarding the opportunity to participate and received three additional responses. After receiving those six commitments, there was no further contact with the school director.

The participants. The six parents who chose to participate were all biological mothers of male children. Five of the six mothers were married to supportive husbands. The other parent was a single mother. Two of the sons were on the autism spectrum, three sons had been diagnosed as individuals with Williams syndrome, and one had a cognitive exceptionality due to complications at childbirth. A recruitment letter (see Appendix B) and consent form (see Appendix C) were sent to each of the six mothers; consent forms were sent back to me signed or were signed prior to the first interview.

Privacy measures. All IRB stipulations and protocols were followed. Parents had the opportunity to review the recruitment letter, ask questions, and consent to the form prior to initial interviews per IRB regulations at Boston University. The signed consent forms were placed in a locked safe. Interviews were recorded with participants' permission. Recorders and recordings of all interviews were stored in the same locked safe. All interviews were transcribed verbatim and kept on a password-safe computer.

Interview details. The first interviews took place in two coffee shops, two restaurants, and two hotel lobbies, which were public venues based on the mothers' choosing. Follow-up interviews took place in participants' homes, at the same restaurant as the initial interview, or with follow-up telephone conversations. To familiarize participants with my experience in music and music education, my 2-year experience as a

paraprofessional, as well as my character and personality, I introduced myself for about the first 5 minutes of each initial interview (Creswell, 2007). I had approximated that the first interview would be only 45 minutes in length, but in actuality all six parents' initial interviews lasted hours each as each parent seemed eager to share the perceptions of their experiences.

Three methods of data collection. Data were collected from interviews, blog interactions, and journals. Initial and follow-up interviews were selected to provide in-depth information in a private one-on-one setting. The blog was selected as a medium in which participants could interact with one another, as well as with me. Participants had the opportunity to share private, thoughtful perspectives in journals.

Data Analysis

Data from interviews, blogs, and journals were transcribed and coded. Following Moustakas's concept of *horizontalization*, I highlighted significant quotations in the transcribed data, which enabled "clusters of meaning" to develop into the creation of themes (as cited in Creswell, 2007, p. 61). I used these "statements and themes...to write a description of what the participants experienced (textural description)," and the textural description was then put into context in the form of an imaginative structural description (p. 61). Finally, from the structural and textural descriptions I derived, I wrote the "essential, invariant structure (or essence)" of the phenomenon revealing the "underlying structure" (Creswell, 2007, p. 62).

In this phenomenographic study I documented the perceived experiences of six parents of young adults with exceptionalities who have experienced a school IEP process

and whose children chose to continue music education into adulthood at a postsecondary music school for students with exceptionalities in the northeastern U.S. The method used in this descriptive research is quite typical for a qualitative study of this nature.

However, the analysis of the findings revealed unique details about the essence of experience in the field of exceptionality and the meanings these six participants made of music education.

CHAPTER 4

FINDINGS

Introduction

Purpose and Questions

The purpose of the study was to document and analyze the perspectives of six parents of students with exceptionalities who attended a postsecondary music academy in the northeast United States. I employed a phenomenographic methodology to discern the essence of the parents' experience and the meanings they attributed to music education. My analysis was guided by the following specific research questions: What perceptions of experience did parents (of individuals with exceptionalities who are pursuing post-secondary music education) have? What meanings did these parents make of music education?

During interviews, parents were asked a single open-ended question. I inquired, "Can you tell me what you have experienced?" Thus began my journey of phenomenographical enlightenment, in which I listened as participants described conceptions of their experiences. Following phenomenographical method, the parental perceptions were documented from the parents' own perspectives, and not that of the researcher. The findings revealed that the meanings these parents made of music education were relative to contexts, situations, beliefs about music, exceptionality, societal norms, IEP meetings and engagement with teachers, and about parenting a specific child with a particular exceptionality. The parents who participated in this study originally had no concept of the meanings and values they would later place on music

and music education for their children.

Participants in Context

Mothers sought opportunities or created them. Confronted with sociocultural systems not yet aligned with their own progressive attitudes about education for individuals with exceptionalities, the mothers in this study relied heavily upon their own intuitions, verve, and fortitude. The meanings they made of the world in which they were thrust when they gave birth to a child with exceptionality and/or when factors prevailed beyond their control led some of them to create environments in which their sons' desire to continue learning could exist. The medium they chose was music education.

Three of the mothers in this study inspired a music camp for students with Williams syndrome (WS) with other parents, reportedly long before anything like this existed. The camp led to the creation of a music academy. Although the academy originated for students with WS, soon students with other exceptionalities were included. The six mothers did not just perceive and experience the educational system, but acted for change based upon on their intuitions. This study revealed their tremendous sacrifice, insight, and perspectives on music education and the American education system.

Complexities of functioning in systems: Creating anew what the system did not provide. Ensuring continued growth through music education began with the mothers' perspectives on exceptionality and how they identified with what they believed music did for their children. Each parent helped their son secure a postsecondary education infused with music education and helped their son locate this opportunity. When opportunities for music and education did not exist, they created them. Each of

these mother participants ensured that their son's strengths, limitations, and potential were not just properly addressed and evaluated by what was standard practice and/or state of the art; they searched for and created that which did not exist. Using current assessments of identification and labels, they each ensured that their son's abilities were also affected by what they, the parent, believed could be or should be.

Parents' Psychological and Behavioral Postures

Themes, questions, and topics that underscored parental postures emerged from the data. From the time of the first diagnoses of their children's exceptionalities (close to 40 years ago for some) to the present, the six parent participants actively engaged in three psychological and behavioral postures: *Parental Perceptions*, *Parental Research and Critique*, and *Parental Actions and Reactions* (see Appendix D). Each mother revealed the same pattern of perceiving/intuiting, discovering/researching, and acting/reacting in order to provide for their children.

Blog

Five of the six participants interacted on a private password-protected blog. The blog contents seemed well received, and participants seemed comfortable sharing information; one participant, however, did not engage in blogging, even after I sent the blog contents to her via email. The same participant opted not to keep a journal. Her initial interview, however, was very informative and detailed. Another participant dropped out midway through the study for personal reasons to attend to her son's medical needs. Four of the six participants actively participated in all three data collections; all six had very thorough interviews, which are included in the dissertation.

Journal Participation

Each participant was mailed a hard-copy journal. Participants were provided subjects that they could choose to write about, but were encouraged to journal in an open-ended approach to write about their experiences. They were given the option to write in the journal or to journal online and to return the journal either in person or in an email. Two participants chose to write in the journals and two others sent journal entries via email; two chose not to journal. I kept detailed field notes immediately following interviews and during the transcription process in the form of a personal journal of my own. This journal documented my own experiential conceptions of the data and experience as researcher during the process of data collection and transcription.

Theme One: Perceiving and Intuiting

Perceptions of Exceptionality

Words evoke emotional memories, thoughts, and meaning. Prior to interacting on the blog with one another, each of the six mothers revealed in personal one-on-one interviews with me that they believed their son deserved a life of stimulation, growth, and continued education. Following initial interviews, the mothers interacted by blogging. I purposely included famous quotations at the top of blog postings based on information gleaned from interviews. These six words, “I have the audacity to believe...” in Martin Luther King’s (1964, para. 6) Nobel Prize acceptance speech, seemed to move many of the mothers: “I have the audacity to believe that peoples everywhere can have three meals a day for their bodies, education and culture for their minds, and dignity, equality, and freedom for their spirits” (1964, para 6). This quote, and others also placed at the top of

blog postings, served the purpose of moving parents rather than specifically asking, “Tell me what you believe...” Interacting on the blog, one parent shared this: “Moved by the quote from Dr. King, I’d like to share a favorite quote from Helen Keller: ‘One can never consent to creep when one feels an impulse to soar’ (Keller, 1904, p. 119). Music means soaring for my son.”

One mother described her paradigm when a private religious preschool rejected her son based on his exceptionality and when, later, she had to force a public school to provide services to him through litigation. By high school, when educators attempted to steer her son into a vocational track of menial labor, she continued to shape her worldview and perceptions of exceptionality. Believing that educators and members of society imposed limits on individuals with exceptionalities, this mother witnessed remarkable progress through music education for her son on the spectrum:

I wasn’t willing to settle for mediocrity during [our son’s] school years, and I certainly wasn’t willing to watch him be warehoused for the rest of his life in a substandard adult services program upon turning 22. Thank goodness there is a program like [the postsecondary music academy] where the study of music provides such a magical and motivational frame work for our kids to thrive in.

She believed the social system was ill-equipped to address the issues of postsecondary life for the growing numbers of individuals on the autism spectrum.

Coming to terms with assessment and diagnosis labels and believing that her son’s potential should not be underestimated or limited by the system/s in which her son functioned, a mother responded to another mother’s blog posting: “Yes, those comments like ‘He won’t ever...’ burned into me, too, and made me want to find a way around them.” Many mothers in this study reportedly heard professionals in medical and

educational systems utter words like “He won’t ever...” many times.

In a blog response, a mother of a son diagnosed with a cognitive exceptionality responded after reading the Marcus (2008) quotation, “Disability is not a brave struggle or courage in the face of adversity. Disability is an art. It is an ingenious way to live” (para. 5).

I think Neil Marcus’s quote and definition of disability describes my son, though he doesn’t have the language competence to label it as “an art.” As an individual born with a host of special needs, least of which is intellectual disability, my son doesn’t know any other way of life. Consequently, I don’t think he would label himself courageous or brave...this is just who he is.

The impacts and understandings of exceptionality. Participants wanted to attach a label to whatever exceptionality their sons had to know what it was and the impact it might have. As parents strove to get accurate diagnoses, there was also another dimension that affected how exceptionality was perceived: the context of society in relation to exceptionality. One mother, having always worked in a corporate position, made a telephone call to her workplace as her/their child was being whisked into heart surgery at week 6 postpartum:

The day I was due back to work from my 6-week leave of absence... he had his first heart surgery. We didn’t know he had Williams syndrome at the time. We just knew he was in heart failure. I actually called [work] from the ER waiting room, and said “I won’t be in today.”

Viewing exceptionality from one’s own lens: Harsh reality of the unknown.

Another participant acknowledged that she saw the world through her own worldview, her own paradigm. When considering the exceptionality, her perspective was framed by unassailable viewpoints:

I see everything from the autism-lens because that is my son's disability, and autism is, I think it is a very fairly new.... I think it is manmade. You know, 40 years ago, it was one in ten thousand, and now it's like one in forty. So something is going very wrong.

One of the participants raised her son as a single parent, and this was part of her lens, her paradigm. The words she recounted illustrated the biases held by those around her, including the medical establishment and the father of her own child: "When he was born they were like, 'Just put him in an institution because he's never going to accomplish anything' ... because he went a long time without oxygen..."

Nurturing those with exceptionalities. In order to generate interaction among participants on blog postings, I used headings of Thoughts on "*Sustaining Human Growth*" and "*Composing a Life*" (Bateson, 1990) that introduced quotations that followed. I felt that anthropologist Mary Catherine Bateson (1990) captured the essence of what is at stake when human development is at risk, a topic all the parents addressed in their initial interviews, and I wondered if a discourse might ensue in the blog if passages from Bateson's book were included. It did.

Perceptions of Music

Exceptionality, music, and the medical system: The effects of music on being. Making sense of a child's *being* takes many forms. One mother, an eloquent speaker, painstakingly, and with great candid and personal exposure, described and revealed what music did for her (and her husband's) son in the earliest moments of his life as their son was laid in her arms to die following human error during the delivery:

While we sat there, I sang to him. First I sang one song, then I sang another, and another, and he never passed away. The nurses would check on us every so often, and they—at some point—the doctors, realized that what we were doing was

treating his edema by taking him off of the fluids, his cerebral edema. And because [of this], he became more alert. I could tell that when I would stop singing, I could feel the little tiny head would turn... and then I would start singing, and I could feel him settle down again.

General perceptions of music and exceptionality. During an interview, one participant described what she and her husband witnessed while preparing to leave a hotel for another day of testing, in hopes of receiving a diagnosis for their 3-year-old son:

At that time he didn't speak at all, so that was the trouble. Well, it was one of his delays. He had some isolated words early-on, but then didn't speak... So then my husband said, "Well, well,..." you know, as I'm fussing for us to get ready for the last days of (testing), and he said, "Well, listen to him. Listen to him!" So I quieted down and listened to him. Well, he (their son) was singing "Baa, Baa Black Sheep," and he hadn't ever said a sentence, and he hadn't put words together, and he was singing "Baa, Baa, Black Sheep!"

This experience helped the mother formulate meaning for music and what it could do to and for her son, a 3-year-old diagnosed eventually with WS. She believed it was through music that she could reach her son. It was this musical experience that first gave her hope that her child was processing information.

Perceptions of what music can do: Providing instruments to WS children.

The same mother shared observations she and her husband made of their son after providing him with instruments. They were formulating perceptions of music:

We began to notice his interest in music, and [we] got him a little tiny keyboard... He treated it carefully, he picked out notes, and did not bang on it. From that point on, I really bought every kind of musical toy for him that I could... a xylophone, rhythm instruments, maracas, a wind-up music box of clear plastic so you could see the movement, a native American drum, ankle bells, a guitar, [as well as] Wee-Sing-Along cassettes.

Another parent of a son diagnosed with WS stated: "And then we realized how rhythmic he was, and so I bought him a drum set for one Christmas when he was... I think he was

either 8 or 9, and he sat down, and he just played it.”

Perceptions of Suzuki lessons for two of the sons diagnosed with WS. One mother’s research led her to find a Suzuki (piano) method teacher for her son. She scoured the literature for any mention of music affinity for individuals with WS and found none. The mother ultimately found a teacher by researching and attending a presentation at a local state college by a private teacher who specialized in the Suzuki method. The father took a day off from work to attend the presentation. The mother had permanently left her university position and was devoting all her creativity and energy to fostering her son’s education, now through the path of music and music education. As a graduate student at a prominent university, and then a professor at another, she was well acquainted with research:

I read an article in a pediatrics magazine by a mother of a child with Williams syndrome who said that her [child] had taken Suzuki piano lessons... And, I really noticed that, in all the literature, music was never mentioned. [In journals,] it was always, you know, about Williams syndrome. There was nothing in it [about music]; it was all about social personality, cardiac ailments, and delays of various sorts, and nothing was ever mentioned [of music].

Perceiving music in relation to exceptionality. Parents hoped that by naming or labeling the exceptionality, this would help them understand their children’s abilities. As they grappled to understand the labels their children were given, they perceived that the labels did not define their children. Mothers, who had initially wanted to discover a name for their sons’ exceptionalities, were now in the process of discovering the essence of what their sons could do and the best ways their sons could learn. In their blogs and interviews, mothers disclosed that they believed their children were innately musical. Mothers revealed perceptions and intuitions about music and its effect on their offspring;

these perceptions were based on conceptions they held of their sons' affections toward, and abilities enhanced by, music.

Christopher Small (1998) addressed what one experiences musically as something he theorized as "musicking":

If everyone is musical, then everyone's musical experience is valid. That being so, a theory of musicking, if it is to have any basis in real life, must stand up to being tested against the musical experience of every human being, no matter who she or he may be or how the experience was acquired....These are important matters, perhaps the most important in human life..." (p. 13)

Parents cultivated their children's natural aptitudes toward music. When the system was ill-equipped to provide opportunities, they fostered and enhanced this musicality and created their own. Three mothers created environments in which this musicality could be experienced, nurtured, and shared. They joined together and networked with one another and created their own social system. At the camp and later at the music academy, they created the "set of relationships" (Small, 1998, p. 13) in which their values and beliefs could come to fruition; their children could not only learn how to play, but their act of musicking could stand on its own, with meaning. Music education was the conduit to a life with purpose.

Community of performance: Variety Hour at the Academy. Friday afternoon performances (which continue to this day) at the music academy were called Variety Hour. This community of performance offered opportunities to socially engage with each other and the audience in a concert venue. One parent described the academy's Variety Hour (with roots spanning back to the music camp that parents had started before founding the academy) this way:

Variety Hour was created early on...as an alternative to recitals, a testing ground for works in progress, a fun format with varied acts like some old TV shows (and some of today's reality shows), a Friday afternoon end-of-week celebration.

One parent described the role of the academy staff at Variety Hour:

And then there is the role of staff in Variety Hour, who accompany, who appear in duets and ensembles on equal footing with the students, who comment with admiration while giving perceptive suggestions.

The following blog entry about the academy's Friday night Variety Hour is from the perspective of a mother whose son is on the autism spectrum:

It's amazing to watch the growth of other students via [the postsecondary music academy] Variety Hour. I've witnessed extreme reticence and shyness blossom into extroverted confidence in so many students. It's remarkable!

Perceptions of Music Education

Participants' sons' first experiences in formal music education took place in public school programs in elementary schools. One mother, whose son is on the autism spectrum, recalled an experience at that level:

The music teacher was a really nice.... She didn't have any special-ed training... Some people just get it, though, you know... She was just a regular music teacher, and you know, he (our son) was forced on her, like you know, "He's in inclusion now, so you're going to have him;" but she just loved him.

The music academy provided a learning environment in which students could continue postsecondary music education. Some graduates of the postsecondary academy continue to study music there and have musical opportunities for performance. This lifelong opportunity of growth and learning was realized through action, but began with perceptions of children and their love of music.

Creation of WS camp: Origins of the Academy. A music camp, conceived and created by some of the parents in this study, ran from 1994 until 2004. The academy,

attended by all participants' sons, was founded in 1999. These two settings, the camp and the academy, began with one mother's vision. This mother recalled sitting outside a piano teacher's studio decades ago, looking over pamphlets for a music camp for regular students. She instantly knew her son could never attend that camp. He wouldn't be able to, for it was not centered on his needs and style of learning. She had an idea: Could there be a way to start a music camp for students with WS? Never before had this community of individuals been brought together.

When the camp opened, a grand experiment, as one mother put it, this was the first time many of them had seen peers diagnosed with WS. Some of the parents, who would attend with their children, were skeptical. Many of their children had not seriously studied music, although they had demonstrated a passion for it.

At this new camp where music education was available to individuals with WS, teachers were of the highest caliber, and students were able to select what subjects they wanted to study. The mother reported that what made the camp experience so intriguing was the combination of the personality and excitement of the students with WS, their passion for this music experience, and the changes that occurred through the music education experience. The passion for music was first exemplified in the energy of the individuals participating in the very first talent show.

Using music as an educational tool. From the ideas first conceived as a music camp came parents' dreams of a music academy. A blog response from a mother of a son with WS offered insight into the academy's vision and the school's first mission statement. She wrote this: "To educate, train, and develop the talent of young adults with

special learning needs in a community that shares a passion for music so they can achieve personal growth and make a positive contribution to society.”

Believing that music could be perceived and used in new ways, that participant wished that there were more ways to perceive music as an educational tool. Having a large role in founding the academy, her personal philosophy and many of her theories about music have come to fruition. Her perception is that music is not only something one does, but that music, itself, can be used to enhance learning. This philosophy of music helped to develop the core principles of the music academy.

Music education at music academy focuses on abilities. In this study were some of the originators of the music academy, mothers who created a place in which music is intermingled with academic and therapeutic education to create unique learning experiences and opportunities for growth for postsecondary students with exceptionalities. When I asked one founder her visions of the school, she stated:

I don't know any other place that uses music as a vehicle to teach. I don't mean offering music lessons. So, there was nothing like that, and there were very few schools that focused on abilities—and not disabilities. And even high school and other schools, you're remediating. By trying to teach, you're remediating. So you spend more time pointing out what they're doing incorrectly—not what they're doing correctly. So, I think that that's philosophically the most important thing: I think you have to focus on abilities, and then try to make corrections, because then you give them the courage and some confidence, and then it negates some of the obstacles that they've developed [for] themselves as failures.

The skill and value of critique. In the interview, the participant shared that students are critiqued at every level at the academy, including after music lessons and performances: “The staff may say ‘You know this is so good. This was your first time; you stood there, you held the microphone.’” She said this in another interview:

Nervousness is an issue for some of the students. It's not so much for students with WS, who have... just an overeagerness to connect which is—comes across as, you know, often very wonderful... They just all want to join in, and so that hasn't been much of an issue, but I see that it is for students with other diagnoses... and certainly it is [beneficial] for everyone, for everyone. And, I think that encouraging atmosphere is really wonderful at the academy in the music education, and I guess that is therapeutic as well. [Do] what you can do, and there's a level of appreciation for people, [and they] seem to get over that kind of nervousness.

Importance of community and social setting for the music academy. Parents disclosed in interviews that considerations surrounding the inherent qualities of those with WS were vital in procuring the best setting for the music academy. When starting the academy, an opportunity arose to affiliate with a university set far away from a supportive social system. Yet the founders believed students could only evolve and reach their potential in an environment rich in educational philosophies and infused with music, one that could provide social and community assets. They believed this would not have been the case at an isolated college campus with regular education students. The founders were, in effect, searching for social capital. When a university in a rural setting came forward to affiliate with the academy, it posed a dilemma because, educationally, the college could have been a good fit. The academy's setting, however, seemed equally important as the academic resources, particularly for those diagnosed with WS:

[The university in the rural setting could have written] our curriculum for us, music-infused curriculum, and that was extremely exciting. Only problem: It's [in a particular community]. It's not a safe place for people who... chemically... have too much, oxytocin, which is a chemical that is [associated with] "friendly"... We wouldn't have been able to keep them safe because we'd be on a college campus, with other 18-year-olds who are doing what they want to do, and our 18-year-olds are emotionally 13, and they're a very giving population, loving, giving. But that was one school that was interested [in a possible affiliation with the then-proposed music academy]... It was a real dilemma, and the school of psychology would have taken over... a fantastic department there...

And when we chose the [present] property... because it was on the bus route, it was in a 20-mile radius of many, many elder-care facilities, and it had 30,000 young people rotating in and out on these busses, and it's a very, I think, good climate for our student body—but we were separate. Completely separate.

The academy is a separate entity, not affiliated with any other postsecondary places of education, and is nestled in an area extremely rich in social capital.

Educational methods at the music academy. Since selecting a stage for social capital to exist and flourish was not enough, the founders' philosophies about the future education at this academy involved much more than an appropriate, safe physical setting. In deciding how individuals would be taught, the founders literally and figuratively set a stage in which meaning could be infused within the social capital environment. A majority of the founders were parents of students with WS. All the founders combined their assets based upon perceptions of the nature of WS, of students with exceptionality, and ways in which students could learn best.

Students flourished. Soon the 9-month model became year-round. The academy, now year-round with 7 weeks of breaks, educates 65 adults under the age of 40. Valuing and understanding the exceptionality, finding the best setting for those with the exceptionality to learn, setting the length of the school year, and funding were not the only considerations. This music academy model was also fueled by perceptions of music and music education.

The capacity for growth through music education. A mother blogged about the capacity of intellectual growth for her son through the study of music:

His capacity for music, especially, continued to grow and grow, from carrying a tune, to playing piano, to taking up several instruments. Even now with years at

[the postsecondary music academy] behind him, he continues to advance in his playing—he has never reached a plateau, and that astonishes.

One participant, a founder of the academy, observed this about a student there who was diagnosed on the autism spectrum and spoke to an audience between sets of a recent concert:

I met him years ago when he first came. To speak so well (now, after music-infused education), you know, it was really a beautiful achievement, and he had a sense of himself. So that's very, very important. We do look at the whole—you know, that's what we want is the whole person.

Perceptions of Education

There was a consensus among the participants that by secondary school, their offspring had just begun making educational strides in intellectual growth, following difficult socialization processes. Mothers objected to educators' attempts to direct their sons into vocational training tracks at that stage. Parents' perceptions of education were driven by memories of their sons' experiences in public school systems, the early days of mainstreaming and inclusion, of IEP meetings, of interactions with school-system professionals, and later, of transitions from secondary to postsecondary education and music-infused educational principles at the music academy. The memories seemed significant because they drove parents to act in significant ways.

Perceptions of inadequacies in educational system. In an interview, one participant described perceptions of her son on the autism spectrum:

He was always really a midspectrum kid. You know, he was not the super high-functioning kid that was going to be mainstreamed all through school and acing his classes, but was socially awkward; but he was not at the nonverbal end, either. And I always saw the potential in him. You know, I always saw that there was intelligence there even though he struggled with a lot. Right off the bat when he was in preschool, I wanted him included.

After a religious preschool had excluded another participant's son due to his disability, she became driven to have him included. She began to research, discover, and ultimately fight for what she deemed best for her son. In an interview, the mother described an elementary school experience in which she perceived that teachers' inadequacies may have harmed or hindered her son's natural progression. The mother believed that teachers had been basing the quality of her son's day on the amount of echolalia he exhibited and noted that getting rid of echolalia was even one of the IEP goals for her child. She recounted in an interview how one young teacher stated, "Ahhh, it was like a horrible day for him today: so much echolalia," and how on other days the teacher would recount, "Ah! Such a great day! No echolalia."

The mother shared in the interview that the teachers' recommendation had not felt right to her. She also remembered, "And then I went to a lecture by a notable speech and language pathologist (Quill, 2000) who said, 'Don't ever let anyone tell you that echolalia is a bad thing. It's language, and it's not functional, but we can shape it.'" Research confirmed that echolalia is viewed as having communicative benefits (Prizant & Duchan, 1981; Rydell & Prizant, 1995; Stiegler, 2015). Nothing beneficial about echolalia had ever been presented to her by the teacher, however. The participant was forthcoming in how this made her feel and react:

So, I mean, here I was thinking, "That damn echolalia; make it go away." And then I learned "No; it's actually a function to it." So, right off the bat, I was starting to like butt heads with these teachers, these fractious 22-year-olds who think they know everything.

The mother shared in the interview that she had not presented this information to the teacher to demonstrate that she had conducted research herself and discovered

something the teacher did not know. The participant revealed that she had done so because she had new information and expected that it would be welcomed, yet she felt as if her own inputs were discounted. She felt strongly about the authoritative stances some teachers took, and she believed that many educators followed a rigid Applied Behavior Analysis (ABA) therapy, one she described as getting “in the way of other therapeutic interventions.” She stated, “The ABA folks think all autistic behavior must be extinguished, and the student must act normal.” The participant believed her son was berated, faulted, and criticized for something that notable speech-language pathologists considered beneficial and inherently natural for someone on the spectrum. It is unknown whether or not the young teacher she encountered had received training in current speech-language therapies for individuals on the autism spectrum.

Reporting that she was not treated as a part of a collaborative team, it seemed evident to me that the participant felt justified in sharing new information about echolalia, yet it was not welcomed, valued, respected, or heeded. Perhaps what affected the mother the most, was that she could not take back time and fix any negative impacts the teacher’s beliefs and actions may have had on her son’s language development nor change how her son felt. The mother was quite aware, however, of how much stress it caused herself and her husband, and to this day is quite emotional and vocal about it—not because the teacher was misinformed or unaware of a new concept, but because the teacher seemed to her to be unwilling to learn.

The parent ultimately found a new place for her son to study. Initially, however, the school system refused to send him to a different school “even though it was going to

save them money,” she reported. She reflected that her son was not allowed to attend the afterschool program, and she was there every day for the special ed van. These experiences shaped the mother’s paradigm of the American educational system.

Perceptions of music therapy: Goal-oriented to train skills. A renowned music therapist, invited to join the staff at the academy, brought the concept of “training our students to become, [as] she called it, ‘music therapy assistants,’” where they assist music therapists in conducting music therapy. A mother whose son did not grow up with any music therapy stated: “I can think of one graduate [of the postsecondary music academy] I know well... who is in fact doing something like that. She is doing it one day a week.”

From information gleaned through interviews, I discovered that most of the mothers in the study had very distinct concepts of the differences between the goals of music education and music therapy. One participant shared this view:

[The music therapist professor at the music academy]... taught us about music therapy and initiated a relationship with the school... The notion that she presents and music therapists are trained in, is you really have a very specific goal as in any therapy. It’s not necessarily musical. It generally is *not* musical. But, the science element of it, tracking it... [is present].

Her son’s development was enhanced through his involvement in music education, but if he had had the opportunity for music therapy, “the music therapy would include probably a goal such as attention span, maybe... verbalizing what you might have to do next.”

Now students diagnosed with WS receive recommendations for music therapy, unlike in the past.

Perceptions of IEP meetings. The following is one parent’s description of an IEP meeting, meetings which are reportedly not “driven” by perceived needs or desires of

the students or parents:

IEP meetings are very tightly run, and they're only like an hour, and when you get around a table of speech therapists and OT, and PT, and special education teachers... they're telling you, "He successfully counted coins one out of three times." Right? And I [asked], "Can I see the coins?" They're plastic. Why would he be counting plastic coins?

She wondered why her son was not taught how to use something relevant to him, his cash card. She also thought that he should have been introduced to concepts such as how expensive items were and wondered whether teachers considered whether he wanted or needed something. The participant believed that IEP goals should reflect the student's interests and needs so that the student may understand why he is doing the task. She disclosed that it was frustrating that her son may have had IEP goals that had no meaning or value to him and that professionals did not seem to understand that.

Challenges for parents at IEP meetings. In describing challenges for parents at IEP meetings, a mother stated:

I don't think that young parents have an idea that you can ask (certain questions). They (the people present at IEP meetings other than the parent) basically say, "So, here's your IEP." And it's just overwhelming: You're reading the IEP. You don't have time to say, "What about this or that?" and of course, if you're not a curriculum person, you'd [have] no idea what questions to ask.

A participant remembered how she reacted after the first intimidating IEP meeting she ever attended:

I was overwhelmed, unprepared and a little terrified of the intimidating group of professionals and agreed to everything they said. After that first meeting and subsequent issues I had with the school, I learned to write down all of my issues before attending meetings, as once I was there I would forget what I needed to convey to them regarding [my son's] educational needs and issues I had with his programming.

Eventually music educators attended IEP meetings for the son diagnosed as a musical savant on the spectrum, but that wasn't the case for the other participants' meetings. One participant stated, "Typically, you know, they invite all the therapists that they choose, and you are lucky if you can bring your advocate." Parents reported that they found resources and information about finding advocates, managing IEPs, and what to advocate for, at association meetings.

Philosophy of positive-based approach to education to teach more than music. A founder of the academy, a mother in this study, believed that the positive, ability-based approach to education at the music academy (in which remediation was sandwiched between positive feedback) was in stark contrast to the usual special education remediation approach. She explained that she was educated in other methods and stated that the positive, ability-based approaches worked. In an interview, the mother provided insight that the academy used music as a tool, with educational intentions and goals that transcended what many considered traditional music education goals:

Our chorus, it really is [an opportunity for students] to work together as a group, to learn to work together, and not to be screaming over other people. Right? Because people with Williams tend to [need to learn to] blend, because people with Williams just need to always be in your face. But to teach people, even the most gifted, to tone it down for the benefit of the community is important, too. And so, you can use all of these musical [tools] to do that.

A different founder of the academy shared that the music academy used an approach of differing models. She stated, "We have the model of going out to the nursing home, greeting the families, and each doing and preparing some musical piece but, talking about it, and you know, learning to even talk to people."

Value of bringing together like-minded individuals to learn together. A mother described the value of social capital in her own way, of bringing “like-minded” people together:

I think that people want to be with other like-minded people—right?... I think this population also enjoys creating music for that reason... I think there’s something very powerful about that, and that only happens if you have enough people who are like-minded.

Turning Point of Educator’s Foci: Steering Exceptionalities into Vocation

A shift often occurs around age 12 from intellectual stimulation to functional training. Professionals attempted to steer every participant’s son to a vocational track when he was around age 12. Mothers were not sure if this occurred because educators were concerned about preparing their sons for jobs at that point. The participants noted that this was the time in which it was more difficult for educators to integrate children with exceptionalities into regular classrooms. One participant was asked whether she felt education ended at the point when vocational training began. She stated, “For some it ends at 12 because they’re put into programs where, it’s all skills of... setting the table, and making copies on the copy machine, and it’s, it’s really not broadening at all.”

Parent not content with vocational training for their children. Another parent of a Williams syndrome student wanted appropriate educational opportunities for her son when he was in high school. She stated:

You know, he was in special ed, and the special ed kids did vocation... a couple of hours a week. I think maybe it was twice a week,... where, you know, the opportunities where they could clean in several different environments.

Another mother stated:

They went to the bank, and they cleaned, whether it was dusting, they went to the churches, and they vacuumed, [and] they went to somewhere else, and they did bathrooms. And I said, “No. This is not who he is.” I said, “Number 1, his fine motor skills are terrible. [Also] his focus is terrible, and there’s no way he’s going to remember to put on gloves.... NO, I do not want him in this environment!!” And they said, “What does he need to do?” I said, “He needs to do music.” This was high school.

Music as vocation. The participant noted that no one had ever considered the possibility that her son might ever pursue music as a vocation. She had not even considered it. Rather, her son was steered toward anything considered vocational without consideration of whether that was, in fact, appropriate and what he wanted.

Transition. Mothers reported that when students were first mainstreamed, there was no planning involved for the transition out of high school. The transition movement, which started in the 1980s (Landmark, Ju, & Zhang, 2010), was in response to documented problems (Hasazi, Gordon, & Roe, 1985; McDonnell, Wilcox, & Boles, 1986; Mithaug, Horiuchi, & Fanning, 1985). One participant recounted a horror story in which a girl in a neighboring town was literally dragged out of class screaming on her 21st birthday. “It (school) ended, and there was no preparation made for... what was going to come next. They were just kind of dumped.” The mother called this the worst case scenario and restated that the mission of those in the transition movement is to never let that happen. She said, “Everybody’s going to have a vision and a plan, and it’s going to be particular to you [the student].” The mother asserted that previously it was assumed:

He’s going to get out of school, and he’s going to get a job, and it’s not going to involve music... naturally not. This [learning] is going to stop.” Whereas [in] this [new concept of] transition, you were really supposed to focus on who the person was, and then you would have this personalized plan that would work for them.

A founder of the academy clarified that the adult equivalent to the IEP is the Individualized Service Plan (ISP). All students at the postsecondary music academy had ISPs if they were served money from the government. They had other plans that outlined expectations if they had private funding, and those plans were not considered ISPs.

Music education an option guided by son's interests during transition:

College. One son attended a transition meeting near the end of his secondary school education. This young man, diagnosed with WS, became actively engaged in his transition when he decided what he wanted to do with his life, as described by his mother:

At age 16 you start, at the ISP, discussing goals and not just academics, but how is this person going to live, are they going to do further education preparation, [and] what are their social abilities going to be? So you're looking at all aspects of that, and you're looking at how are they going to prepare, and what services... they need now. We were at [our son's] ISP, and they were starting to discuss work for [our son]. He might have been a junior in high school...or senior.

His mother stated, "[It] was a new practice for him to attend [meetings]... and he never spoke up... and all of a sudden, as we seemed to be going on about what work he might do..." In the meeting, he said, "I want to go to college." The participant whispered in the interview, just as she had done that day at the transition meeting: "What?" Her son stated emphatically, "I want to be a musician." The mother stated:

He formulated those things, and that's when I looked into [a local] community college... one of the very few community colleges that has a music department. So that's where he went. That came out of that ISP meeting: that he would go to college.

Attending a college without disability services. At college, there were no disability services to make modifications, so the mother did that herself. Referring to

college, she stated:

There, the big difference is, there's no disability education. There's a disability department, and you can ask for accommodations, but no one's there to evaluate you to say, "Oh yeah, you would need these accommodations." So again, I had to do a lot of advocacy... [to] go to [them], and to say, "What kind of accommodations does he need?"

The mother interjected what she told the community college: "Well, he could use a note taker, somebody, another student, whose notes he could use." When the mother stated, "... we wanted the benefits of that music program," she did not stop to discuss what she meant. Instead she went on:

And he handled the classes well, and when [the postsecondary academy] was established, I told the teacher there (at the community college), that he was going to leave and not continue, and we were going to this [other] program. She was so sad to see him go... So [at the college] he did the instrument lessons, he did ensembles, he did piano workshop, and he did theory. He did [musicology], and he did a wonderful class in jazz. He did reports and so forth, which I kind of helped him with, but he could use a computer. He could do basic research.

These are the things her son did, all of which no one had ever imagined he would do. For an individual with WS to attend college, with the scope and dynamics of the exceptionality, and succeed, it was a tremendous hurdle. The mother stated that he continued to grow intellectually and musically, and he set his own goals. Referring to college, she stated: "So, it was amazing that he could negotiate that."

Difference between experiencing college environment and learning at college.

This mother had very distinct perceptions that there is a difference between offering students with exceptionalities opportunities to experience college and opportunities to learn at college. She told me:

There are a lot of programs now, the big thing is: Have your young person who has this disability attend college. And by that it's meant, be at the college, be

exposed to others that are not special needs, attend a few things, and this is your college [experience]. And that's called the ICE program. There are a lot of people pushing for that, even statewide; they think that's a goal. And my feeling is, it's a little condescending, because the feeling is, "Here you are, and we are going to expose you to like "the normal folks." This is going to be what you want and need." The thing is, you're kind of still different, and you're not having peer friends, so I don't think exposure to college is, is as standard... I guess, for me, that's not good enough. That's not good enough!

Social capital: Network of peers in specialized environment versus regular peers. The dilemma this parent faced was that, as she was engaged in helping to found the postsecondary music academy for students with WS, she "wasn't absolutely sure [where her son] should go, because he had never been in an all special-needs environment." Her son was already finding intellectual enrichment in the world that had excluded individuals with exceptionalities for so long. He was already at a community college. In one very important sense, what he was already doing was groundbreaking in personal and social gains.

The postsecondary music academy became a place in which students could interact and develop social capital, networking and exchanging ideas, participating together as peers in education, performance, and working in the field of music together. The academy was designed to give them quality education, quality intellectual stimulation, and opportunities and purpose in the field of music education and performance. And, they would be among peers, something vital to social capital.

No accountability: Schools not tracking or reporting lack of services. Two mothers in the study (one with a son on the autism spectrum, and the other with a son with WS) reported that not only were they concerned that students were not necessarily receiving needed therapies in secondary schools, but that some school districts did not

even track therapist cancellations. Parents were not told if their child did not attend therapy sessions even if therapist cancellations occurred for extended periods.

One mother, who interacted professionally with parents in her own vocation, stressed the importance of therapists' interactions and communication with families, the importance of progress and tracking of progress, of accountability and repetition, and the value of collaboration between specialists and parents. She added: "So how speech pathologists in the public schools can continue to see a child and work with him for 3 years on [the letter] *S* and the goal hasn't changed? I don't understand that, and then the child gets frustrated. They don't want to go."

A parent stated:

But not all schools are the same... Our school district would not inform parents if a speech pathologist was on sick leave. The child wasn't being seen; wasn't being seen, where in other districts [they would look for subs]. But in our district, they just wouldn't provide the services; this child would just miss out, and then the parents wouldn't even be aware of it.

Skeptics in medical system: Parents discover something new about WS. In a landmark study, Bellugi, Wang, and Jernigan (1994) reported that mean IQ scores of those with Williams syndrome are often in the 50.8 vicinity, yet Lenhoff, Perales and Hickok (2001) reported that many have perfect pitch. Their social nature and their ability to be calm when under pressure helps them in performance settings. By enhancing these skills, Semel and Rosner (2003) suggested that "WSs may be able to realize their academic potential, expand their social, recreational and vocational opportunities, improve their ability to handle frustration, and enhance their self-esteem" (p. 251). Yet when diagnoses for sons in this study were being made, participants reported that no one

realized the music affinity in those diagnosed with WS.

As previously stated, one mother with an academic background personally conducted research, scouring journals for information. She noted that there was no mention in any research of any WS individuals' affinity toward music at that time. It was she who soon envisioned the initial music camp. Yet, there was reported skepticism from those in the medical system that the link between WS and music even existed, even after the music camp was started. One mother described this and the nature of musical affinity within those in the WS community at the camp. By coming together, individuals and parents of individuals diagnosed with WS were beginning to establish social capital.

The camp provided a place for all to learn:

So we learned all of that, and then we learned through the camp that even the kids whose parents came saying, "I really don't know why I'm here because my son has no musical ability," were able to do things... if they kept going for several years, and if the parents then found ways for them to do it at home... if they could nurture that, something always came of it. So that's kind of what we learned. It's not that they're [necessarily] savants... [perhaps] exceptional, but... not perfect by any means... But the musicality, it was clear, was there. And the passion... The music just moves them... but not all of them; but it moves lots of them. They just want to be around it, too... The littlest ones, you'll see them with the sensitive hearing that some of them have, they'll stand there like this (with hands over ears) [but] they don't want to leave.... They're just making that a little more palatable for themselves.

Perceptions of Social Services System

A mother of a son on the autism spectrum had a different social worker every 6 months. Each time this happened, she said, "I had to go through the whole story all over again, and they were not particularly nice to deal with." She understood that Department of Developmental Services (DDS) workers are "overworked and getting slammed, and they have all these new cases, not enough money." She also knew that her own paradigm

was very much affected by the need she felt that she had to, as she stated, “raise holy hell with DDS” with the nature of the system and the turnover of workers. She had some very real worries to share; she believed her son’s future was based on what she perceived to be the state of the social services system.

Belief that social services system not set up for individuals with autism.

Voicing concerns about the American social services system, one participant stated she believed that the social services system was based on a past model set up to serve individuals with cognitive exceptionalities. She stated, “Adult services are really not set up for autism” (see Appendix E). She elaborated:

The adult service models that exist right now are basically for, you know, adults that had mental retardation or were cognitively low IQ, but they did not have behavior problems. They would sit there and make widgets all day, or they would come out in the community and go bowling... not make any trouble. Ten-to-one: ten clients per staff. That worked. Okay, so now you’re getting all of these kids with autism who have had one-to-one or two-to-one their whole lives because that is what they needed to control their behaviors, and now they’re all becoming adults, and it’s like: They don’t know what to do with them.

Existence of IQ score loophole. This mother reported that “in order to qualify for DDS, historically, you had to have an IQ of below 70. If your IQ was 70½ or 71, you got nothing.” She disclosed that this caused a tremendous amount of stress during transition, knowing a lifetime of services was dependent upon a seemingly arbitrary IQ score based on a subjective test. She stated, “He can’t not have a diploma and have no services. Like what is he going to do for the rest of his life? So that really lit a fire under me, like, we have, *I* have to figure this out.”

The single mother of the son diagnosed as blind and on the spectrum addressed this same topic:

In [a different state in the country] in order for developmental services to take the child, he has to be the IQ of 69 or below. For the commission of the blind to take over, he had to be a 71 and above. Guess what they gave him [my son]? They gave him a 70. So both of them said, “We can’t do anything for him.” It’s like... “You can’t... you know...!” So... to try to fight it.

This mother believed that “Of course they put him there so they wouldn’t have to be responsible.” She knew that once he turned 21, they would drop all services. She was working 12-hour days with a 100-mile commute every day in a job that required her to be there a lot. Based on the lack of future services, she knew couldn’t stay there and was forced to move.

Positive effects of Department of Developmental Services funding. Regarding DDS funding, one parent of a son with WS offered another perspective of a young adult, her son, who is now able to work in the music field with other musicians diagnosed with exceptionalities from the academy:

I thought I’d never be able to say this, but the DDS... funds [our son’s] work as a musician. That’s his vocation on his ISP... That took a long time to get there. But it is working. I mean, to my amazement, he’s playing several times a week and... most of (the academy performance groups) gigs are for money. He gets to do a variety of music.

Perceptions of Social Capital

Conditions affecting social capital. As parents began to connect and network, social capital was created. Parents created opportunities for their children to establish their own social capital, as well. Changes were occurring in society as some parents grappled with theories about the potential causes of the rising number of cases of autism. Additionally, in the newly formed WS community of parents and children, parents helped other parents identify their children’s exceptionality.

Parent-to-parent social capital perceptions. Two participants reported that at the very first Williams Syndrome Association convention in 1990, it became evident to parents in the audience viewing a documentary that a noted scientist was unaware that his child with exceptional musical abilities had Williams syndrome. Parents reached out to him and paid for him and his daughter to attend another convention to “instill an inspiration for us” as his daughter had extreme musical ability and extensive training. “As soon as she walked in, he (the noted neurologist father) just fell in love (with the community) because he knew right away: It did matter to find her (his daughter’s) own kind.”

From a social capital perspective, one mother said: “You know, when you have a special needs child, you have a very small community, and you really know who’s there for you and who’s not.” Husbands have been part of that community for five mothers in this study. Referring to when it was necessary to spend time away from her husband attending to their son’s needs, one mother stated, “It was not a great situation when I was not there for a few months; but, you know, we’ve been married so long that our marriage could endure it.”

Parent-friend social capital perceptions. That same participant reported that you can lose part of your social network, your friends, if you become too intent upon questioning socially accepted practices (such as immunizations). She said in jest, “Most of my friends think I am absolutely a whack-job,” due to the intensity of her convictions. This disclosure revealed her perception that there was a fragile balance between possible support and rejection. Her strong marriage, sharp mind, and witty personality seemed to

serve her well despite what she may have viewed as challenges from a social capital perspective.

Parent-teacher social capital perspectives. The capacity for growth, as perceived by mothers in this study, was not conceived by all members of society, including many educators. One mother stated:

I have heard the words, “He will never” many times, and sadly I have even heard them very recently. The good news, however, is that for every person who utters, “He will never...” there are several who are quick to say, “He will.”... It is through those like-minded and very special friends that I have found it within me to remain positive.

One mother of a son on the spectrum reported that staying true to one’s convictions often came without perceived social capital. She stated, “In general, parents like me who do believe that there is a connection [between environment and autism], you know, we’re laughed at. We’re mocked.” She added, “School is 6 hours out of the day. The teacher needs to know what is going on the other 18 hours a day and vice versa.”

From insult to compliment: The trailblazer. A mother had a meeting with a math teacher who was refusing to integrate her son into the class even though she was considered a highly acclaimed educator, one who had won accolades for her practices. The mother never forgot what she perceived as an insulting, derogatory comment made by the teacher in a meeting. Both parents, as well as an advocate, a private therapist, and the principal, were all present. The teacher stated, “I’m perfectly capable of *dumbing down the curriculum.*” Two years later, the principal told the mother:

When you first came here with your son, I thought, “Why are you asking so much of my personnel?” And, a lot of the personnel came to me to complain. But then I realized that... you are a trailblazer. And that there are so many students now who

are able to avail themselves of services because of what you have done. And, I want to commend you.

The mother added, “Parents did not even know that their child had that right to be in that classroom with modified curriculum that’s appropriate for them in how they can be instructed in regard to math skills.”

The so-called “difficult” parent. Another mother reported seeing something that made her question how educators viewed parents:

Teachers would have these continuing-education [seminars], and there was one thing that they were going to [learn about and discuss] once, and I saw... it was posted in the hallway near the teacher’s room. It was called “Dealing With a Difficult Parent.” And I thought, “Wow. You’re spending this energy on dealing with a difficult parent when they... Have they had any courses on how to work with parents?” How to work as a team? I’ll never forget that. And I thought that... you were a great parent [by educators’ standards] if you went along with everything. As soon as you challenge anything then you are a difficult parent, and you are one of *those*.

Educators as parents. One participant disclosed:

People I know who are educators whose kids went in the schools and their kids were having problems, and they’d come to me and say, “What should I do?” (nervous laughter) “Well,” I said, “you’ll have to call a PPT (Planning and Placement Team) meeting,” and they would tell me that they (educators in the parent role) were now being looked at differently (after the meeting took place.)” That there was this cool... [demeanor].

She made these recommendations about the Planning and Placement Team (PPT) meeting:

Calling a PPT meeting to go over, you know, what the issues are, and planning for testing, and I also recommended that she go outside the school. Because if you pay, [and] you don’t ask them to pay, you pay for it yourself, and it is so well worth it because their recommendations are usually binding. They have to present at the meeting, and that report is educationally implicating. She said it was really difficult because there was a shift... (in attitude toward her by other educators).

One parent was told by another parent:

“I just want to tell you that, I know the teachers really didn’t like you.” She said, “But I thought that if he were my son, I would want to have your skills as a parent.” But when I walked away, I wasn’t taken by the compliment, but I kept thinking about what she shared: The teachers didn’t like me. I mean, not that it was a surprise (nervous laughter) but just the admission of it. It validated that, you know, that there’s something wrong with the fact that there are talks on how to deal with a difficult parent. If you had talks on both collaboration as well as much in-servicing on appropriate ways to do x, y and z, then you wouldn’t have to have a parent saying, “Why aren’t you providing literacy education to my child?”

These perceptions confirm that parents may have perceived a disconnect between the education system and the family system. Parents held perceptions about how they believe they were perceived and treated by educators, and these perceptions often caused them to feel isolated, misunderstood, and even unappreciated before, during, and after engagements with educators.

Social capital resources. *Perceptions of the advantage of having an advocate.*

One parent reported that she had an advocate who accompanied her to each and every meeting. This mother created her own social capital by hiring the private education specialist who (a) developed a history and a personal and professional association with her son and (b) offered the mother advice and support. The participant said:

She started working with him when he was about 3. And she worked with him until he started at [the music academy] at 21, and she attended *every* PPT meeting with me... Planning and Placement Team Meetings. ... So, I have to give her credit, because she was there every single meeting. She’d have poker-face completely at the meeting, but afterwards, we would talk about all of the things that we made notes about. So she was, she was my sanity.

Support found at national conventions and associations. The mother who worked as the head of a major foundation stressed the value and impact of social networking at national conventions and associations. “We basically provide support to families throughout the lifespan.” Part of that support included reaching out to families

with information on the website, through social media, and at 4-day conventions. “Sixty speakers [are] coming in. We have all these programs for the kids, tons of networking opportunities, because, as much as we learn from the professionals, we learn a lot more from each other... They create and provide social capital.”

Perceived reality of the absence of social capital. In a journal entry, a participant described the impact a friend’s view had on her:

When [our son] was a toddler, we spent Thanksgiving as usual with longtime friends. The husband had a career in social services and knew the ins and outs of government support systems. Watching [our son] play, he observed: “You realize, you will always have to advocate for him.” The remark surprised me, and alarmed me, too. Would I have to do more than I was already doing? My friend’s remark alerted me that my life would change, that I had to be watchful, active, push beyond my comfort zone—forever.

A parent, whose Williams syndrome child had a hard time in middle school, described a birthday party experience. The entire eighth grade had been invited to her son’s party:

He turned 16 in eighth grade, and we had a party for him; he invited the entire eighth grade, and not one kid came. Fortunately all of his... friends from the special ed groups... the enrichment groups, were all there... [His sibling] made sure that all the kids in the neighborhood came, so there were plenty of kids there at the party, and [our son with WS] didn’t notice. We noticed that no one [from the entire eighth grade] came.

The value of social systems for individuals with exceptionalities. The mother of the son diagnosed with WS noted the lack of social support at community college:

He was invited to a party. People were nice to him. He had... a friend who was nice. But [our son] wasn’t really, you know, one of “the gang” [at the community college]. I’m not sure there really is “a gang” (meaning a clique) at the community college, and he managed, but... in starting [at the postsecondary music academy], what he had immediately was a peer group.

Ensemble as social system. One mother noted that the fortitude of a camp director led to student social capital through musical ensemble:

Another thing [the camp director] started... not just individual lessons, but she started band.... The same thing is at [the postsecondary music academy]. They all want to be in a band!

Parents were aware of the importance of social skills for their children, and they believed the postsecondary music academy provided a setting for them to learn these skills through the use of music and music ensemble and by being surrounded with peers learning together. This setting also offered opportunities for gleaning social skills, life skills, as well as musical skills, and therapy. Many of these students lived together in group homes, parent-owned private homes, or rental property.

Awareness of Son's Strengths, Limitations, and Potential

In interviews, the mothers were forthcoming, using language to frame memories of perceptions based on experience and intuition. The following examples demonstrated the magnitude of their perceptions of what they believed were strengths, limitations, and potential in their offspring. But much more was revealed in this discourse; each mother disclosed a tremendous depth of knowledge and experiential wisdom. In describing others' qualities, their own qualities were exposed. These mothers never acted vulnerable. They presented themselves as mature women, confident, and filled with mission and hope.

Language and exceptionality. In knowing her son's strengths, limitations, and potential, a participant whose son is on the autism spectrum stated, "He is an amazing kid, and you know, I always saw the strengths." The mother provided valuable insights

about communicating with individuals with autism:

Most adults, and teachers included, tend to pummel kids with, you know, “How was your day? What do you want?”... That’s another reason why people give kids with autism a hard time about the eye contact. You know, just because they’re not looking at you doesn’t mean that they’re not listening. They can’t listen and watch at the same time.

Understanding son’s strengths even when those working with him didn’t. One mother’s son was completely blind. He left public school around age 7 to attend a specialized school for individuals with vision impairments. He grew into a very, very articulate young man on the spectrum. Both mothers whose sons were on the spectrum realized that those in the educational system were confused by echolalia and echolalic responses. In this case, the son’s teachers had been impressed by his ability to answer questions. It was clear to the mother that the teachers did not understand what the mother, herself, understood about echolalia and her son: “[They] call him Rainman. He was very echolalic. He’d say, *yes* or *no* but it didn’t really make sense.”

Considered a musical savant, he also has ear for languages and has other strengths. In addition to being a musical savant, this same student had a love of language as a young adult. The mother, aware of this aptitude, believed that music and language are synchronistic:

He loves language so whenever he meets someone who has a different language, he’ll learn it. But everyone says he (my son) has no accent. Because he learns online from native speakers, and he’s got perfect pitch, too, he can do it easily... But language... and music, I think they kind of go hand-in-hand.

Cognitive challenges: Decoding the written word. A description one mother made of her son with a cognitive exceptionality disclosed perceptions she had of her

son's learning style:

He loves to have stories told to him; he loves to listen to books on tape, and he follows along... He can't just listen to them. It helps him to understand by looking at the words, but he can't simply decode. He follows along to the text and listens to it; he reads maybe two or three chapters at a time, and he'll stop, as I'm in the kitchen, and he'll say, "Mom. What was your favorite part there???" You know, he just really loves it.

Awareness of limitations: A WS perspective.

Mother hires paraprofessional to help with limitations not met at school. A

child with Williams syndrome had a hard time in school when he was young and had only limited one-on-one assistance. The mother knew his limitations and what he needed, and she still blamed herself that she did not do more to insist that the school system needed to provide the assistance he so badly needed, which they had limited funds to provide themselves:

Academically, you know [our son] has, you know, he had a really hard time. Because ... most Williams kids have a really hard time with math skills. [Our son] had that—in spades, unfortunately. He was able to read, and you know, he read really well pretty early on, but his comprehension lagged behind. But mostly, he couldn't sit still... There wasn't yet assistive technology or those kinds of things which have helped kids with Williams syndrome tremendously in the classroom to access grade-level curriculums. So, [our son] would go to a special ed class, and you know, they'd give him a piece of paper with twenty multiplication problems on it, or fifty, and a calculator. Well, he figured out how to operate the calculator, but... it didn't mean anything to him.

He had a paraprofessional in the first grade special education classroom who worked with all of the students in the classroom. The mother reported that no one knew how to teach a child with Williams syndrome in the district, as he was the only one.

This mother lives with regret that she did not somehow insist or force the school to provide a paraprofessional one-on-one:

He absorbed some things, but he was never really being taught—because I couldn't get them to give him a para (paraprofessional). I couldn't get the school district to do it. They wouldn't. Our district was just absolutely opposed to it. They just wouldn't do it. And they, you know, would find 100 different ways to talk you out of it, "It's not inclusion because it's just... He's going to be special by himself..." Well, you know, any good para-pro is going to bring in others around them and do all that. Like I said, they made every excuse. They wouldn't do it, and ... in any setting without one-on-one help, he couldn't do it... So that was, you know—I fault myself often that I didn't make them.

Fear of retaliation against son if mother advocated too much. The mother was scared of retaliation:

I was always of the mindset that if I made too much noise, then they wouldn't like [our son], and they all loved [our son], and I didn't want to destroy that. And, at the time, when you walk in to an IEP and everybody tells you how much they love your kid, you sort of get snowed by that piece. You know what I mean? I had IEPs that were 4 hours long... because he had so many therapists (nervous laughter), and he had all these people. And the therapists, the one-on-one people, he did fine with, but educationally, in the classroom, he just lost everything, and I feel he'd be in a much better place [if he had had a paraprofessional].

Limitations and potential in context: Musical intelligence. Referring to individuals with WS, another mother shared her views on how they have "musical intelligence" (Gardner, 2006). Referencing Gardner, she said, "Aha! I recognize this is exactly what my kid has, you know (nervous laughter)." No one's ever said this, that there's something called musical intelligence. It's a rich part of life."

The mother disclosed that had she been more aware of the concept of musical intelligence when her son was developing, she may have seen signs of musical intelligence early on. She recounted that an occupational therapist used a shaker which he loved when he was 18 months, and, later, she valued that her young son's disappearance during a musical festival, only to be found later dancing on a stage, may have had

meaning. Only relatively recently did she realize why her son scratched a screen repetitively:

I know what it was: He was listening. He was listening because it made a very interesting sound. He must have been listening to sounds made by the screen, a string vibration. Seeming so passive in the world, here he was an active agent, making something occur that gave him pleasure. He discovered on his own that he could make music!

Making sense of the value and potential of music in a life. One mother noted that, in considering the concept of disability, societal and cultural biases abound. Additionally, she theorized that members of our society may be measuring musical success by a pinnacle reached by only a very few. Individuals within the field of music may encounter cultural biases stemming from society's views of the perceived value and worth of music, and this may be especially complex for musicians with documented exceptionalities:

There's always this thought [in society] that if you are low functioning in one area, that's it, you know. Dummies. Dummies. You know, for [our son] it (music) was the one thing he could do really well, whereas for [our other child], you know, [he or she] could do everything well. [Our son] just had this one thing so... I mean, you really felt it was something... I have friends who haven't heard [our son] and [they] say, "Well, could he be in a symphony?" I say, "No..." You know, they don't understand: That's not the only criteria. He was in the youth symphony at [a large state university] which was very selective. They had selected people from 50 towns, and he made that, so that was really amazing... But somebody else who maybe isn't as good as [our son], you have to say [about them], "What can they do as far as they can?" and "What do they enjoy and how can they contribute with that?"

The mother of a child diagnosed with WS was able to look over the journal she kept as part of this study, and the conceptions she shared in the journal helped her to formulate an overview of the interactions and behaviors she and her husband had in rearing their son whose development was immersed in music education:

I was almost amused at myself in going back, and I read the journal, and I laughed at myself because at every point, I would make [our son] prove to me that he wanted a thing, to move forward. But, once the initial move we made to give him private lessons [occurred], he kept pushing for various things.

Discovering one's strengths, limitations, and potential is a process, a lifelong process. A mother stated, "Well, I laugh at myself... You might think, "Oh I'm the parent who's always promoting the child," but really, he's the one that is always leading me along, leading us along:

Music was never part of his IEP, but in fourth grade he asked to take up the saxophone for middle school band. This came out of the blue; I thought he was going to be a pianist. I made him wait a full year, and in the meantime bought him an electronic saxophone so he could try his hand at managing the keys without having to supply "the wind." He rapidly mastered playing tunes and proved to me that his desire for a sax was not a whim. In fifth grade he began lessons with the band teacher and joined the band, where he continued throughout high school. Band became a big part of his identity. I was always worried about how much he could do and was continually surprised. When he marched with the school band in his first Memorial Day parade, I walked along the route, ready to rescue him – because I doubted he could play the instrument and walk at the same time. One day he brought home a flyer, an invitation to an informational session about a local drum and bugle corps... "No, you are doing enough," I said. He nagged me until I gave in.... This led to joining the corps, with its weekly practices, many parades, and even field competitions. Now he was doing maneuvers on the field and playing an instrument. Who would have thought?

One mother described her son as "patient and kind," and stated that her son's love of and ability to play music are his greatest strengths. She added, "He is an excellent cheerleader, giving encouragement to others playing sports or music activities. He loves to spread his love of music to others and make them happy." Recognizing these strengths, she has always been aware of his limitations as well as his potential. During his first year at the academy, he exhibited some behavioral issues and this mother recognized that her son's behavioral issues were related to playing solos rather than being engaged in

ensemble groups:

I think after the first year here they were almost ready to kick him out because he was having some behavioral issues. And I said, "Okay. No more solos!" [Now] he's always only been allowed to be in groups [by] his second year here at (the postsecondary music academy). Now he loves it, and most of the kids [at the academy], whenever they have the duets, and there are a lot of singers there, he plays backup piano for them. So...it's like, "Oh, are you performing at this Friday Hour?" He's like, "No. But I'm accompanying somebody." So he knows it's not his performance.

The behavioral issues resolved.

Social capital.

Parent-created social club of regular peers at school. The topic of knowing a son's strengths, limitations, and potential overlapped with the taking action and reacting topic. For instance, one mother had an idea to start a club at her son's school when he was younger, and she acted on that thought. But the root of this action was her perception that she knew what her son needed and what he was lacking. In this case, her son needed a social group of regular peers. The lack of social capital was a limitation for her son.

Working with a social worker in the school, the mother disclosed:

I had put together a kind of a Circle of Friends for him... You know there were friends that he had, like neighborhood friends... *They* were friendly to him. They didn't take him places for the most part, but they... all agreed to join this sort of club for [our son], and they would meet... 2 times a week or something with our son, and they would work with the social worker... on conversation skills for [our son]. It was my idea to start the group... I had learned that at conventions... all of the trends that were happening then. You know, Circle of Friends was a big deal, and we didn't have it [at our school], so I just said... I wanted to make it.

Theme Two: Parental Discovery Through Research and Critique

Introduction

Within the posture Parental Discovery through Research and Critique, mothers subconsciously questioned, “Specifically for my child, what do I believe is effective and/or ineffective about...?” Analysis of the data revealed that mothers wanted to discover whether certain topics (music education, music, social system, education system, social services system, and the medical system including medical expertise, diagnoses, and therapies) were effective and/or ineffective for their children.

Research and critique is the second of three postures of perceiving/intuiting, researching/critiquing, and acting/reacting. Research and critique enabled mothers to evaluate professionals and existing support services. Research here is broadly defined as seeking information.

The evolution of social capital from newsletter to the net. In the early days of special education, Internet searches did not exist, but there was a hard-copy newsletter paper edited by Betsy Weaver entitled *Parents* that connected parents (throughout one region of the country) and provided information. “She led us to a lot of good thinking, and so I brought those (newsletters) to the table (at meetings). You could pick it (the newsletter) up in the corner of a beauty parlor...”

One mother’s research led to creation of camp and then the academy. As previously noted, one mother in this study informally conducted her own research. She began noting parents’ reports of musical affinity in their offspring diagnosed with WS. Upon searching the literature, however, she did not find any research that documented

this connection: “Though ‘musicality’ was not featured in the medical and psychological information available on Williams syndrome, I had noticed in our parent newsletter the frequent mentions of music ability that stood in contrast to other deficits. ‘Plays the drums.’ ‘Picks out tunes by ear.’ I highlighted all these passages.”

In response, this mother connected to other parents including a noted neurology professor. This creation of social capital led to the creation of the music camp which started based on this mother’s theory that there is an affinity toward music in individuals diagnosed with WS. The creation of that camp led to the creation of the music academy. All six sons of mothers in this study attend or attended this academy. This topic is included in Theme Three.

Even after a 2-year certificate program, some students stayed on at the academy and continued music education. There were opportunities for some students to become employed in musical performance. As students continued stimulating their minds through music, they continued to grow and expand their abilities to function with some assistance in society.

My son is in a band, and he entertains once a week in nursing homes, and he gets paid to do it, and, and he’s got cooking class and independent living skills class, and science class. You know, he’s got musical theater ensemble, he’s got his private piano lesson, and his private voice lesson... musical theater, jazz and soul.

Education System Relative to Son

The same mother who conducted the research offered critique of the educational system. In her initial interview, she recalled that she had been profoundly shocked and had never forgotten what a guidance counselor had said in the 1980s at a K–3 school meeting. “The guidance counselor of the school was a musician and in charge of the

special ed guidance, and she told me, I just remember this so distinctly, ‘Well, (our son’s name) will *never go to high school.*’” The mother admitted that her heart had been broken:

It was, because one of the things that they were telling me at [renowned hospital in a major city]... when we went again when he was age 5... We didn’t know whether he could be schooled! You know, they had that awful term that they used to use: *uneducable.*

The impact of professionals’ words: Individuals representing systems. Based on perceptions, such as believing they were aware of their children’s strengths, limitations, and potential, the mothers in this study took active roles in their children’s lives. They researched and critiqued, subconsciously asking what was effective or ineffective about what was being offered, what was available, and what they were being told. In this study, based on their experiences and their intelligence, mothers encountered individuals within systems who had no idea of the mothers’ abilities to stand up for their children and their willingness to question and/or challenge not just individuals, but entire systems.

These are the mothers who persisted, whose children are thriving due, in part, to the mothers’ perseverance. Having made enormous sacrifices along the way, they created and/or found opportunities through research and critique. Reportedly, these six mothers were affected by individuals within the education system who functioned as representatives enrapt with their own biases within their own paradigms.

Finding right school choices for son. By secondary school, all six sons were steered into a vocational track. Mothers in this study, however, acted on their perceptions that they still had voices and choices in their sons’ education. They perceived, used

research and critique, and then acted. One mother in this study was aware that she had choices to make (involving research and critique) based on what she perceived:

And I was given an opportunity to send him to a different school. We were taken on a tour of a language intensive school for nonverbal children. And, it had all the best speech therapists and all the best techniques, and my reaction was, "This is not the place for [our son] because he learns by imitation." So, even though I didn't know much about Williams syndrome (at that time)... That turned out to be so true.

Choosing the regular public school rather than the vocational school. When asked if public school was the "right choice" for her son, she stated:

I made that decision then... and at a later point, skipping ahead, when he was to go to high school, we were at a tour of a vocational high school... We had been asked to consider a vocational school for him in eighth grade. The vocational high school introduced all the programs that they had: ... horticulture, culinary, carpentry, metalwork... clerical, cosmetician, and air conditioning. I said [to my husband], "None of these is appropriate for [our son]."... Hands-on, he is not good at all. Not good at all... so I couldn't see him doing any of those for years. This would not do. In a vocational aptitude test that I witnessed, he could not screw a peg in a hole. Furthermore, there was no music department.

Music was considered part of an academic program. Her son was interested in academic subjects and thrived relative to his abilities. Music was not considered vocational:

Better for him to continue in an academic program where part of every day was music, and, besides, he liked learning the academic subjects with extra help from the resource room. But there was the idea since, if you had a lower intelligence, you should lay bricks or something. But, (nervous laughter) at the same time, he had been in the middle school band. Not just the band, but he was also kind of academic... He loved social studies. He read. You know, he was interested in the news...

The mother said, "No" to the vocational path:

And so I thought... they were not going to do that... [because] they were going [to], you know, cut down... It was going to be all practical life skills.... So, he did

well [in school]. He even took economics at [his public high school]... He's a good person, so of course the teachers liked him, and he would do his best, and I have to admit I did a lot of helping..., you know, getting him through papers and whatever he had to do.

He and several other students with exceptionalities attended classes together, mainstreamed into regular classrooms.

At 9 years of age, a different son diagnosed with Williams syndrome was allowed to participate in regular school. Prior to that, his mother drove him to an integrated school a town away. Unable to keep up with his regular peers by about fifth grade, his parents moved him to a collaborative school, a regional school comprised of students from many towns. By ninth grade, this student was also steered into a vocational track. At this school:

The only thing he did regular was chorus. That (school) had more higher-functioning people who may be more... maybe... using academics. They still want to do academics, because they could still do academics, but also then, [it] focused on vocation. They start the vocational tracking... in ninth grade. And the vocation was the typical cleaning, cafeteria work, and trash removal.

Lack of intellectual stimulation in vocational track. The mothers expected a purposeful education for their children. They wanted clear objectives in pursuit of intellectual productivity. Counting widgets, as one mother put it, did not suffice. They did not want their sons to be kept busy without clear educational objectives for doing so, objectives that were goal-oriented for intellectual growth. The mothers believed students with lower IQs were deserving of educations with intellectual stimulation:

They said they would like to try in the cafeteria. [*That was an option?*] Yes, and he said he'd like to do it. And they said, "He's doing it, and he's doing a good job," and I said, "I'm going to ask you a specific question: How many forks and knives is he putting into the basket in the 40-minute time that he's there?" (nervous laughter) I think he must have been socializing for the 30 minutes, and I

think he put in maybe 10, or 30, or 40 [forks]. And I said, “There is no productivity. No....” How is he supposed to have a sense of accomplishment? He’s really not there to be productive. He’s there for... You say he’s there; he’s doing an introduction, but he’s not... his outcome is not productive. Especially for somebody with Williams, with such special deficit issues.

She did not want him doing tasks without a clear objective for the tasks.

I can’t imagine them (students with exceptionalities) being successful in that. This was his education. (nervous laugh) So they did laundry in school, and you know, it was not a meaningful experience to do laundry at school. It would have been more meaningful if he had done washcloths for the cafeteria, but [to] bring two [washcloths in]—so they can put them into a wash, that you never use, is not meaningful.

Non-vocational system offered educational capital for students with exceptionalities. The mother wanted something that he could “shine in,” something that had meaning and purpose.

You know, I think they were able to adapt some things, so they were able to adapt some things that were of interest to him, but I don’t know how cognitively he was moving forward in terms of abstract thinking. You know, certain things are, at middle school... very difficult: concepts of money, for example. What does it mean to be a slave with no money versus a wealthy...? They are very difficult ideas; right? So even the basic things become very difficult.

While some mothers grouped together to form a camp, others proceeded either alone or with an advocate. They strove for, and many started creating social capital. In school, however, their sons were often isolated, reportedly separated by educators as children who behaviorally functioned well together, perhaps out of convenience and ease. Parents who had fought to have their children included were faced with a lack of educational capital for their children in the school systems in which they were “included.” Students with exceptionalities were physically present, but the educational system was ill-equipped to provide meaningful educations. Inclusion may have helped

members of society to become more accepting and aware, but these mothers believed these students deserved educations with purpose to render intellectual growth.

Schools miss opportunity to use music as a tool. I asked one mother if the school system was aware of her son's musical abilities. She replied:

I think they were aware that he was passionate, but no schools are prepared to use music as a tool, whether it be using music to reduce anxiety so that he could perform at a higher level... Public schools don't offer music, most of the time, and then to have to allocate a lot of money to use music as a tool, and of course, how many people are going to be like him that are auditory people who could use music as a tool for learning.

One might make a presumption, hearing the statement "public schools don't offer music, most of the time..." that the reference was to an entire music program at a school. In relation to other classes, in fact, students spend very little time pursuing music education in schools. What this mother literally meant, however, was what she said: "Public schools don't offer music (without biased concepts of what music is relative to societal paradigms), most of the time..." She meant music without preconceived boundaries or definitions. Music, as applied to other academic areas. Music, not just as a subject in school, but as a tool infused within all aspects of learning. Music, to enhance auditory learning.

Mother noted that students were separated by behavioral or non-behavioral issues. I asked her if her son was in separate classes with other people with exceptionalities, or if he was with other people who have Williams syndrome, or if he was with a mix.

I think it was a mix... I didn't see another person with Williams syndrome. I think that they separate them by, you know, behavior or non-behavior issues. So, if he's in the non-behavior/okay behavior, that's a better climate for him. But sometimes

when they're better behavior, then they have more deficits. So, it's really hard to find similar peers. [*When he was able to meet other children who were similar?*] Yes, it was in the camp, because he stayed in the camp [when he was 13].

Ineffective at teaching one son, one system utterly failed. A single mother and her son moved more than once across states for her son to attend specialized schools for the blind. In reaction to experiences she and her son had, she based her decisions to move on perceptions formulated through lived research and critique. Ultimately, she and her son moved, again, for the son to attend the postsecondary music academy for students with exceptionalities. These moves were not just symbolic of a mother's search for something better. They were, in fact, a testament of survival for a mother and son in a modern world of progressive education. He had already been assessed as blind, on the autism spectrum, and a musical genius, a savant. The journey, physical and emotional, was captured in her journal:

When [my son] and I were living in [a particular state, my son] was around 4–6 years old. The local school district decided it would be best for him to attend a special needs program in the nearest city about 20 miles away. I felt that it would be good for him to attend a special needs program where he could get more attention and where there would be a teacher for the blind to assist him with Braille learning and occupational/mobility services.

Accountability: School forced medication as solution and lack of services. This single mother took extraordinary measures, hopeful for the best educational environment for her son, based on research and critique. What they experienced was far from ideal:

The school forced me to have him go on Ritalin, which I was told all students who attended the program took, for ADHD (which he did not have). It caused [my son] to act erratically (literally bouncing off the walls), and he barely slept at night (he was so hyper).

The mother's wishes were not heeded:

I finally decided to meet with the program directors to voice my concerns on his medication and lack of services. The school refused to stop medicating [my son], even after I told them he was to no longer be given it. I found out they were giving it to him illegally for months.

The mother saw no other alternative but to move again to a different school for the blind.

[My son] and I moved to [another state], in the hopes of getting him to attend [a specialized] school for the blind. [My son] started off in a special needs classroom with children [all of whom] had severe and profound disabilities. We all felt that he did not belong in such a program. The school district then decided that he needed to attend the regular public school with a full-time aide.

The school district moved him from this second school for the blind to the regular public school. The mother questioned the teacher's abilities and capabilities despite the fact the system had deemed the teacher qualified. This was a school system that began sending the son home:

[My son] ended up with a teacher who got her qualification for special ed teacher just by student teaching for a short time at a school for the blind. The only qualification she had was, if you work with blind students for so many hours a year, you can use that time to be considered certified [as a] teacher for the blind and [as an] occupational and mobility specialist. The teacher had no idea how to work with [my son], and I was called in to pick him up from school at least once a week. The school did inform me that they would not mark his time out of school for [my son's] benefit. I later found out that they did that so they would not have to record that they were unable to meet his behavioral/education plan. I finally decided to hire an attorney to force the school to meet his needs or to send him to a school out of district.

The mother's critique of the education system was profoundly affected by the experience she had:

I had to endure the humiliation of having Social Services called on me for "abuse" as [my son's] punishment for being kicked out of class, was that I would not allow him to play during the school day when he was with me and was only allowed to sit and read his Braille books until end of school day. The social worker decided that the claim was without merit, but I did have a record with DSS claim being filed on me. (I was attempting to adopt a child at the time, as well). I

found (out that) that school district has done (the same thing) to other parents to dissuade them from filing claims.

More information was shared in the initial interview:

The school system called Social Services on me, saying that I was abusing him by making him sit and read. Apparently the school system: They do that to all the parents if you try to fight them to let the kids (go) to another school, they call Social Services on you, and I was in the process of trying to adopt another child, too. And I was like, you know.... I can't have this.... and of course it's on your record afterwards. I mean, [go ahead and contact] Social Services: if I was beating him; if I was slapping him; if I was starving him. Fine, but, you can't put a child in time-out and have him read a book!?! I said, "He got his snacks at the table; he got, you know. He just couldn't do anything fun until the end of that school day, so until 3:30.

The parent had to use legal means to move her child out of the school, had to prove that he was not receiving what he needed. The school system did not want to release him; the mother presumed it was because he was a resource for that system.

In public school, her son had been placed in a classroom with severe-to-profound students who did not speak. Because he was blind, he was unaware that he had peers, as teachers tossed toys at him. The educational systems in which the mother and son lived and functioned had not only failed the son, a musical savant diagnosed on the autism spectrum, but had failed the mother, herself, as well as a child she was then never allowed to adopt. Moving to a new school district had seemed imperative:

And I realized, oh no, you know, I'm taking him out of a school ... that means.... you can't provide for him. He was literally licking walls, and they were like, "Every time he went to the bathroom, he was licking the walls." I [asked], "And you didn't stop him?" [The teachers did not] know what to do with him, [and they] didn't have mobility. He can't do without sight-guided [assistance] outside of school. He needs sighted-guide. He needs someone to guide him.

The mother's research and critique, based on perceptions of her experiences, led her to advocacy:

I did not relent and was finally able to get [my son] the services he needed, and he was able to attend the [specialized school] for the blind, as they were best suited to deal with his education and behavioral issues. From then on, I learned to be [my son's] best advocate and to do research and put into writing what I wanted to convey in the meetings. I didn't get everything I wanted, but [my son] was able to get the education he needed to become a productive member of society.

Her son was placed in a vocational track: Finding an educational setting with meaningful objectives was challenging:

So they tried putting him into a school for autistic kids because they had a program, but everything is so visual... and... a lot of the autistic kids like a schedule. It's very black and white so, [my son] is completely not that. He's completely a creative soul, and, you know, I mean at his school, you had to wrap utensils, napkins and they have to put 25 of something, widgets, and wrap them up. He hated that, but that's what the school is, because they didn't have much of a music program, but that's what they did for their job for the last couple of years at [one particular school for visually impaired].

Her son was now considered an extraordinary, high-functioning musical savant employed as a musician. Reportedly, he spent a great deal of time wrapping utensils and might still be doing so had the mother not perceived/intuited, researched, and critiqued, and acted/reacted.

Educator critique. One mother, an accomplished specialist, stated that the period of time her son was in high school level was challenging for her, and she questioned the teachers' abilities to adapt and to learn:

The high school was probably the most challenging, the most challenging *for me*, from an educational perspective. It was really the most challenging. That's where I found the teachers, um, ah.... I want to say most resistant. But in some cases it was incompetency, and a failure, and a resistance to learn. [*The teachers were not willing to learn?*] Were not willing to learn. And um, and that was just a shame. It was such a shame.

“Everybody loved him, and nobody taught him.” One mother of a student diagnosed with WS with processing and attention challenges described her son’s experience and the belief that teachers perhaps subconsciously took advantage of the social and easygoing nature typical of the syndrome to offer less challenging curricula:

He had a tough time in school. It was very hard for him, and of course, in those days, inclusion... was very new, and I could never talk the school system into doing it (i.e., inclusion) for him. They just couldn’t ever figure out how it would work with [our son]. So consequently, you know [our son] was one of those guys, who he’s... he’s extremely social and very happy and very polite, and so, you know, everybody loved him, and nobody taught him. You know, it was one of those deals where they didn’t quite know how to teach him, and he wasn’t causing any problems, so they just let him be there, and he didn’t learn much. [*“There” is in a separate classroom in the public school?*] Yes. He was always self-contained.

During high school, the mother acted on her perceptions, insisting on a different track:

Finally, when he got to high school, I made a lot of noise, because the special education room just wasn’t the right placement for him, and I knew it, and so I got him placed in the learning disabilities track. You know, so, the kids who are kind of... can do everything but math, you know, kind of the resource room track... which at least got him into sort of regular education.

The parent (who remembered the guidance counselor telling her that her son would never go to high school) reported a positive educator critique:

We really did have a series of positive and wonderful teachers—classroom teachers and special education teachers... It seems to me that he was always allowed to go as far as he could, and then, you know there would be some tutoring in an area, you know, math for instance.

An invaluable resource: Teacher’s insights helped create social capital. A second grade teacher took one mother aside to suggest which classmates might make good playmates for her son:

“Have you thought about asking other kids over to play with [him]?” She said, “This person,” and she named a certain person, “is very friendly, very nice with [your son].” And she may have named a few others (son’s classmates). Well, I

hadn't really thought about that. But, she really put me on a path to kind of finding a little group of friends.

A social network was considered unusual. The mother later realized, based on what other parents told her, that the social network she created for her son was unusual for students with exceptionalities. She emphasized that it was through the actions of individuals such as this teacher that her son's future was positively affected.

So he had a group of, maybe five kids. Guys. He went to their birthday parties, and, you know, but he had them for his parties... and they went to each other houses to play. And I find that's very unusual when I talk to other parents. That they have not had that... And I realized later on, [our son] was bullied by... a friend that who wasn't such a real good friend; he was maybe a troubled kid, himself. But there was this basic group of really nice boys, and you know, there was a family that used to invite [our son] to hockey games with their son. So he (our son) had... a pretty normal social experience.

The mother realized this was beyond the scope of teacher expectations, for the period:

She (the teacher) wasn't called on to do that (i.e., to suggest a peer group). But it helped me. Because I was so focused on "Is he reading yet?" or... "Can he form his letter? Can he do this, that?" and she really pointed me to something that was important... You know people still talk about [our son] as being very kind, you know—that he's a good person... So I was very grateful to that teacher. So people did things like that.

Medical System Relative to Son

One mother of a son diagnosed on the spectrum diligently researched and critiqued the medical system, asking questions and looking for answers:

He was diagnosed by a neurologist, but you know, even back then, I felt like they really didn't know what they were talking about. (Nervous laugh) If the kid had any language at all, then they would call them Asperger's, you know they really didn't understand, you know, because I don't think that they were seeing it to the extent that they are seeing it now. They, they didn't know, you know.

Her doctor admitted that the medical system had not been prepared for the sudden influx of cases:

I mean, my doctor told (me) that when he was in med school, he saw one case of autism, and he was told (in medical school), “You’ll never see this again, so come take a look.” And then, wham, all of a sudden, his practice is being flooded. So, anyway, they really didn’t know.... So the fact that he (our son) had language, [they said], “He has Asperger’s,” but that wasn’t really it at all.

Originally she trusted the system, but, based on research, critique, and perceptions of her experiences, she soon believed that she needed to be direct and to take a leadership role:

I mean back in the day, you know, I listened to everything my doctor told me and, you know, was also extremely disappointed about what my pediatrician could offer... *I* became the expert, and what I knew eclipsed what he knew pretty quickly, so I mean that’s been frustrating, too. But, you know, the best advice I got very early on, was *you* need to become the expert... and you know, I think I really took that to heart.

In addition to the worries she faced when confronting the educational system and having to fight for her son to matriculate, she questioned whether yet another system may have caused and/or contributed to her son’s change as a toddler: the medical system. She believed she could not blindly trust a system that could not answer “Why?” or “How?” Her son did not have a chromosomal anomaly such as the case with WS, and she had had a normal delivery. Knowing many people who believe their children were fine until their offspring had had many immunizations at once, made her concerned:

You know, how many friends can you have [with] the exact same story that, “My kid was fine. Here’s the video, walking, talking, pointing, looking...” You know, totally engaged and then, you know, [he or she] went to the doctor at like 15 months or 18 months and had like six shots and was never the same. I mean, (nervous laughter) how many times can you hear that story... and not pay attention? Parents know what happened to their child. But that’s a whole other, you know... thing.

Whether this theory is true or not, her opinion underscored an important message: Parents often believed they knew something, had something to say and to add, yet some also perceived that their visions, values, and opinions were underappreciated and often

unheard. Her research led her to believe that part of the problem is rooted in “the way doctors are trained” with only one day of education in things such as nutrition, and she believed many physicians think that things such as immunizations are safe for everyone. She had desperately compared the differences between her two children, noting that “the one with autism had a hepatitis vaccine on his first day of life, whereas my older son got it at 5 going into kindergarten.” Her critique:

Well, what the hell does a newborn baby need a hepatitis vaccine on the day he is born? I mean he also happened to be (born) during that drive-through delivery time, when I was in the hospital for... [not very long]... But I’m not high risk for hepatitis, you know. I’m not an IV-drug user. He’s (her 1-day-old newborn) not going to be sexually active or doing IV drugs, so why does he need a hepatitis vaccine on day 1? I wished I knew.... “Slow it down.”

This mother in the study has lived with regret, wishing she had not just heeded and blindly trusted medical professionals’ advice and that she were more aware then of what she believed now: Individuals have rights to question and challenge the systems in which they live. She believed, however, that those who challenged systems, who critiqued and questioned, who demanded that more research be done, were often the ones facing challenges of their own. She believed that those who challenge or question systems are often viewed as radical. Additionally, they often faced those challenges in a world devoid of social capital.

Mothers’ critique of medical-related topics.

Seeking alternatives to traditional therapeutic methods. A mother reported that therapy could be incorporated into the arts rather than administered by usual methods in clinical settings:

We had a student with (a physical condition affecting muscles), and instead of doing physical therapy every day, she danced for an hour and a half every day...at the school (the music academy). And my son, when he had parts of his body that were too tight, [the doctor]... said, "He should be seen by a physical therapist." And I said, "He's already had so many surgeries that he's going to be scared to go to, yet again, a medical-type environment which usually the physical therapists are located at. I said, "Why can't his dance teacher incorporate some of the stretches and things that that physical therapist would be doing?" So that's what we did. That allows a person to not be frightened. You know, you just say [to a person], "This is what you have to do to get ready for the dance." You know, and you can incorporate it that way, and I think that's the kind of the thing we should be doing: to address some of the (accepted practices of) remediation with them.

When this mother interjected her personal philosophy, she incorporated her values and insight as a mother aware of and sensitive toward how an individual had felt or might feel:

They see themselves as a victim. Right? When you're always sick, you feel like a victim... like a patient. Maybe not so much a victim, but as a patient. A patient is not something that we want to be. Right? So I think that allows yourself to empower yourself to do that. So that's really just taking a little twist by using the arts to learn things.

She referred to patient "empowerment" but, in this case, the mother herself exhibited empowerment. She questioned the medical system and interjected thought into how therapy could be incorporated into life experience and how a person, a patient, might feel given conventional and unconventional methods.

Mother noted side effects of prescriptions. A mother noted that a possible side effect of a new medication her son was prescribed was potentially affecting his musical skills and his behavior when he suddenly perceived that tones were no longer on absolute pitch:

He... started with seizures... and he just started the [anti-seizure] medication 2 weeks ago, and it (i.e., the potential side effect from the medicine) started making the music sound flat. And I'm like, (inhaling) "Hhhhhhhuh, this kid's got perfect

pitch! It's going to drive him crazy to not be able to hear it." After a week they tested to see if it's still in his system, but then they never called in the prescription, and so he went 24 hours without it, and then he got the hearing back, so now he's started back on it, and... he said it seems to be sounding okay—starting to sound more normal.

Son marched to music when he learned to walk years after life-saving

measures. One mother recounted extraordinary medical interventions for her son later diagnosed with WS. Due to the complexities of the life-saving cardiac surgeries, her son was left unable to develop as other children, and it seemed he would never walk. Using custom bars designed by her husband, their son learned to walk at age 4½. The mother stated, "When he finally walked, it was to music. He was marching..."

Music Relative to Son

Each mother stated in one form or another that music is the conduit to their son's life and continued growth. One mother of a son diagnosed with WS stated:

And that's what I see with [our son], his growth as someone who thinks and reads and who handles his own money and his belief in himself; I mean, so many things have kind of spun over into his life from music.

Critiquing the roles of music and music therapy. Another son, a musical savant, first was introduced to music therapy, and that helped him understand life skills:

[My son] started in a music therapy program at his grade school, and it was the best thing that could have happened to him. [He] learned that he had to concentrate on what was going on around him and to listen to cues to when his part was to start. As his classroom had nonverbal students, he didn't understand that there were others who needed attention, too. With music therapy class he had to learn to take turns, and it offered him the opportunity to interact with the other students he spent his days with. [My son] learned to communicate and be around others through his music by playing for others and talking about what types of music they liked. Before this [he] was very echolalic and didn't voice what he wanted. (I used to have to give a couple of options for him to decide what he wanted.) He learned how to console himself by playing classical music to relax

when he is feeling bad or sick. He'll play different types of music depending on his mood. Music gives [him] a chance to get out and meet people and to show off his talent. He gets excited when he gets introduced to people after he performs, and they say "I didn't even know you were blind!" because, as he says, "With music it doesn't even matter!" As an adult, [my son] is using his music as a career. He is part of a group who help to make a difference in the world by showing children/adults that even if you have a disability, it doesn't mean that you can't do what you set your mind to.

Before early awareness of WS affinity toward music, music therapists

presented. Even before those in the Williams syndrome community knew of the connection between music and the syndrome, knowing that music was important and a vital part of a child's life was evident for one mother. At a music therapy session at the second annual WS convention, this mother and her family were first introduced to music therapy when her son was 6 months old. "It wasn't until he was... 8 (years old in 1994) that we (the WS community including medical specialists) started talking about the music."

There was a music therapy session there (at the conference), and not that they knew any connection at all, it was just about... here's another way, you know, that's good for kids. And it was clear immediately to us that [our son], that music did something... He was only 6 months old...

Like other mothers of sons with WS, it soon became apparent that her son favored music-oriented toys:

Like at a year old, the only sort of toys that he ever played with were the musical ones, so then we would introduce more musical ones. [When] he was about 2½, I found a music therapy group and..., I got him in the sort of mom and tot...with Orff instruments. I would just find whatever I could because I knew he loved it. When he would get upset, I could put him between my legs and turn on a music program, and he'd calm down. It was just very clear.

She had even played music for him in utero, and later "when he was in the hospital for those 3 months, that was what calmed him down. That was 'the thing.' [*The same*

music?] The same music. Vivaldi's 'Four Seasons.' It really made a difference to him...

And... I would sing to him!"

A mother of a son on the spectrum noted that she "did buy him drums when he was quite little, like 3 (years old) maybe, and he did enjoy them at first..." However she also pointed out that one challenge for individuals diagnosed on the autism spectrum is "the whole noise and the sensory piece."

When asked if her son was always musical, the mother of a musical savant described his extraordinary abilities:

From 3 years old, he was playing piano. He could hear a song once and play it. [*But no formal instruction for a while?*] We tried when he was 5. He didn't like to be touched. They (piano teachers) would play on one piano, and he would play on another. After the first month [of study], they had him perform at the college because he's a musical savant. He just has to hear it. He could tell, he can tell what each key is. He can hit 10 of them at a time; he would tell exactly which they are [*And he could do that at age...?*] He was about 5 years old. Once he learned what they were... but so... he wasn't really talking then, but he could match what they (the notes) were... because he's a musical savant.

Music Education Relative to Son

Mother developed way for her son to learn to play piano—using Velcro. One mother of a son diagnosed with WS discovered that he was unable to use his fingers independently. She developed a way for him to learn:

[That] he didn't have fingering (wasn't able to use his fingers independently) on the piano was really a surprise to me. So like [his] thumb (she's thumping her thumb on the table like playing a thumb on the piano) Like, "Do, do, do, do, do..." he couldn't do it. So I said, "Show me your thumb; show me your 2nd finger; show me your 4th finger; show me your pinkie; and that's what he did. So I numbered his fingers with a pen and then I put negative Velcro. And I put positive Velcro (on the key) And I put a sticker with 1, 2, 3, 4, 5 and that's how he had [position] feedback; he would stick to the key. [*And do you know if anyone else has used that technique?*] No, I don't know. That's what I used. [*And here you have something that you came up with? And it worked?*] It did because he needed

that level of, um, input in order to remember that, that he had separate fingers. Yeah. [*And it worked?*] It did. [*And then when you removed it, he remembered?*] Then he was able to separate his fingers so he wasn't just using his hand like a glove. He's able to isolate.

“Same song, different notes!” When asked if piano was her son's first instrument, the mother said, “[Piano was an] introduction, and then we did more vocal work...” I noted that mothers often used the word *we* to describe themselves and their sons, and I commented on this in my journal (see Appendix D). She continued:

He still can play by not looking at the keys; I don't think he'll ever be a brilliant pianist. He just would play by ear. And I think he knows thousands of songs by ear, but not left hand—so much more, the melody. And sometimes I'd read the notes and say, “That's not the same song.” “No,” he said. “Same song, different notes!”

This mother was not sure exactly when or where her son learned such an expansive vocal repertoire:

I never know where ... when he's learning it, but he learned all kinds, everything from Broadway, Porter and Hammerstein, anything from 1900s, maybe prior, he knows all the Civil War music, all the sea shanties, gospels, spiritual, opera, but he doesn't.... If you [ask him], “Can you sing something?” It would be like, “Well, I don't know.” But if you had 10 books, he can pull [out] a book, [and] without opening [it], he can sing.

I wondered if this indicated that the son needed something to trigger the memory. It was as if the memory is there, but he needed the trigger to access it.

From the autism perspective, a mother critiqued the way her son learns:

Well, that's where I see [our son on the autism spectrum] really struggle with his piano, I mean, he's learned to read music, which is great, but, it really is from an executive functioning point of view, I mean... It really is very challenging for him. I mean, he has to scan—He's visually scanning; he's deciphering the notes; the left hand, the right hand, the chords, multiple... There's a lot going on. So it's hard work for him. His teacher really challenges him... So he gives him very challenging things. I mean, he might work on them (pieces) several months until

he can play it smoothly. The piece he's working on now, it's just such a piece; he's really struggled with it...

Two of the sons diagnosed with WS started Suzuki piano lessons at early ages, and their mothers were very involved in their sons' music education. One mother remembered learning with her son on the first day. She was sorry she could not help him at home since she had not bought the tape to record the lesson; she could not remember the homework:

And I had to laugh; I'm a visual learner. I'm not so much an auditory learner, and after the first lesson, I came home and they give us chopsticks, and you have to do the rhythm. I couldn't remember the homework, because I didn't record it... [My son was] between 7 and 9. And she (the teacher) had just showed us like two times, and I couldn't remember the homework, and he did. And he was looking oblivious, until I was like looking stressed!

A savant's music education: Learning to be part of a group. As a savant, this son was on a musical journey starting from the realization that, by age 5, he had extraordinary musical abilities. Early days of socialization in school were difficult; however, his path led to the postsecondary music academy where he would become a professional musician:

When [my son] attended [a specialized school for the blind] and started piano with a music teacher, they brought up the option of him possibly going to a music school, in [a major city], for adults with special needs, after graduation. I never thought that there was an option for him to do it, but we both agreed when he was a preteen that it was his calling to be a professional musician.

Although the secondary school he attended did not have a big music program, it was there that the mother and son learned of the music academy:

When [my son] and I moved to [one state], he attended [a school] for the blind; his biggest regret on the move was that the school didn't have a very big music program other than chorus and saxophone lessons. It was discussed at [this school] that his future should include attending a postsecondary program for

music. Once decided, he was taught how to read Braille music, which I was told was difficult to learn; [my son] worked hard to learn to master [Braille]. [Although he could already play by ear, he] learned to play music by reading it in Braille [only] and not by hearing it first, and he took to the challenge with gusto! The school did give me a booklet about [the postsecondary music academy] as a possibility for [my son] to attend once he graduated from their school. I discovered that there would not be any funding for [him where we were] once he turned 21, so I petitioned our school district to have [my son] attend [the postsecondary music academy] his last 2 years of education, and [he] graduated in 2015!

The ways he learned best. Although a musical savant may possess inherent musical abilities, the course of action to hone those natural talents must take into consideration the person's other inherent qualities. The mother shared in an interview what she later reiterated in her journal:

[My son] learns music best by hearing and repeating. When [he] was little he did not like to be touched by others and would not do hand-over-hand to learn the notes on piano; instead the instructor played on her piano, and he repeated what he heard. [My son] still learns by hearing on the radio, CDs, or computer. Once he learns (after one to three times listening to it), he can play [the music] on whatever instrument he is playing and is able to change [it] to sound... [like] different genres of music. Although he knows how to read Braille music now, he still prefers to do it by ear. It is not like you can play the piano and use fingers to read the Braille notes at the same time.

The mother stressed that for her son, a savant who was totally vision-impaired, much of his music education was learning that he can function socially, with others:

[My son] is an amazing musician (I know I am a little biased). He is able to pick up an instrument and learn quite quickly how to play it. He was called a savant when he was 5 and [was] playing complex pieces on the piano. Music education for [my son] is learning to be a part of a group. So much of his life has been as a solo person/musician.

Ensemble brought socialization to her son.

He was always an introvert in the corner of the room with little to no interaction with others. During [his] second year at [the postsecondary music academy] I felt that it would be to his benefit to only perform as a part of a group. It allows him to

help/interact with others and to feel a part of something special. Music education also includes learning to take care of his instruments and learning the appropriate social interaction needed to be a part of a band/ performance group. [He] is continuing his music education as an adult at [the academy] because it allows him to give his gift as an entertainer to the public, through his many performances, and allows him an opportunity to work as a piano accompanist for vocal students at the school. Music is always a learning process. By attending [the postsecondary music academy] he is not only learning music, but social interaction, which is tough to master with his blindness and autism.

This same mother described his musical abilities this way:

He doesn't read music with Braille. I mean, he reads Braille, but he doesn't use the music so much. They taught him [to read music through Braille] at his last school. I mean, you have to read it with your hands... so it's not like he could play the piano, so he'd have to memorize. But *he'd* only have to hear it, and then he could play it, so. Anyway, he has a gig in a couple of weeks, and they're like, "Oh, you think he could learn it?" I'm like, "Yeah. He just has to hear it," and I said, "(Calling him by name), did you practice that?" And he goes, "No, but I heard it on YouTube; I'm good." I'm like, "Nooo... You need to play it on the piano." He goes, "I *know* it, Mom." I said, "You need to show me that you know it," and he played it, you know, practically flawlessly, and... a year from now, if he hadn't heard that song, he'll play it again. He's incredible. Once he learns a song, he never forgets. It's crazy. He's got like thousands of songs in his head.

He started formal music education when he left the public school and attended a specialized school for vision impairment, at age 7:

He had a music, a piano teacher, [an] unbelievable woman; she was very elderly then. She had to have the patience of a saint, but he had already taught himself by then. And you can't teach him different. He can play classical music, but he plays everything with his own flair. He won't play it exactly as it's supposed to be. So, it was a big frustration, and his fingers weren't where they were supposed to be because again, you couldn't touch him when he was younger. You know, the hand-over-hand, he wouldn't.

His piano and saxophone teachers used the Suzuki method. The mother described how her son went through three Suzuki saxophone books in 1 month: "You know, he'd listen on the CD, and then he'd just repeat it." When asked how many instruments he played, she shared:

Flute, saxophone, harmonica, piano. That's it. He just got a soprano sax. He tried guitar. He would tune them all because they all had to be exactly right, so I think that [the tuning] would bother [him]... so he wasn't as good... Anything he wasn't as good with, perfect, like, right away, he would just stop.

I wondered whether the mother considered herself musical and if she sang to him when he was born:

Oh yeah, I sang all the time. I'm not good at it, but, yeah, I can sing. There's always radio on. I always have to listen to something on... to have music in the background. But he remembers; he's got the memory.

Music education in order to pursue all else. At this point in the interview, (when the mother was talking about how her son might get frustrated with a music teacher's style), I wanted to know, since he likes to do music his own way and because he was interacting with teachers, what type of music or style of teaching the mother wanted for her son, a musical genius. I asked the mother what she wanted him to learn. She surprised me. Her answer had nothing to do with music and everything to do with social capital:

[*Right. And what did you want him to learn?*] (Pause) [*What did you feel was important*] Um [*at that stage?*] I only cared about social interaction because he never had friends. He never really had friends. So... As a mom, you want your kid to [interact with] other kids.

That is what she wanted her son to learn, and she was aware that his particular personality and learning style directly affected his ability to become social:

But he has the obsessiveness with [asking other people], "What toys do you have? What dog do you have? What music do you have?" Like, he wouldn't understand that... like trick-or-treating. You couldn't just go and get candy. No, you'd have to go in. You'd have to talk to people, and he'd have a meltdown... He wanted to be social, but he didn't know how to be social. Kids... didn't want to be really good friends [with him] because everything [was] just around the music or just around the dog, and that was... "You can tell them about yourself, but you need to ask them."

The mother gave her child the words that he could use to help him express the innate abilities of concern for others that she was aware he had. She believed this awareness (of other people and social interaction) was an important factor in his education, and this social interaction, of being part of a group, could occur within music, whether as a performer or as a member of the audience. She recounted:

He's very good at cheering other people on and... he's very encouraging. Because the one thing I always put into him was, like, you know, "Cheer for other people when they do something. Say 'Good job'" or... A lot of people get nervous, so, if he's at a performance, he can tell if people, by the sound of their voice, if they're nervous... [Then] he can yell, "You can do it; you're doing good!"

By being a student at the music academy, her son learned how to be social, much of which occurred in part to the nature of musical ensemble, and through a mother's consistent dedication.

More critique: A mother's view. I wondered how having perfect pitch may have affected her son's interaction with peers in ensemble:

[*And does he critique other people, when they're out of tune—does he let them know that, because that bothers him?*] Um, not so much anymore. But so he's gotten out of it (the habit of worrying about it all being in tune), so like I know we have, in the saxophone quartet... one of them is always off. Whatever he's playing in his head, he... is off from the other three people. So it totally messes it up. And, [my son] is just fine. He just goes with it.

An opportunity to partake: Exposing creativity and gaining self-esteem. When asked about whether her son composed music, this same participant described her son's involvement in a documentary at school in which he used his own composition and had a musical experience that seemed to combine social skills, music, and music education featuring the concept of music therapy:

[Does he make up his own music?] Yes, I would love for him to compose. He composed a song... There's a documentary every year [at his previous school]. So what their class one year, they did it with, at the [school for visual impairment], [it was] about music, music therapy with students. So they were doing it (the documentary) with the chorus, and they met [our son]. And they were like, "Oh my goodness." So they, like changed their whole meaning [of the musical]... He had composed one song, which he plays all the time—so he composed the music and the words to it, so it's a really good song. [And so he composed it because of this show?] Yep. So that's playing in the documentary. [And did they help him with it, or did the school...?] He did it 100% himself.

A mother's concept of composition. The mother went on to share:

He's always playing things (original compositions)—He says, "Just a song in my head." Like, I'll say, "Have you heard a song like this before?" and he'll say "No! I made it up." So [So did they suggest to him that they would use his song, and so he made it up?] Yep. [And he's never done it again?] No! And I'm like, "You did so good, you know, you should do, you know, do that. "I'm too busy, Mom." "You've got to do it," because I think he definitely has a talent. And some of the stuff that he'll play, it's not like he can write it down, so I'm like, then record it. So then, you know, you just expound on it, and that was his big thing, though, because he didn't really talk much. So [in this documentary] he pretty much just did the music. You can't really ask; he's such a smart kid, but unless it's something that interests him at the time, he's just not going to talk about it. It's an autism thing. So, you know, (nervous laughter) I'm like, "You should compose; you should do this and that."

The mother stated that he makes up music all of the time, but she distinguished between that and the piece that he wrote for the documentary, which is complete, remembered, and played over again.

The musical connectedness in life. She perceived that music connected and influenced all her son's other interests. "He loves to travel... He likes the satires, political satirists... Music is a huge difference." The mother was aware of her son's interests, his strengths, and his limitations. Like others, she based her critique upon the perceptions she held within her own paradigm. She shared that music education is not just a subject one learns with the goal to learn that subject or to create the product of a finished piece. It

also entails a community of interaction and inspired individuals to become more self-aware. Considering music and music learning as therapeutic, she referred to music therapy for her son this way: “It’s completely drawn him out, so he does interact with others, and he wants to, he wants to be with others.”

The value and roles of music education and music therapy. She provided this example:

I think [music education and music therapy] are very similar. Music education and therapy both teach how to interact with others and to be a part of a group, taking turns and being mindful of your impact on others. With [my son], being a part of the postsecondary music academy community includes not only his music education by learning different instruments, it teaches him how to project himself, i.e., how to look professional while performing in public, to reduce slouching, and acting appropriately when interacting with the audience before, during, and after the performances. His music education also teaches how to play as a cohesive group making sure he keeps tempo with other members of his group and how to refocus and continue with a piece when mistakes are made.

Effectiveness of Suzuki method for WS individual: A role of parent in music education. The mother who found a piano teacher versed in the Suzuki method found the teacher through research. Both parents were involved, but she and her husband believed it was the mother who had the right combination of patience and consistent dedication to commit to the Suzuki method with their son. The critique the mother used was based on perceptions of her son’s limitations, strengths, and potential, of the teacher’s techniques, and of the Suzuki method. This critique was always grounded by an underlying personal philosophy she held, exemplified in a statement she made: “In almost all of us, there is a capacity for music that can be extended.”

He began lessons with her and continued for 7 years. Initially, he had about a 15-minute lesson because that’s all he could tolerate, and then I had a 15-minute

lesson while he sat near the piano... In almost all of us, there is a capacity for music that can be extended....

The idea [in the Suzuki method] is that the parent models the music... I had to take weekly lessons and practice daily with [our son]. In the beginning, while I had my 15-minute lesson, he was allowed to play on the floor. This teacher's techniques were perfect for him; she was used to preschoolers. For our first group recital, after only a few weeks of lessons, he nevertheless was included. He was asked to participate simply and formally: to stand and bow from the waist and receive applause. The Suzuki education became our model of music education: close relationship with teacher, imitation, daily practice and listening, frequent group performance.

The mother recalled in her journal the OT's surprise when the son played Mozart.

The participant went into greater detail in the journal than in the interview, and offered a critique of the benefits of music education:

When it came time for [our son's] "Book I" recital, to demonstrate he had mastered that repertoire, we held it in our home and invited his occupational therapist from school. I knew she would be surprised to see him playing pieces such as the Mozart "Minuet in G" with both hands, and she was. She was working with him on fine motor skills such as turning a coin over with thumb and forefinger. There was a striking contrast between what he could do when motivated by making music and what he could not do otherwise. In the long run, the gap was narrowed due, I believe, in no small measure to his early music education. Attention, cognitive skills, motor skills, all improved. He performed better in school academically than his tests would have predicted.

In an interview, the mother credited her son's success with the Suzuki method this way:

What's so wonderful about [our son's] first Suzuki teacher: Well, first of all, Suzuki teachers work with very young children. So [our son] presented as kind of a younger behavior at his, at age 7, and I'll never forget some of the techniques that she used that were so good. He would kind of play everything, (demonstrating) not pounding, but heavy... and [with] the same... dynamics. And she said, "[Our son's name], now I want you to pick up this," and she had this rock. And she said, "Pick up this rock and feel how heavy." And she said, "Well that's how heavy you're playing. But now this next part, I want you to play like this," and she had a feather. "Feel the feather." *That's* how I want that sound of this to be." ...So many examples like that, which were not using an intellectual... just a sentence to say, "Alright, you need to play softer." You know, you can say it 10 times: "Play softer." But if you (almost whispering) put a

feather in your hand, that is another way of learning it. And of course, he's gotten it. Dynamics! She had those wonderful teaching techniques that were appropriate to children, young children.

The mother continued:

He was a member of the group. The Suzuki group, and he had learned to get up there and bow from the waist, and you clapped for him—so it was part of the beautiful formality that she had inculcated with her class; I liked that.

Critiquing the role of music teacher... and worrying, “What’s he going to do?” In contrast to private piano lessons, the mother remembered a public school music event:

In first grade at our elementary school, there was a... pageant... three classrooms of first graders all. They put on the pageant, with costumes and singing, and, well, so many of the parents had this same feeling: I always felt embarrassed or worried, or worried about being embarrassed, about what he might do. So I went to the pageant, and [our son] was up there, on the riser, because you remember this... kind of giggly, “Ohhhh, what’s he going to do?” you know.... So, then it kind of goes on...

He had the opportunity to be like the other children, which he was. The mother was shocked at what happened next, under the guidance and foresight of the young public school music teacher who “got it” when this mother’s son was in first grade at the pageant:

And then he’s called out, and he has a solo line. It’s “Michael Finnegan,” I think it was, which is a little tricky, and he sings it beautifully! [*And he was in an inclusion program at this...?*] Yes, with some things pulled out for, but he was, yes, he was in a classroom with the regular children. And, I always thank her... for that... tell her how much that meant to me because I could see that he was being like the other children, and also that this was rather special that he could stand in front and sing this nice... very short little solo. So he did have that, and we did have, you know, he eventually got into the instrumental solo program in our schools.

Inclusion, to this mother, meant more than being present in the classroom among regular peers. Like the private Suzuki method piano teacher, this public elementary school music teacher provided the opportunity for this son to be part of the group.

Higher Education

Transition and value of son's own interests being met: "I want to go to college." In recounting her son's desire to go to college, she offered critique about the job coach who assisted in transition:

I never knew where the music was going. I just knew that he kept advancing. You know, and... if that was he was advancing, and gave him joy and us joy, too... then he should keep doing it. His actual job coach from this organization is a musician, but never found any really musical [opportunities]... for him. [*Never found anything musical for him?*] Never found anything musical for him. He kept saying that [our son] needed to play in a community group. There's a lot of feeling in the disability community that you shouldn't have a person with a disability with another person with a disability. They should all be out in the community. That's why (?) breaking up all the... um.... sheltered employment... I can compare the two because [our son] did well at... community college (see Appendix E).

Critiquing what works: Music education borne out of purpose. According to a parent whose child was on the spectrum:

There's a lot of kids with autism who can't say a word, but they can sing. You know, the brain and language. [Our son has] always had language, but he really struggles to communicate, (nervous laughter) you know. And he couldn't really have a conversation, but I feel that since he's been at [the postsecondary music academy] and since he's been studying music, his language skills have exploded.

She researched and found the music academy first and then realized that her son could pursue postsecondary music education. She stated:

Well, see, so it's interesting that, when I found [the music academy], I made the music fit! I made him fit... and not the other way around. You know, when I asked them about it, because you know, I've met with [the director at the

academy], and um, because I didn't... I don't really know about, coming into this, about [the academy]. I realized, you don't have to be these... (*I interjected and asked, "Someone, who's necessarily gifted like a savant?"*) She stated, "No, [you don't have to be that], you just have to love music!"

In addition to pursuing a love of music, life and learning at the academy has created social capital for her son:

That's the other thing that this school has done for him is you know that people with autism are not... or they say they are not inherently social, but, I have to say, he wants friends, he wants a busy life. He wants to connect. Initiating is difficult, but he enjoys being out and about and being with people.

"What we love about... (those with visions at) the academy..."

But that's, you know, what we love about, you know, some of my conversations with [a founder of (the music academy) the school, and I thank her for her vision. You know, she said to me, which is exactly... these same words that came out of my mouth, "Everybody deserves a life of dignity, and that's what music provides." Everybody deserves a life of purpose, you know what I mean, and that's what the music provides for these kids. There's life of purpose, and they're using it to teach them other skills, you know. So... I just think it's fantastic.

Community's social capital enhanced by academy, and not just vice versa. The music academy extended its services into the community, and the community was benefitting from engagements with and performances by students and alumni of the music academy. The social capital surrounding the academy was extending into the community. One parent offered her conceptions of music education at the academy relative to her son with cognitive exceptionalities, as an opportunity for him to contribute and to make choices:

He's taking voice, jambe or drums, and he's just started keyboard. [*And what do you think that's doing for him?*] I think it helps him... to have some contribution... to contributing... to considering what would be something wonderful for he, himself, to be able to present. Kind of like at an improv group, to be able to stand up and do something. It's like, "Hmmm. What do I want to

do? Do I want to do this or do that, you know, to entertain people?” He actually has the ability to think about “What music do I want to choose to present? What piece do I want to perform?” and that’s never happened before.

In contributing to his own education, there was an acknowledgement that her son had choices in his life and what he wanted to do:

“You’re in a *choir* and this is all the pieces you’re going to be doing. You’re in this *chorus*, and these are all the pieces you’re going to be doing.” So as he moves forward, some of... the choices he makes are not just because he likes that piece or he thinks the audience will like it, but it will be based on what his goals are... During the feedback session they said, “I’d like to see you move into a different genre of music. That would be nice to hear you do something a little different.” So now he’s thinking about that... or “I’d like to see you do [and/or] think more in your upper range or...” You know? I think that that allows him to think in a way, [to] allow him to think in a different way than he’s ever thought before and give him some freedom... that he’s never had. So that’s a great thing that they offer. And that really comes through the feedback sessions and... they are working... to help him really grow as a performer.

The enjoyment of him... “seeing his own growth.” The participant added:

That’s what I really want, my husband, too... We don’t just want him to grow; we want him to enjoy seeing his own growth. And they do give that kind of feedback, too. They (the teachers) will say, “When we first started...” [Or] they’ll say to a student, “You know, I had no idea that you had that range...” or “I had no idea you could also do keyboard as well as strings. You know, you are really quite versatile.” And the student is just (face bright.)

Conceptions of Therapies

Perceived differences between music therapy and music education. A mother whose son was diagnosed with WS talked about her conceptions of the differences between music education and music therapy. Her son came to the music academy having had music education at every level starting with private Suzuki piano lessons and music at elementary school though regular classes at a community college with an excellent music department. She wrote in her journal, “I would define music education for my

child as any systematic effort to cultivate his capacity to make and appreciate music.”

Helping to found the postsecondary music academy, this mother questioned whether the academy would be a good fit for her son as he had already pursued music education as a regular student without a major at a community college. Once at the postsecondary music academy for students with exceptionalities, she realized that her son would study, perform with, socialize with, and live among peers like never before. While her son had never had music therapy in all his years, she became interested in learning about it and was happy children with WS now have music therapy available to them. However, she also hoped that parents had the opportunity to know of the value of music education and the qualitative differences between music therapy and music education and how the two seem not to be mutually exclusive from one another, but beneficial in a myriad of ways:

You know, [our son] has, I think, done beautifully, and that (music therapy) might have been something added to his program. [However], I would not have wanted it to be instead of music education, and I do fear that some parents, just know knowing about music [therapy], and they're [thinking], "Okay, music therapy," and they're not getting, you know, they're not getting musically challenged or, you know, so it's not the same at all.

The evolution of the academy includes music therapy. The mother said:

Much of the verbiage and the talk about and the mission statement is directed toward using music to foster these goals of communication, social skills, vocational skills, but originally we who founded the academy weren't thinking along those lines. That was sort of a second thought for us. Truth, historically. We really had children who were drawn toward music, and we thought they deserved to do and continue it, and we weren't thinking so much, but it became clear that, (pause) the question: What are they going to do with it? What's it for, and all that, so... Um, and music therapy. And, in fact, when you can point to so much change, you can point to so many of these students [at the academy literally] speaking up. [One student] who has pretty heavy-duty autism gave such an amazing [speaking] presentation [at a concert in which he played music as

well]; they each gave a little short talk about who they were. They didn't do it all at once. They did it in between the sets of, ah, the clarinet trio playing and then a person might talk. And that's when the music therapist also spoke about herself.

Most participants reported that music therapy enhanced the ability to learn important social skills. When asked about music therapy, one parent of a son with Williams syndrome explained the differences between music therapy and music education:

No, no, my son had piano lessons and singing lessons, and I used to take him to music therapy which was lovely, but it wasn't very music focused. It would be, "[Our son] is playing the piano, "Boom. Boom" [Our son] is playing the drum. "Boom. Boom." I mean I would have to knock on the door and say, "You know he already knows about a thousand songs; he's 5, but you're singing the same damn songs. This just isn't working out." [*So it wasn't educational, the therapy?*] Music therapy really is... you use music therapy as teaching other non-musical things. Spatial things. Right, you know, right versus left, or projection or special... things like that... articulation, oral motor control, but it doesn't really speak to the highest level of brachiation and how you might do crescendo or pianissimo, but you can use that to modulate your voice so that when you're talking to people, when you say pianissimo (she's speaking very quietly) and no longer has a loud raised voice. Right? He's learned to do that through his singing, which is a lot less stressful than having someone tell you, "Shhhh." [*And he got that from education and not music therapy?*] Yes.

Ever-present goal to enhance music education with music therapy. The mother stated, "I learned that from the music, the education part... to learn how to use the music education part through therapy philosophy, but not allow music therapy philosophy to command the music education part." Some of the mothers warned that the natural tendency is to confuse the goals of music therapy and music education. Doing so might, in a sense, diffuse the fact that music education was an intellectual pursuit in and of itself. Music education was an intellectual pursuit that is also therapeutic.

She went on:

Any music therapist might say if you're singing off key, "Great. You're singing great." Because you're, you're singing. There's the courage of singing. You're opening your mouth, you're using your voice; whereas a music teacher might say, "You have to sing it on key. And this is how you sing it. Can you practice singing on key?" And if you have absolute pitch, you know what that is, but if [all you do is] to sing off key, you don't know that's not right. So matching pitch is very important if you want to be an average or above-average singer.

Another mother described the assets of music therapy while her son, who was blind, was in kindergarten and first grade. (Many of her other conceptions of music therapy have already been noted in this study.) She remembered:

He started music therapy in the public school, and I think that's when it taught him he had to take turns, he had to learn that there are other people around him because the kids didn't talk, but they would be able to react... and learning that there's other people around that, you know—he has to get the music to sound good [and] had to do it in a certain order or something. In music therapy, he always had other people in class. So that gave him—that was more for social... That gave him more social interaction. So um, because he would, he would also, you know, all the kids were very impressed because he knew each tone, what it would be, what note it is, and all this, so that he could help others.

The mother clarified that music therapy was not necessarily for teaching music skills, but more socialization skills such as taking turns, and "in order for something to sound right at the end, you have to learn how to interact." This is where music education and music therapy were combined, but not in a confusing way.

One parent of a son with Williams syndrome described the difference this way:

And, you know, most of the musicians at the academy are musicians. They have a very different viewpoint of music [than music therapists]. And, it's important, I think, for [our son] because he's a performer, to work with someone who is also a performer. You know, music therapists think everybody's, you know, it's all about how much you enjoyed it! (nervous laughter) Not how good you are. Ah, and he's in public, and he needs to be, he needs to know, you know, what he's doing. How to do all that.

This mother asserted her critique that her son is also a performer, so she wanted an

enhanced concept of music therapy. Her son applied what he had learned through music therapy to helping others, including his own mother:

I think their (music therapists') emphasis has never been in the right place for... some of the performers, so I have always tried to add that, you know, in one way or another. Somehow. Which is good. I mean, for [our son], that it's always been a natural part of who he is. He's very, very comfortable. He just loves it. He once said to me, [when] there was a convention coming, and I was going to be doing a speech... [at] the opening [where] there were like 500–600 people there, and he said, "Now Ma, just remember: If you get nervous, just take a deep breath, in and out, and then you'll feel better." And I said, "Oh, is that what *you* do?" He said, "Well, no, I don't get nervous, but I heard that works!" (laughter)

There was the perception among mothers that concepts of music education and music therapy were considered as one entity, whereas participants' critique revealed that there is worth and value in each because the goals were quite different:

He had lessons as well. We had always had private lessons for him. I always had both. [*And those were two separate?*] And their goals are very, very different. For [our son], I think, had he only had music therapy, he wouldn't be where he is. I really don't, don't think so. He would still perform, again, because he loves it, and he's comfortable, but I don't think he'd be the performer that he is.

Need and desire for more therapies: Parents' plea at IEPs. Another parent shared:

You never get what you want in an IEP. Other than that, you never get what you want. Ask for the sun and the moon, because you know you're not going to get it. You'll at least get a couple of things that you want if you ask for a whole bunch. They'll give you a couple... Especially therapies, you know, try to get that, but if you have people that aren't trained in it, it doesn't really help. Occupational therapy is a big thing, and music.

Theme Three: Parental Actions and Reactions

Actions and Reactions

Theme Three, acting and reacting, is framed by a first-order perspective in which parents posed a theoretical question, “How am I going to react, and what am I going to do to equip my child in society in which he/she will function through...” The topics parents reacted to include: research and becoming informed, advocacy and/or legal actions, hoping and/or planning for the future, and parental sacrifices (voluntary) and/or stressors (involuntary).

Introduction. Within the tri-framework (perceiving, researching, and acting) of psychological and behavioral postures, the mothers brought together what they perceived and believed to be true. They then researched to find out what existed to formulate a concept of what was available, and they used critique to assess this information. The final theme, reacting and doing, then occurred, but these postures did not necessarily happen in a stepwise, orderly fashion.

One mother was an individual who has journeyed through this life without everything going as planned. She encountered individuals in each of the systems who not only represented the systems, but were acting as agents of the systems, be they medical, educational, social, and/or legal, with a supportive husband. Her postures may have been considered the same as any mother functioning within society, one in which one interacted with individuals with inherent bias from her own paradigm.

Once her son was diagnosed, it did not take long for her to act and react. And when she did, her style was direct, and the response she received was immediate:

Right off the bat, the very first thing I did when he was diagnosed, was: I went to the Basic Rights workshop that your sped-pac... [The] sped-pac is the Parents Advisory Committee, I went to a basic rights workshop, and they literally handed me the book that said, you know, "This is supposed to happen within 6 weeks; this is supposed to happen within 6 months..." And right away, I could see that nothing was happening the way.... So I started raising holy hell, and my sped director called my husband and me into her office, and said to me, "You think you can fix this by throwing money at it, by throwing services at it?" And I said, "You're damn right! (nervous laugh) Of course I want to fix it," you know, like, "Yes; I do!" I was calling her to the carpet because things were not happening the way that they should, and so right away, we were, um, enemies (nervous laugh) and [we] remained that way for many years until like we eventually... I know now that she respected me. I mean, I made her life difficult, but...

Sharing her research and critique is an action: Adding to social capital.

Building social capital is something she felt compelled to do. She stated, "I feel that I've made it my life's work to help people (nervous laughter), you know what I mean? If a stranger calls me and needs advice on what to do for their kid, I help them." She increased her social capital by networking with other parents at meetings:

The second that we got diagnosed, I joined... my town's special education SPEDPAC, Special Education Parent Advisory Committee. And I started going to meetings once a month to see, (nervous laughter) you know, who else was there. ...A school system is mandated by law to have a SPEDPAC... I think throughout the country, that's probably true.

She embraced her own personal style:

I was always the radical. "I don't want to hear the official party line; I want to know what's really happening." You know, I want the radical... you know. I want to hear everyone's struggle and what they're doing about it. So... I learned, and I networked, and I, you know, met other parents.

She reported that networking with other parents was one way to become informed. She emphasized the give-and-take nature of social capital, to help others, but to also be helped:

So, yes, and parents need to support each other and help each other. I feel like that's, "Pay it forward." That's the way it should be; so yes, I've tried to help a lot of different parents. You know, I wanted someone to give me the road map. It's like, don't make me go out there (nervous laughter) and try to figure all this out, you know... I know you've been down the road, you know, like, "Tell me what you learned!"

According to this mother, it was imperative to know and exercise rights, yet not all parents are equipped to do so:

So... ah, but yes, it is incumbent upon you to know your rights, and you know, not everybody has the energy to ah... to um, to make sure that they (the laws) are being followed, but ultimately if the parent doesn't do it, then it's not going to happen.

Reacting and Acting to the Educational System

Failure to modify curriculum in a public school system.

Sacrificing to fill in the gap of perceived inadequacies. A different parent discovered that the school was failing to evaluate individuals with exceptionalities. This is a case in which the mother perceived, researched, and critiqued, and then acted and reacted. Curriculum was not modified for her son, so she gave up her own career to volunteer to modify curriculum. This included changing assessments to multiple choice options "because if you can't decode ... [without multiple choice options read to you], how can you complete it?" He "would miss his understanding of the material because it was expecting him to express himself verbally—or maybe even write his answers, and he couldn't write." The parent described the volunteer work she had done at the school, stating that she spent most of her time modifying curriculum. An opportunity for a tutor to work with her son arose in high school, and she described the situation, first talking about how draining the situation had been for her:

It was exhausting and relenting. Unrelenting. By high school, he had a reading tutor that worked with him. The school ... agreed to pay for him to go see a reading tutor. They didn't agree to transport him, because the tutor was not in the school.... He would leave at 12 noon, and I would drive him about a half hour to this tutor where he would be tutored for maybe an hour or an hour and a half or something. When he graduated from the transition academy, which was 2 years later... he read his graduation's speech, and I sent it to the tutor. I said [to] the tutor and the person who did the assessment, "You know, he never would have been able to do this if it weren't for your efforts to help him to decode."

It should be pointed out that the mother believed it was imperative that she, herself, modify her son's curriculum, not just because it was not being done, but because it needed to be done. The opportunity for a tutor to work with her son was a case in which the educational system agreed to provide services; however, there was no system in place to facilitate the ability to render the services. If she had not insisted on and assisted in factors in her son's education, she was convinced his intellectual growth would have been negatively impacted. Not only might he have not progressed, but he may have regressed.

If her son were to grow intellectually, she had no choice other than to sacrifice her own professional career to provide what the system did not. Laws had been enacted that assured that students with exceptionalities would be included—but at whose expense, literally and figuratively? The countless times she spent modifying curriculum for him—not to mention the time she spent driving him to a tutor, as well—were essential; she believed her son needed the tutor's assistance. While the school system eventually paid for a tutor and, since there were not provisions for funds for transportation, this opportunity for growth was literally unsupported. Had she not transported him herself, the tutoring her son received would not have taken place. She stated that she wholeheartedly believed that her son's accomplishments made it worth every second of

her time and effort. Her son would not be the man he is today if she were not aware of his strengths, limitations, and potential, and had she not voluntarily made sacrifices.

While her son was in high school, when he was being directed to learn in a resource room (and not in regular classes), she knew that consumer math would be a perfect course for her son. However, she was told, “Well, most of the kids who were in consumer math, you know were the ones who were kind of the rabble-rousers. You know, the troublemakers. You don’t want him in that class.” Her response was: “Well, actually, I do want him in that class because the curriculum is appropriate for him.” She insisted upon the most appropriate and fulfilling educational opportunities for him and acted to make them happen. If her son were to fulfill his potential, she had to step up when society failed to provide, and she did.

One mother brought opportunity for all students for music therapy to school. A mother of an individual diagnosed with WS was able to secure a grant that brought music therapy to an entire midwestern school district:

So I said, “I’ll tell you what, if I can get a grant for half the money, will you provide the other half so that we can bring music therapy to all the special ed classes in the district, and [our son] can be the music therapist’s assistant? That’s what I want.” And they said, “Okay.” And, I got the money (for the district). It was a win-win: All of the special ed classes in the whole district, district-wide, that was a pretty big district, got music therapy, and [our son] got to work with a music therapist... He was the... “job coach,” and he went to all of the classrooms, from age-3 through high school.

Program dropped from school after mother’s involvement ended. After her son left the school system and the mother was no longer involved, this opportunity for other students ended:

I was hoping that the [music therapy] program would carry on. It didn't, once he left. There was no one else... There wasn't another kid in the pipeline who wanted that (to be a job coach) so unfortunately they didn't even keep the music therapy for the kids—which was a crime... It was really a shame, but at least for him [my son], he got to do music.

Advocacy and/or legal actions. Some mothers reportedly did not feel they could advocate, in fear of retaliation against their sons. Mothers of sons diagnosed with WS mentioned how much their sons' friendly, easygoing demeanor affected how much teachers seemed to like their sons. But, reportedly, this may have affected whether at least one son received instruction or was allowed to wander or sit idly, not bothering anyone including the teachers. Not bothering anyone and also not receiving a stimulating education.

The mothers of the two sons on the spectrum and one son with a cognitive impairment advocated and fought for appropriate educations for their children. One of these mothers described her own need to advocate this way:

It's like, *I will* become the expert, *I will* become the expert on what he needs, and I will become the expert on how to get it for him and that's, you know, and that's the whole advocacy piece.

This same mother stated:

So [I'm] constantly on the phone to [the state representative] offices, you know, complaining, (nervous laughter) you know, telling them my story—Just like, “This is what's going on” ... because I feel like they need to know.

In referring to insisting on services from the public school, another mother stated:

My son got home-based services, which the school wasn't going to offer to me, but, you know, at some point along the line, I came to value the home-school, like somebody used that terminology. My son never would have learned to cook or tie his shoes or certain things if I hadn't had those services.

The need for legal actions. One mother noted, “All the advocating I did for [my son] in the early years... I never had “an advocate.” I did it myself.... In the later years... I had to hire an attorney.” Another mother disclosed that she had to hire an attorney to fight for the right to place her son in a school for the visually impaired. She could no longer stand what she perceived to be egregious treatment of her son at the public school prior to going to a specialized school for the visually impaired, a right she was able to secure for her son. (This was the same public school system that reportedly contacted Social Services as a retribution for the mother’s practice of seating her child at a table to read during school hours when the school was unable to teach her son and kept sending him home. It was also the same school that reportedly isolated her vision-impaired child in a room with children who did not communicate, the school that had allowed her son to lick walls when they brought him to the bathroom.) Individuals at the company where the mother worked helped her hire a lawyer. The mother listed all of the services the school was not providing.

A parent of a child with a cognitive disability noted that “in order for him to be successful in school, he needed a lot of assisted technology. And at that time, our district knew very little about it.” Additionally, the preschool refused to integrate. “They had *only* children with exceptionalities in their preschool, and they would not include other students.”

Classroom settings. Parents had opinions about the type of classroom settings where their children are placed, and school systems struggled to get the right fit. This was a source of concern and stress for a mother who had to advocate for the best suited

classroom setting for her son:

Because for so long he was in classes, [in which] the kids were worse than him; they didn't talk or didn't, you know, push [challenge] him. He needs to be pushed and because... he was starting to want to be around other people so he would have to learn to interact.

Reasons for advocacy. A mother described the reason for advocacy:

Advocacy exists with purpose. It's giving kids a better quality of life: this advocating for them, getting them what they need, you know. They (the students) may not have the big brains or abilities, but their quality of life (can be enhanced) by advocating for what they need; [and] everybody needs something different, so we have to find out what it is.

Music education advocacy: Mothers fight for sons' desires and needs.

Advocating for person-centered, following a person's interests and skills. A

mother had a peer, another mother outside the scope of the study whose child is also on the spectrum. Her peer's son was musically gifted at a vocational school:

Our kids had very different educational tracks. [The other person's son] was at the vocational school and again, they were trying to peg him into, you know, "Oops, he'll just work in a kitchen or he'll cook, and..." You know, and they [the parents] were saying, "No, he's a... musically gifted.... Like, he's been studying voice for... You know, he wants to perform, and they weren't listening to her, to her vision, you know, so she had to hire a lawyer, too.

Changing band director's vision and understanding. One student diagnosed with Williams syndrome had success in music education in elementary school, but by the time he was in high school, the student's experience was initially affected by the paradigm his band director held of (not) including this student in his band. At the end of the student's tenure in the high school, however, the band director admitted how much the young man had affected him and his own worldview of exceptionalities. The participant described this secondary school experience:

And when it was time for high school, I went in to the band director there, and I said, “You know, I just want you to know about my son... And you know, he needs to be in band, he’s got... processing issues; he can’t be in a pit running about between 10 percussion instruments. He won’t be able to get there fast enough. He’s a kit player. He needs to be in the jazz band.” And the guy said, (the parent speaking in a man’s voice): “Oh, no.” he said. “Our jazz band is very competitive, and they have to audition, and it’s, you know, it’s way too cool for him.” You know, “He can be in the freshman band, and he will just play snare.” And I said, “Okay. We’ll start there.” And, um, so he did.

One day, however, the band director heard her son playing the drum kit:

But, [our son] always hung out there, and his special education classroom was right next to the band room, which was fortuitous, (nervous laughter) and so he would go in, and he would [ask to play.] One day he (the band director) asked him if he (our son) could play the kit. And so, [our son] said “Yes,” and he (the band director) was like, “Oh! He can play!” And you know, he (our son) didn’t read music so that the stop gap, that was a thing, but he realized that if [our son] listened to a song once, then... you know, the song would start; he would come in on the third beat, maybe, but he come in exactly right. He wouldn’t come in behind. He came in on the right thing, so, um at the end of freshman year, he said to me that he would like [our son] to join the jazz band (see Appendix E).

“He’s taught me more than I could have ever taught him.” After 1 year of keeping the student with exceptionality out of jazz band, and then later, not allowing him to initially participate in band competitions, the band director had a very powerful admission: *“He’s taught me more than I could have ever taught him.”*

When he graduated, [the band director] was the one regular ed teacher who was always at his IEPs because, because that was... [our son’s] main speci... regular ed class, was band. At (our son’s) exit, [the] sort of exit IEP, he (the band director) said, “I know we’re here to talk about what, what [your son’s] learned, but I just want you to know he’s taught me more than I could have ever taught him.”

The student with exceptionality, her son, had been acknowledged by his peers, the audience, and the band director. Because of music education, high school was reportedly *great*:

So that was really, really nice. And he gave him the... jazz award, and all the kids gave him the... standing ovation, and [it] was a big deal, and it made high school great... Like I said, each year [our son] would take that next step, you know, little by little. And so when he (the band director) came to me when [our son] was a senior, and he said that “[our son] had taught me so much” (referring to the band director,) that’s what he learned. That he (our son) could be much more than a problem, I guess.

Advocacy: Led by individual with exceptionality. Perhaps a mother’s advocacy for music was best described by the following eloquent passage. The mother credited inspiration from two sources: her son and Dr. Robert Brooks.

My advocacy for music for [my son] has been led by him [my son]. I felt and still do feel that I only follow his lead. Mostly it was a pleasure, it rewarded me to see him in a positive light, when I spent so much time going to doctors, hospitals, and therapists remediating his weaknesses, enmeshed in worry. If for him music was an island of competence, for me it was an island of safety as well as pride. Dr. Brooks (Brooks & Goldstein, 2001) recognized an island of competence. He proposed building on strengths to diminish the ocean of inadequacy in which the student with learning disabilities floundered.

Mothers felt united with their sons in this advocacy for music education. They embraced this advocacy in their sons’ best interests and also with their sons wholly a part of the entire process, leading the way.

Creating what did not exist: A camp and later, a music academy. Perhaps the most extreme example of advocacy was mothers’ involvement in the creation of a music camp and then the music academy. One humble mother in the study did not call her inspirations and tenacity, her abilities to network and work well with others, to attract leading scientists and experts, and her research and discovery of the affinity toward music for individuals with WS anything specific. She and other mothers were already gathering, and they reached out to a noted neurologist, a professor. Together, with him, the visions of the camp and the school were born. Just as she had done before in an interview, the

mother recounted the creation of the camp, now in her journal with greater detail:

[The professor] soon sent out a query: Anyone interested in meeting to consider ways to promote music education for our children with Williams syndrome? Our meeting in [a major city] attracted only three parents: a museum curator who suggested Saturday enrichment programs; me, who suggested a music camp; and a professor... whose adult daughter sang with a college-based group [in a western state], who suggested a music academy. The camp proposal seemed the most doable, so we agreed to work on it. Miraculously, within a few days, [the professor] had lunch with an old friend who said “he knew just the place,” a prestigious girls' camp in the [relatively nearby] where he [the friend] had been supplying the food for many years. [The professor] visited [the camp] with his daughter, and persuaded the owner of this “fine and performing arts camp for girls” to allow us the use of her camp for a week. Soon [my husband] and I visited to confirm the plan and convince her further. [Our son] was asked to play piano; the director murmured “He is very well trained.” The camp had forty pianos! Thus began my mission to coordinate the novel camp program, secure partnership with the [foundation], and attract families.

The camp was the predecessor of the music academy; the essence of learning, the core philosophies from the camp, are carried on at the academy today.

What I learned about music education at and from [the music camp we created]: At that camp, music education was *individualized*. That is why [our son] had his choice of any instrument. Campers gathered in age groups for chorus, music theatre, dance, swimming, and art. But their music lessons were one-on-one with talented musicians. The educational program was *flexible* ... The camp's aim was not entertainment for a week, but *growth of the whole person*.

Her son benefitted immensely from his experiences, including those at the camp:

[Our son] has been very fortunate. He benefited from Suzuki instruction, the public school music program, and community college music classes and lessons. All were excellent, but had their built-in limitations of schedule and set curriculum. At camp, though only for 1 week each summer, he was given a wide-open opportunity. The philosophical legacy of the camp continues at [the postsecondary music academy] and is what makes it so unusual.

As well as students', parents' lives were also enhanced at the camp. It was at the camp that noted researchers met with parents and campers:

I remember a conversation I had with neurologist Dan Levitin at [the camp] in which he observed that the Williams syndrome campers had a unique appreciation of the “timbre” of sounds. Salk Institute brain researcher Dr. Ursula Bellugi had brought Levitin to the camp to help her understand the unusual expressions of musicality she was seeing in the population—he went on to study and write about Williams syndrome. By the end of that camp week, surrounded by sounds of practice emanating from the various practice rooms and drum sheds, as well as the frequent performances, I found that I, myself, had become more aware of the “soundscape.”

The concept of the camp had come about when the mother was in a waiting room of the Suzuki piano teacher’s home:

I sat in the small library next to the lesson room, and listened or read. One spring day there appeared on the bookshelf in that room a selection of brochures about music camps, evidently placed there by the teacher as an encouragement to her students and families to think about enrolling. I read the brochures. A light bulb moment: So this is what serious music students do in the summer. I imagined [our son] immersed in music instead of having just the weekly lesson amid the pull of academics and other activities. He would be in seventh heaven. But as I read through the brochures I sadly realized that he wouldn’t be able to keep up, the young musicians would be competitive and there wouldn’t be support for social and physical challenges ... And then I thought, “Well, what if there were a special camp? What if there were a camp just for children with Williams syndrome just to pursue music? And this is where my life really changed, because.... (nervous laughter)... I realized someone’s got to do [it]...that I would really work on this.

The nature of the parent group. The participant shared:

The nature of the camp brought together groups: a group of students and a group of parents. The group of teachers were there already, in place from the regular camp on a different week. The director of the camp said that the parents could stay there if they wished to, in separate lodging. And, that was key because when I brought my parents group out there, they said, “Oh, yes. We like this—very much, but we would want to come. We wouldn’t feel... alright sending our children away.”

This social group of parents were looking for opportunities for their children, some of whom were grown. At the camp, the opportunities came to fruition, thanks to the philosophy of the parents and a camp director whom the parents perceived as excellent.

One parent described the camp director as “the model of advocacy,” but exemplified, the model of creating social capital, as well.

Camp director’s social capital and individualized attention for whole person.

The director of the camp was the model of advocacy because she would say to you, “Your son is studying piano, but that’s not really what he is. He’s really a singer. Let’s give him voice lessons.” And she would encourage them in other ways, because one young man, he could barely... climb... a set of stairs, and he’s a self-taught drummer, and she said, “You know...” to his mother, “he really needs to have, ah.... begin exercising. Join a gym. Do something like that.” It was a recipe for the whole person.

Social capital: The value and investment in nurture. Captured in a speech the mother gave about “encouraging musicality in your children,” she stated:

I brought along three things. I had a... pocket watch, and keys, and a dollar bill. And I said to the parents, “If you want to encourage your child’s musicianship, it’s going to take time... it’s going to take *your* time, and that’s what that watch represented. And I said, “It’s going to take a lot of driving,” and that’s what the car keys were. “And, it’s going to, you know, it’s going to cost something.” Because this is what I’ve found with the Williams syndrome population, talented as they are, parents don’t have the time, or they don’t understand that a level of nurturing (is important).

The mother’s reflections: Factors that inhibit recognition of aptitude. The mother stated, “I never could have thought that it would come so far, and I just wish that we could reach more and more children who (have) special needs.” Referring to musical aptitude, she stated, “Students with special needs are equally... represented. Very high, in the middle and in the nothing. They have extra challenges... so that’s going to kind of hold them back.” The mother recognizes factors that inhibit recognition of aptitude: “The school system that doesn’t help them; the mentor that doesn’t find them; the parent that

isn't musical; the behavioral issues that exclude them." She stated matter-of-factly: "But the problem is, I think, that their *aptitude* isn't recognized."

Hoping and planning for the future. While perhaps there was no contrast between what can be created and what exists, finding existing resources seems to be more than a challenge, but instead might be deemed a stark reality for one mother navigating the system. Even if music education might hold some key toward living a more fulfilled life, it did not solve certain issues faced within society for a son on the autism spectrum (see Appendix F).

Parental sacrifices and/or stressors.

Challenging role of advocacy: Learning and living without established social capital. One mother mentioned that she was familiar with hard work—of being a graduate student. Things, she reported, were easy when she had had their first child. However, she was comfortable with hard work in an established educational system rich with social capital. She had first given birth to a child in a world filled with social capital for her, her husband, and her firstborn. She had studied and worked in environments rich in social capital for herself in the educational arena. Now she and other mothers were forced to, in a sense, "create a life" anew. The mother discussed the roles of parents, of sacrifices, and of *someone* having "to take on" the challenging role of parenting one with exceptionalities. She had been happy to follow others' leads in the past. She thought:

I'll look around and see who will take this on (nervous laughter), but *I* had to take it on. But then when it came to the school... (two others) became so active and took it on, then I could kind of work with her (them)...

Giving birth to a child with exceptionalities into a society ill-equipped to support

that child is a source of worry and, thereby, stress. This mother of a son on the spectrum admitted that she made tremendous sacrifices: “I gave up my career. I gave up everything to get him to where he is today, and my husband is extremely supportive, and he’s a very good father. But, you know, he makes the money, you know, to put the roof over our heads, and I do this!”

She voiced very real and practical concerns about the future of a society that has based social and educational systems on models from the past. She stated that “there’s not enough money to go around...” and “it’s hobbling school systems because they have to provide these... special education services....” She added that “it’s hobbling social services, too, the adult services world....” The financial stress that this will put on a society is immeasurable, as is the stress for parents who worry about their children’s futures.

Faced with the reality of unprecedented and soaring numbers of cases and the very real uncertainty of what the future holds, she reaffirmed her concerns: “I think it’s not sustainable. That is what is so scary about the mushrooming numbers of autism, is that I see how this is just not sustainable. It’s not sustainable for school systems. It’s not sustainable in the adult services world.”

The National Institute of Mental Health

(<https://www.nimh.nih.gov/health/statistics/autism-spectrum-disorder-asd.shtml>)

confirmed that Autism Spectrum Disorder (ASD) rates are 1 in every 54 eight-year-old children living in eleven areas of the United States. As this parent stated, “The worrying never ends.” Funding was a source of tremendous stress for parents, as well. As one

parent stated, “It’s just harder and harder to get funding now because there’s more and more students looking for it.” Funding for residential housing was becoming more and more limited, according to one parent. For each parent, DDS funding is a source of stress and worry unless the family is independently wealthy or if the child received some sort of legal settlement. However, when funding ends, what were parents to do? This was a constant source of stress and worry for most.

As parents made sense of the exceptionality, they also made sense of the systems in which they and their children functioned:

And all those things that they got in school, and specials that made them feel, you know like art and music and gym, that gave them an opportunity to blend in and integrate, that all disappears as well (at age 22). So... maybe you can find an adult music class for kids with disabilities, for adults with disabilities, but it’s not integrated.

One parent lost her career in the arts and was unable to pursue other creative endeavors as she dealt with evident stressors. Even stopping for a moment to fill out consent forms to participate in this research project was just one more thing to do in a life focused on advocating and providing for a son with an exceptionality. She shared:

I haven’t [done my creative work] in over 2 years because my personal life has been so tumultuous, and you know I’ve tried to get back to it... but I just, I just can’t seem to... Part of it is my aging brain, it’s so out of it that I just can’t seem to... Which is why, say, downloading your form [to join this study] and having to (nervous laughter) fill it out and then scan it and send it... I just, I don’t know.

Another mother also left her vocation in the corporate world but was able to do some work on weekends within the same field. When I asked the mother, [*You had to advocate for him? You were constantly, as a mother, I guess, looking...?*] Constantly. [*for things*] Yes. [*for him.*] Always. For his whole life.

I asked a question about sacrifice to a mother whose son was diagnosed with WS:

[How do you feel about the sacrifices you've made along the way?] (breathing)
Well, I... I feel that the outcome has been more than I could have ever imagined. And that I feel that whatever I've done with [our son], and then helping communicate that to others has created something for many people that continues to evolve and to help people, and I feel very good about that. So, sometimes I think well, I didn't do this other thing (my former career), and there are other women who do both (career and parental advocacy with child rearing) ... but for me, I didn't feel that that was what I could do. So I feel, um, you know... I feel that I've really done something that's good, and I'm very happy about that.

Another parent stated that she had brought up the entire advocacy piece, including the need to hire educational advocates, because: "My point of bringing all of this up: I had begun spending more and more of my time modifying curriculum for him." She continued:

Advocating for him, and at some point, as the curriculum became more and more sophisticated, and was more time consuming for myself, I thought, "I just cannot continue my practice" ... So at some point, you just can't... it's just not financially feasible, and I don't regret that at all.

While transcribing, I wrote in my own notes that perhaps this mother had no regrets, but still she was forced in a sense, it seemed, to make this decision. It was certainly a notable sacrifice and had the potential to cause great stress as the participant realized that she would have to choose between her career and the need to do something society could not fulfill.

The conceptions of the actions this mother took have been included in the perceptions of education section of this dissertation, but it was at this point during the transcription process that I recorded more in my own journal (see Appendix D).

One mother worked hard and made extreme sacrifices to assure her own child deserved the education he needed, and she described her actions as "exhausting and

unrelenting.” A single mother was willing to move time and time again to get her child into specialized programs for the visually impaired, to get the best education for her son on the spectrum. As specialist in business, she had to find work each time she and her son relocated. Even though her son was in better settings than in the public schools, it was stressful considering the placement within particular classrooms. She would have resorted to anything, as reported when she stated, “I’ll clean toilets. I don’t care. I’ll get a job wherever I can... to do something, you know. Move up here...” to get for her son what she believed he needed and deserved.

Asked about her own identity, she talked about some of the stress and sacrifices she made (including her stay in the hospital during pregnancy) and the support she received from her parents when she got sick:

[Has your identity become “being his mother”?] Oh. Absolutely. [You know, people see you, and they know you as his mother?] Yeah. So. And that’s how I see me. [And that’s what you’ve been for a long time?] Um-hum. Yeah. Forever.

She reported that she is not infallible and needed her own mother when she was sick. She stated that she had given up on having a social life of her own. Her life didn’t turn out the way she thought, but “I’m happy being his mom.” She was always there to support him, despite the fact that it was over a decade since she had a date. “He’s, my life is all about him, whatever he [needs].”

After a long interview, it could have been time to turn off the recorder, but I noted in my own journal:

The fact is, she didn’t want to leave, and neither did I. We were two people with common interests... with very different backgrounds and perhaps very different outlooks on life, but we were comfortable being around each other.

Competition to be in one band limited by enough performers. There were reportedly only so many positions available in the postsecondary music academy band that was often hired out. Other good performers who had the skills to be hired were, instead, in a band with other performers not as accomplished. They were left without the same performance opportunities and without music as a vocation. Parents found that they had to advocate for their children at that level to secure the best opportunities in an environment which advocated for their children; the academy did not have enough students to fill two bands at a level that was in demand beyond playing at assisted living places. “The academy will get him some of those jobs at the assisted living places, but not beyond that. The opportunities beyond that, we have to sort of work hard to make happen.”

Living independently. When one son came home for a year, the mother was worried he would lose skills he had gained at the academy. It was time for him to move into his own home where he could live independently with assistance and still study at the school. Another mother described the future for her son beyond life at the academy, an action that took place at the end of data collection and is reflected in her journal.

Even at that stage, it was the presence of a good support team and social capital that made it work for her son. She shared:

The process that he and I followed to make this new path a reality was rewarding. I called a couple of adults who had worked with [our son] in the past and who knew the community better than I did and together we invited a list of several local musicians and folks who knew [our son] well to brainstorm with us. [Our son’s] input throughout the meeting was critical as well [as we] brainstormed where he might be able to make a difference in the community and the type of supports he would need. Following that meeting, [our son] and I wrote a proposal and created a budget to DDS for funding through their “personal development”

funding. Our proposal was approved and [recently our son's] new program was set in motion.

Assessment of experiential conceptions. As disclosed in interviews, each mother in the study held initial conceptions of the diagnosed exceptionality, itself, in which they defined and seemed to make sense of the exceptionality. Additionally, each mother assessed assets and limitations within the current system in which they functioned. Three of the participants in the study, whose sons' diagnoses of Williams syndrome were later confirmed through genetic testing, recalled in detail how and when these diagnoses were made, long before much was known about the syndrome. The parents' initial foci of getting proper diagnoses and initial therapies for their children shifted to advocating for their children's educations. The high esteem and meaning parents held of the power of music and music education were based on what they believed music and the process of learning music created for their children (see Appendix E).

Realities of social capital. One mother reported that initially she had spent a lot of time wondering how or why exceptionality presented itself, and that she had become aware that the medical and educational systems in which they lived and functioned had the potential to be rapt with inherent, cultural biases and lack of support. At first her son seemed to be without any notable exceptionality. Once he received a diagnosis, she spent a great portion of her own life and most of her son's, not just wondering how or why the exceptionality of autism presented itself, but advocating for his rights.

Through her experience, the participant noted that those functioning as experts in the field within the medical and educational systems in American society (i.e., doctors and educators) had the potential to be motivated by financial resources or lack thereof.

She asserted that the well-being of her own son, and others like him, hinged on society's ability to capitalize on not just the limited financial resources and the visions of those who appropriated these funds and created the laws, but the visions of those who used those funds and created or modified new and existing laws and policies. She also noted that there existed the potential for biases: of disability in general, and of various exceptionalities in particular. There was a prospect for potential biases to be held about those who had the exceptionality and about those who gave birth to the person with the exceptionality; i.e., the parents.

While this was clearly one parent's view and generalizations obviously cannot be made from such a study as this, her experience and the meanings she made of that experience matter. It is widely accepted historically that improvements to the United States educational system are made by parents like her and her husband, who forged their way through legal battles and advocacy. This education system is one in which children with exceptionalities are now included, but were once excluded. It is common knowledge that that exclusion, in a relatively new system that developed through reactionary, however evolutionary means, was once socially accepted.

Referring to the day before a follow-up interview with me, this same parent noted:

So anyway, I just felt that I... just when I thought I had everything figured out now it's changing. [*So that stress level never really...*] Well, no, it never really... But he's so happy; I mean since the school year started and kicked into overdrive, he's just so busy and happy so... Although every morning we're testing—like this morning, he had a gig, and he's like, "What should I wear?" (see Appendix E).

Six parents disclosed experiences that were important to them. All of the participants believed that extremely positive changes had taken place in their sons' lives,

including opportunities to continue to grow, flourish, and become active participants in society. They believed that these opportunities were due to an education immersed in music education at the postsecondary level. The similarities of the collective ideology of six participants offered a far greater insight than individual experiences, themselves. The data disclosed the meaning participants held of their experiences.

Caine and Caine (1997) asserted that education could be driven by paradigms that were deeply entrenched in “dynamical knowledge” (p. 115). Those impacting education could embrace and incorporate “underlying purposes, values, assumptions and beliefs” (p. 110). Otherwise educations would be based solely upon “surface knowledge” and/or “technical or scholastic knowledge” (p. 115). As one makes sense of conceived experiences and values (including the historical connotations surrounding these conceived experiences and values), one is left with one very important and very clear picture: Some of the very mothers who have implemented change within the special education in the United States perceived that music and music education offer much potential. They believed that potential lies beyond most current systems in place, yet it was effective and captured by the practices at a postsecondary music academy.

The mother who advocated so long, described her son’s journey in music education this way: “The thought of him, you know, the thought of him riding the bus, and just being out in the community, it’s just... it was unthinkable... just 5 years ago. Unthinkable!” (see Appendix E).

In order to teach, in order to lead, perhaps the best recommendation might be to understand those whom you teach and those who are present at meetings and know their

children best. Knowing parents comes from understanding the experiences they have encountered, those past experiences that they conceive, now held in memory. One mother captured the relevancy of experience among exceptionality and the relativity of exceptionality in this following last testimony in the study of one whose exceptionality was caused by accidental human error:

Having this path, having the courage to keep moving forward no matter whether you are taking two steps back or not, you're still—you're accepting that taking two steps back is part of the journey... Perfection is not, if there's such a thing anyway, you know, that's not really possible. That's not human.

This mother chose music as the conduit to her son's life; she, and each of these mother participants have sons whose lives were enriched by music-infused education. Their own journeys were intertwined with their sons'. They helped their offspring, now grown, live in an environment in which they may not only *learn* music, but *use* music. Music education, in this sense, according to the participants, is all-encompassing, is primal and instinctual, natural and motivational, and can be used as a conduit to a more fulfilled, whole life.

The data suggested that parents functioned from at least the three postures that emerged in the analysis. Simply stated, these postures are perceiving, critiquing, and reacting. One might say that all beings function this way. However, what seemed to be different in these cases, for at least these six parents of offspring with exceptionalities, is that their psychological and behavioral postures were instinctual actions and reactions driven by not only the perceptions parents universally had of what was, but also by what could be—and by what was not present.

Parental actions seemed to be very much affected by parental evaluations assessed

after encountering professionals who functioned within systems. Parents perceived situations and then assessed them including information gleaned by the treatment they perceived they had received from professionals. This assessment included parents' perspectives of professionals' strengths, limitations, and potential for change. Parents then reacted to this information and acted. Their actions were reactive and were thereby reactions. The reactions of six mothers in this study evoked change within systems set up to serve them. These systems were often composed of professionals, each capable of basing their own actions and reactions on individual, and cultural, biases. These systems were set up to evolve based upon evaluations and assessments by professionals, and not by parents. Parents elicited change through advocacy and, frequently, litigation. Members of society such as parents often cast blame on individuals such as teachers. Where is blame to be cast in a society devoid of social capital? Teachers may have perceived, critiqued, and reacted when social capital, in the forms of training and proper resources including time, finances, curriculum, aides, education, etc., was lacking for them.

CHAPTER 5

CONCLUSIONS

In the previous chapter I documented and analyzed the perspectives of six mothers of sons with exceptionalities who attended a postsecondary music academy in the northeastern part of the United States. I sought to discern the conceptions they held regarding personal experiences and the meanings they attributed to their sons' music educations to answer these two research questions: What perceptions of experience did parents (of individuals with exceptionalities who pursued postsecondary music education) have, and what meanings did these parents make of music education? Every mother in this study had been thrust into an environment devoid of adequate social capital for herself and her son, an environment she believed had limited its usage and perception of music education. This led each mother to navigate using three postures: perceiving and intuiting, researching and critiquing, and reacting and acting. These three postures, while distinct, overlapped and integrated with one another.

Mothers' research and critique, whether formal or through lived experience, revealed that reacting and acting were imperative. The actions these participants took ultimately led their sons to a postsecondary education immersed in music education. All of the participants believed in the positive effects of music and the benefits of music education for their offspring with exceptionalities. Each mother believed in her child and the child's right to lifelong intellectual pursuits with purpose and intent. The meanings participants made of music education and the actions they took were all relative to the environment and the period in which they lived. It is to Bourdieu (Lamaison & Bourdieu,

1986) that I turned to identify, to question, and to delve into concepts that contrasted the ordered, empirical, worldly strata of life with that of the theoretical world of social capital.

In an interview with Lamaison (1986), Bourdieu defined habitus as an embodied “system of dispositions” (p. 111). Habitus affects individuals’ actions guided by an embodied sense of societal influences. Using an analogy of a game, Bourdieu identified that individuals are faced with the necessity to not only be aware of the rules, but to be “equipped to perceive them and carry them out” (p. 113). He clarified that individuals sense the existence of social regularities, and so he believed that the word rule in this context could be misconstrued; these regularities are not rules that one must follow as “objective regularities” or consciously developed principles (p. 111). Rather, there is a third sense of something that influences individuals to regulate: an embodied sociocultural awareness driven by social capital.

What I have alluded to as a natural motherly instinct, Bourdieu would not have attributed to nature, but to habitus, which is directly related to social capital. Mothers approached society’s acceptance of their children, their ability to matriculate in schools following the passing of Public Law 94-142 (1975), with hope and excitement, no doubt. For their children to be included, it meant that societal barriers had been broken. However, what they encountered was a system, an educational system that was driven, supported, and influenced by something beyond the apparent structure and mission of imparting knowledge. Bourdieu (1989) theorized about the presence and effects of social class within educational systems. In this study, it is evident that factors of ability-class are

also present, not only in the educational system and its formation and practices, but in society itself. Autonomous worlds, which Bourdieu (Lamaison & Bourdieu, 1986) described as fields, developed and evolved within society:

As societies become more differentiated and as those relatively autonomous "worlds" which I call fields develop within the chances of true events appearing, that is, encounters between independent causal series, steadily increase and, consequently, so does the freedom that is granted to the complex strategies of the habitus, integrating necessities of different types... as the more or less explicit principles which govern relations between relatives cease to apply beyond the boundaries of the family, only the complex strategies of a habitus shaped by various necessities can integrate the different necessities into coherent courses of action... Perhaps in societies less differentiated into autonomous spheres, the necessities of kinship, not having to reckon with any principle from a competing sphere, can assert themselves in an undivided way. But this would require verification" (p. 119).

My study indicates that for at least six individuals, Bourdieu's conceptual "necessities of kinship" (p. 119) developed among the participants, for it was often not available in the medical, educational, and community systems about them. The mothers in this study were agents with embodied strategies of the habitus. They were not reacting to established rules; however, they were reacting and acting freely in "coherent courses of action" (p. 119). They were guided by their own "system of disposition" habitus (p. 111).

Boix and Posner (1998) asserted that "social capital is, at its core, a set of institutionalized expectations that other actors will reciprocate co-operative overtures" (p. 686). The participants in this study disclosed that they expected to be treated as equal members of collaborative teams. Agents whom the mothers encountered did not always reciprocate the co-operative overtures they expected, however. Boix and Posner's concept of cooperative actors working together was often not present. Mothers often felt

it was imperative to react and act.

Thrust into a world of exceptionality, each mother found herself in a society that had made changes to include her son. However, when she attended meetings at the school and in medical offices, she was not necessarily treated as an equal, a member of a collaborative team. The answers she sought were unavailable, and the range of therapies which were extended to her son depended upon authorization from higher sources, often not just dependent upon funding and availability, but from the paradigm of an authority. This authority may have considered her an outsider, a problem, or a difficult parent for not going along with prescribed recommendations. As she sought to discover what the exceptionality entailed for her offspring, she found very little established social capital for her son and herself. Ultimately, she discovered that was not the only problem: even as she fought and won the small battles along the way, the educational system was narrowly focused and lasted for only a small duration of her son's life. Being included, although enacted by law, did not mean support systems were in place, for the parents, for their offspring, and the teachers who taught them.

The Actions of Participants, Common to All

The experiences of the six participants in this study led each of them to act in very similar ways. Each mother did the following:

- Exhibited what might be classified by some as instinctual motherly behavior.
- Came to terms with a diagnosis and advocated for her child.
- Researched what was available and used creative or adversarial means to

get what she believed her child deserved.

- Ensured that her child had medical and therapeutic care and went to countless doctor and therapy appointments and meetings with educators and other specialists.
- Wanted her child to continue academically past the traditional limitations set by social services and educators.

The Beliefs of Participants, Common to All

The beliefs of participants in this study shaped the meanings they made of music education and of exceptionality. Each mother believed the following:

- An education infused with the arts, and specifically music education, not only enhances their children's beings, but is imperative for their offspring's abilities to thrive and grow intellectually well into adulthood.
- Vocational, social, and communication skills are greatly enhanced through an education infused with music.
- Education must significantly impact students with exceptionalities by being meaningful, pertinent, challenging, and progressive.
- Individuals with exceptionalities can and do have continued growth well into adulthood through music education and deserve a life of dignity and mental stimulation.
- Persons with exceptionalities need and deserve education and educational opportunities well beyond age 21 or 22, the age when funding ends in most states and education for individuals with exceptionalities halts.

- Their offspring's strengths, limitations, and potential should be valued and respected.
- Parents should be treated as members of collaborative teams and enabled to function in cooperation with medical professionals, therapists, and educators.
- The two separate entities of music therapy and music education are important for students with exceptionalities and should be funded and available.
- IEP meetings are important, and the presence of parents at meetings is valuable; however the meetings are often staged as opportunities for teachers and therapists to present information and goals with limited time for and interest in parental perspectives.
- Their children's potential may extend well beyond accepted social margins, practices, and legislated rights.

The participants believed in the power of music and the value of music education.

Summary of Findings

When confronted by those in society who, intentionally or unintentionally excluded or limited their offspring's potential, the participants in this study resorted to creative, adversarial, and/or legal means to assure educations, lifestyles, and opportunities they believed their offspring deserved. This was despite extreme sacrifices and potential stress incurred in the process, and often meant working at ground levels to elicit change. The greatest insight revealed in this study is the meanings the participants hold of music

education. Education can be enhanced through the use of music, music as a tool and an inherent force embodying human spirit and motivation. Music education can and perhaps should be conceived in new ways. Parents report that this is being done at the music academy for postsecondary students with exceptionalities at all levels of interest and abilities.

Call for Future Research

In an interview, one participant discussed her own perceptions of the need for future research: “There is a lot of research on music and the brain. What is needed, as well, is research on the effects of music education on individuals with special needs.” She called for action: “For that to happen, those individuals must be included in music programs. School assessments ought to cover all the kinds of intelligences, not just linguistic and mathematical.” And ultimately, she called for change: “And the conversation about “interests” should not wait until the transition IEP, but should be there from day one.”

There is a need for research that seeks out parents’ experiences with and perspectives of music education for their children. Parents’ beliefs, concerns, desires, and experiences are not adequately documented through research. More research is needed to document the essence of experience as disclosed by individuals with exceptionalities.

DISCUSSION

Making Sense of the Findings

The research questions and the purpose of this dissertation could have led to a superficial documentation of the essence of experience. It was not enough to ask what

parents experienced. Once I narrated the data, conducted an analysis, and reported the experiences, I had to ask why. Why did parents experience what they experienced, and why did they formulate the meanings they formulated? Participants' experiences and formulated meanings of those experiences were relative to perceptions of the presence or absence of social capital; their reference was to the absence of social capital.

It is widely accepted, and documented in this study, that parents were in the forefront of the impetus for change that included their offspring in educational systems. Mainstreaming and inclusion placed students with exceptionalities in schools. Dropping students into schools without infrastructure and foresight did not guarantee adequate and appropriate educations. The participants in this study revealed that while members of society may have been ready for popular, progressive attitude about an inclusion, no plan had been formulated to support the teachers, the parents, and the children affected by the legislation.

The mothers revealed that they were not satisfied with merely having their offspring present in classrooms; they wanted their children to have educations in those classrooms that were not only appropriate, but were progressive as well. Every participant in this study wanted to function in collaborative teams with professionals; mothers wanted to share their inputs and their insights about their children, and they wanted to be treated with respect, as experts who knew their children better than anyone else could. The mothers often faced isolation and were forced to fend for themselves in an environment where they were devoid of social capital. They also had to create anew what did not yet exist.

If one were to generalize from the mothers noted in this study, one might state that mothers transcended traditional notions of social and human capital. They discarded biased concepts of the spectrum of human worth; they did not deny human individuality, but accepted and expounded upon it. They were willing to make sacrifices beyond the calls of duty. Mothering, to them, it seemed, was not duty, but human existence and human perpetuation, itself. This study did document experiences and meanings of experience of six mothers of sons with documented exceptionalities pursuing music education, but it also documented human spirit, human nature, social norms, and the historical evolution of education and, specifically, education at a postsecondary music academy for individuals with exceptionalities. This is an academy conceived of and created by parents, many of whom are mothers. This study reveals mothers' perceptions that human lives, all lives, are treasures that can be affected through the power and spirit of music, but who function in relationship to the world around them.

The concept of social reproduction exists in an ethereal, theoretical way, one in which society catapults its members forward, evolving to ensure members produce and sustain cultural and human capital. Social reproduction requires reacting and acting in informed ways that move beyond mere quests for desired ideals. Otherwise, not only is time at stake, but so is humanity and its environment. Freedom is measured by a society that supports it, in all aspects, giving its members not only a place to go, but knowing they matter and are supported in the journey. Culture is not only a byproduct of the quest, but the tools of the trade, something six mothers know and embrace. Music is an intellectual, boundless pursuit, and although it holds the value of being entertaining and

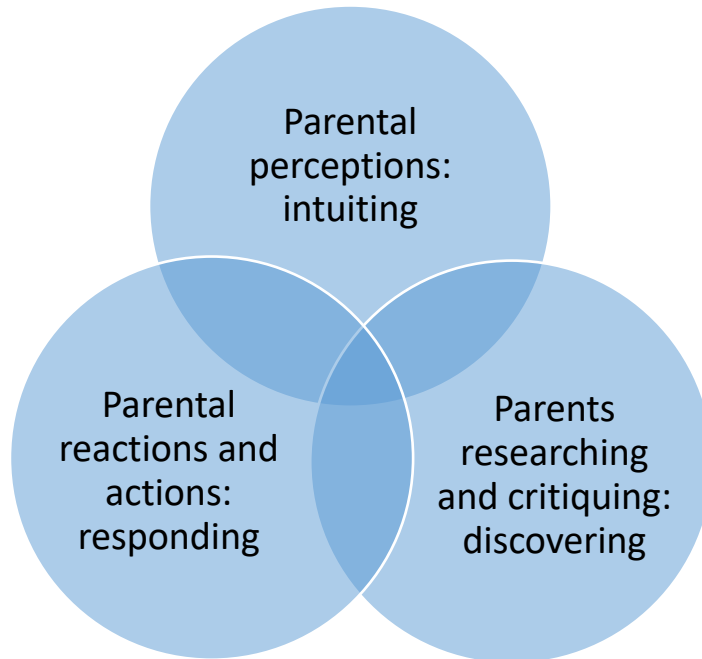
therapeutic, these are not the only ways in which music may be conceptualized and embraced. Attempting to thrive in a society that has not set up a system to adequately support them are the parents and their children and the teachers who teach them, among others.

The mothers in this study provided new insights into the possibilities of music education and the dynamics of an evolving society of systems. My perspectives and personal philosophy in my journal were disclosed and part of the journey of documentation within this phenomenographical methodology. This study concludes with my own journal entry:

Climbing out of a 1942 Stearman Barnstormer biplane day before yesterday, I had the opportunity to reflect upon what placing one's feet on the ground is about. It's all relative. I also had the chance to reflect upon not just what flight was like in the early stages, but what I was like before I was given the opportunity to take to the air in such a remarkable way, such a historic way. Each of us is given opportunities to not just reflect and remember, but to experience history in ways in which we can wonder, dream, and believe. It doesn't take a dreamer to capture the essence of where we have been, where we are, and where we may be blessed to go; it takes relativity, it takes consciousness, and it takes time, perhaps the resource we take the most for granted. Today we have all of these things at hand. While we cannot be so sure about tomorrow, I believe we owe something to human prosperity, something that researchers may define as human capital. Is it the same? Whether referring to prosperity or capital, we must never forget, that when one affects other human beings, one is responsible. We have a duty not just to right wrongs, but to ensure honorable, dignified, and purposeful actions today. For tomorrow. No, I cannot ask the Wright brothers of their memories, I cannot capture the essence of their verve, but I can climb out of a cockpit and wonder. I can tap into motivation driven by new eyes, aware not only of possibility, but the vision, the sacrifice, the intuition, and the force of "she" whom we call mother, creator, provider. It was a woman who brought me into this world, and yet another woman who took me to the skies day before yesterday, yet another trailblazer, another mother whose son also touched down and climbed out of yet another biplane in a five-ship about to perform a missing-man formation, the symbol of never forgetting. I am an American educator, and I dedicate my life to serving others. We have the opportunity to do more than to learn from the lessons of the past. We can take a relative stance that accepts exceptionality not as

difference, but as perhaps the only constant life truly provides: The potential to perceive what is ever present at, below, and beyond the surface and not just what is on the surface to behold. So much is taken for granted. So much is lost. So much cannot be changed back. But we have the opportunity today to fly.

APPENDIX A: THREE PSYCHOLOGICAL AND BEHAVIORAL POSTURES



APPENDIX B: RECRUITMENT LETTER

Dear Parents,

Education for children with exceptionalities developed in the United States as a direct result of parental beliefs, persistence and advocacy, yet parents' experiences and insights have rarely ever been documented in music education. I would like to select six parents to participate in interviews, to interact on a blog and write in journals in an effort to disclose your perspectives in a confidential manner. This small qualitative study is not intended to make generalizations, but it will document parents' involvement in the education of students with exceptionalities, your particular experiences and perspectives and may very well promote the potential for further research in the field. You (and your grown children who are attending XXXXXXX Music Academy, continuing education in the field of music) have had many experiences in education in the United States, and your perception of your child's educational experience over the course of his or her lifetime is significant and should be documented.

While working as a paraprofessional for 2 years in the early 90s in an inclusion program while finishing up a thesis in music education, I had an experience that changed my life and, I believe, the life of the child with whom I had the honor of working. The student's parents and I began corresponding daily in a journal, enabling the incorporation parental ideas, beliefs, needs and hopes into the child's education even though a supervisor was skeptical of the need for the interaction. I believe the experience I had when parents not only entrusted me with their child, but also shared their ideas about their child's education changed my life and personal philosophy and affected their child's education and experience in positive ways; I am dedicating my doctorate to those parents and to six volunteers from XXXXXXX Music Academy.

I would like to provide six parents an opportunity to join my research that will document parental insights and perceptions about music education. I am Nancy Rice and my 36-year background is in piano performance, voice, theory, composition, and music education. I have taught many years as a music instructor privately at home, at a private high school academy, and at a state university. Presently I am a doctoral candidate at Boston University.

I would like to meet you, to hear the perceptions you have of your experiences and share your insights in a published dissertation. Please contact me at [personal email address] if you are interested or want more information. Thank you for your consideration. I look forward to meeting you.

Sincerely,

Nancy F. Rice, B of Mus; MM
Cell: [personal cell phone number]

APPENDIX C: CONSENT FORM

Consent Form for Participation in Research Study Entitled: “Beyond the IEP Meeting: A Phenomenographical Study of Parents’ Perceptions of Music Education for Grown Children with Exceptionalities”

Principal Investigator: Nancy F. Rice, DMA Candidate, Boston University College of Fine Arts

If you choose to participate, please read fill out the form below and return to Nancy Rice. (You may contact Ms. Rice via email or telephone for a stamped pre-addressed envelope.)

I, _____ (please print name) understand that I have been asked and may be selected to participate in a research study entitled “Beyond the IEP Meeting: A Phenomenographical Study of Parents’ Perceptions of Music Education for Grown Children with Exceptionalities” and that I willingly volunteer to do so. The purpose of this research project is to identify the essence of the experience I have had, and the beliefs I hold, in music education for my adult child who is or was enrolled at XXXXXXXXXXXX. I verify that I have attended IEP meetings for my child prior to his or her postsecondary music education.

I will willingly participate in private interviews, interact with five other parents in a private blog and privately journal in a notebook provided to me. I understand that it is estimated that I will invest no more than a total of 8 to 8½ hours of time participating in this research project over the course of 5 weeks without any compensation whatsoever and that interviews will be scheduled at my convenience and may not occur during the 5-week blog and journal writing period. I also know that my participation may add to the literature of research in the field of music education and may be reflected in a published in a dissertation as partial requirement for the researcher’s completion of a Doctor of Musical Arts degree. All research will be conducted, recorded and stored in a private and confidential manner in which I (or any family member of mine) will not be identified or known by name or any other identifiable method. Whether or not I am selected to participate, should I choose to volunteer, I understand that I will be contacted by the method I choose, by telephone, email and/or mail so that I may plan accordingly.

- 1. Two 45-minute recorded interviews** (1½–2 hours total) will be scheduled at my convenience will take place on campus or at another agreed-upon predetermined location in which my privacy will be maintained and where I will feel most comfortable. No one other than Nancy Rice will interview me or will see my private identifiable information. Interview clarifications may take place over the phone or, if necessary, I have the right to agree to a third 45-minute interview to be scheduled at my earliest convenience. No interview is anticipated to take over 45 minutes, but if I choose to discuss longer, this will be my decision and will not be imposed by my interviewer. My information and everything I choose to discuss will be regarded as personal and will be kept confidential at all times. In interviews, I understand I will be asked two open-ended questions: “What have I experienced in music education in the past...” and “What contexts or situations have typically influenced or affected the experience I have (and I believe my child has) had in music education...” in order to allow for themes to emerge which we can discuss. I will only talk about things about which I feel comfortable, and I have the right to stop the interview at any time, for any reason.
- 2. I will join a Blog** in which I will plan to interact with five other participants, spending an estimated time of **15 minutes, three times per week for up to 5 weeks** (estimated total

of less than 4 Hours) at a time convenient to me. I agree to use an alias name and an alias name for my child if I refer to him or her during this discourse with others in order to maintain privacy. Nancy Rice will prompt us to discuss past influences, contexts and situations we have encountered in music education.

3. I will willingly **write in a journal 10 minutes a day, three days a week for up to five weeks** (estimated total of less than 2 ½ hours) which will be provided to me, in which I will be able to elaborate about my views of past involvement, contexts and situations I have experienced and to describe the meanings I hold of music education for my grown adult child.

I understand:

- All data collected will be coded and grouped into themes to be presented in a dissertation.
- It is my right that any and all of my personal identifiable information will be kept confidential including, but not limited to, my name, telephone number, the name of my adult child, my address and any school, principal and teacher names I may choose to mention.
- The information I provide (in recorded interviews, a secure private blog and journal) will be transcribed and kept in a safe for seven years at which time all information will be destroyed.
- All identifiable information will be coded and stored in a safe. All coded information will be documented and analyzed on a pass-protected computer. The private blog will be pass-protected and secure. Journals will be locked in a safe.
- I am entitled to privacy and confidentiality. The main risk of allowing us (myself and my advisor) to use and store your information for research is a potential loss of privacy. We will protect your privacy by labeling your information with a code and keeping the key to the code in a password-protected computer.
- I have the right to not participate at any time.
- I have the right to view the research proposal at my request and I may voice questions or concerns to Nancy F. Rice or of her Boston University (BU) advisor, James S. Imhoff, DMA at XXXXX and/or the Internal Review Board at BU at XXXXX
- There are no foreseeable risks to this investigation, and at no time are any physical, psychological, social or economic risks anticipated.
- There are no direct benefits to participating except to know that my participation may allow for the enhancement of research in the field of music education. **INITIALS** _____
- Participation is purely voluntary. I may refuse and/or choose not to participate at any time and so doing will in no way reflect upon my standing or loss of benefits including those of my family members. I may request a copy of this consent form.

Signed, _____

Date _____

Volunteer Participant

Name.....
Street Address.....
City.....
Zip.....
Telephone.....
Cell Phone.....

Email.....

Please circle one of the responses below: I have participated in IEP meetings in the past before my grown child attended Berkshire Hills Music Academy: (circle one)

yes no

Please circle any or all methods you would like to be contacted to know whether you were selected:

Cell phone telephone email mail

Please provide any information below about your adult child which may be used to purposely select six volunteers of like or different similarities. You may include your adult child's name, brief history and/or any information you think appropriate:

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(If choosing to participate, please print your name on p.1; initial p. 2; sign, date & fill out p. 3.)

My contact information is listed below. In order to return pp. 1–3 of this consent form to me, please contact me using the information below. Six volunteers will be selected to participate, and all volunteers will be contacted. I want to thank you for your time and consideration of participating. Although six volunteers will be selected to participate, all those who volunteer to participate will be contacted.

My Personal Philosophy and Promise to you:

I am humbled by the dedication and labor of those parents who, before us and now, enlighten/ed a nation that all children are worthy and deserving of an education. I promise I will respect and honor your rights and time and will do my best to understand you and your experiences and the meanings you attribute to music education. (In case you are wondering, phenomenography is a giant word that means the study of the essence of what one believes from that individual's first-person account to better understand the meanings that person attributes to something and the definitions they make of the world around them. It is an accepted and valued qualitative research methodology.)

I am passionate about this subject for many reasons: I believe your perceptions are important and have mattered in the education of your child and should be documented; I believe in the spirit and uniqueness of humanity, the nature of music and the value and inherent right to be educated; I

appreciate that I have witnessed first-hand much of the short history of education for individuals with exceptionalities in my over half of a century of life, and I acknowledge that the policy that governs and affects all individuals' educations can and should be critiqued, analyzed, potentially refined and/or amended and is subject to change; and finally, I would like to participate in that history even if only in some small way through this research project. Your perceptions may contribute to a better understanding of education for all children, promote further research and may even affect how future music education and music education policy is viewed. I thank you for your consideration to volunteer and hope to hear from you soon.

Sincerely and with much appreciation,

Nancy F. Rice

[Contact information withheld]

APPENDIX D: RESEARCHER PERSONAL JOURNAL ACCOUNTS

Combined identity: The “we” rather than he in music education and beyond.

I notice that the majority or all of the participants use the pronoun “we” They seem so connected with their child’s development that their experiences are shared. I would say, “My son’s introduction and then he did...” but seemingly because the parents with children with exceptionalities are so [integrated] in the process of learning, and the experience is learned together (often with the parent involved in the very essence of creating the experience, itself, or the advocating and fighting for the setting in which the child is receiving the care or education or modifications he or she needs), the parent seems not just participating with the child or for the child but, in essence, is a part of the child. These parents seem so much a part of their children, for without the parent, it seems the children would not only “not thrive,” but falter. So, the energy, the synergy of the actions of acquiring what their children need and deserve has the intensity, momentum, and seriousness as if it were life and death, and that while knowing that the path they forge is full of sacrifice and dedication, time and energy, in a sense, they are, in fact, fighting for themselves, for they are one and the same as their child. This may be a far reach from a parent attaching Velcro on fingers and keys, but the energy and dedication, the passion is there, in her voice. She was on a mission to find out what would work for her child, for him to become better, for him to find a way to learn. And she did.

Desegregating exceptionality.

Could it be that with the onset of inclusion, of desegregating the exceptional community, we have lost the vision or tainted the impact that there is value in being with peers? Could it be that in attempting to be “culturally accepting” of differences, we have removed the opportunity of what the parent points out is available at [the postsecondary music academy]: a peer group? And I’ve witnessed the interactions of the peer group at performance nights and in the halls of the academy when I went in to meet the director seeking permission to talk with some of the parents. It’s more than what I would envision I would find at a group home, because, the students there aren’t just living, they seem to be learning and thriving. They have purpose. They have intent in their days, not just to do a job, but to become more than they are. That’s what is available to students in higher education establishments, to university students, should they choose to spend their time in educational endeavors; but, my own experience is that presently opportunities are limited for students with exceptionalities in university settings. At the period of time that [their son] attended a community college, it was an extraordinary endeavor borne out of his own vision, hopes, and dreams, his own desires, and with parental backing and support, it was accepted by a transition team literally making history. But what would have happened if the parent at the meeting did not believe in her child? What if she had, instead, balked at the idea? Surely the support team would have also discounted the idea. But this parent is [an exceptionally brilliant and educated individual] and dedicated her energies to advocacy for her child; her own education is at the highest graduate level from what is considered the pinnacle of academics. She has published creative works,

and at the time of this transition meeting which she described to me in the interview, she was in the process of starting an academy with other parents and select individuals who envisioned music-infused education. She didn't balk at her son's vision of pursuing education. She may have been surprised at his candor, his outspokenness, at the meeting, but I highly doubt that she was not surprised that he, an academic in his own right, may want to continue to expand his intellect in ways beyond learning to fold a good towel. I know I am exposing my bias, my passion, in this, my journal. It's what has led me to my own endeavor in this study and to this specific topic. This documentation of a handful of parents' experiences is more than a mere record of events; it is not statistical analysis of quantifiable measurements. It is documentation of events driven by passion and desire, of hopes and dreams. That sounds trite because it is. Of course these parents are passionate; they are parents. Of course they have desires; parents often do. Of course they have hopes and dreams for their children; many, if not most, parents do. What is different is that these parents had children in a time in which very little was/is known about their child's exceptionality. If very little, relatively speaking, is known about something, it follows suit that a system of support would not necessarily be established. Cultural and societal biases existed and exist about disability. It's the reality parents live in, past and present. And if they are parents with passions and desires, hopes and dreams for their children, in a world of conditions we all live in, this may be the reality of what they may feel "up against"... what they have to perhaps fight for and live through. And so, the humanity within me gets... choked up... by the enormity of it all, by the human spirit and the mothering instinct that I, too, possess. There are those in the educational field who are unsung heroes, who "included" in ways that even the parents found surprising. They gave these parents hope in their own children's abilities. It is and was, ultimately, the parents who fight and fought the long, hard battles. It is the parents who lived with stressors that far exceeded those that other parents face/d. These are the parents with visions that have shaped the history of education in the United States. Not just special education history, but the inclusive history. These are the parents who found that music, our ancient, persistent heartbeat of sound, of song, of performance, has a place in their children's lives long after they have transitioned out of mainstream education, and whether it can be documented or not to be true, one cannot discount that it is working at a place in the northeastern United States. Lives that could have been relegated to menial labor are thriving, and skills are still becoming mastered, academically, socially, and vocationally. How could I not be affected by the magnitude of... not these stories.... these testimonies? This isn't about existence. This is about thriving, adapting, growing, overcoming. There is much to be learned here. It can, should, and will be documented.

Mothers' roles to drive advocacy.

I have more thoughts. Music was present, bringing life to this child, and presently music is a great part of this adult with exceptionalities. Music. The power of music. The lifeline of music. Inseparable, perhaps, from life itself.

Another thought is that these mothers, these participants with the exception of the single mother, have husbands very much in the picture, yet, I notice that when these mothers

recount their journeys, they are making reference to their son and their own active participation. Not the father's. It has been the mother's role to drive the advocacy, whether fueled by human, motherly passion and instinct or not, (which I believe it is) they clearly have had a front-seat role in driving their sons' educations, their lives. The typical mother seems to give birth and then relies on the systems in place, be they medical and/or educational. The typical mother of those with exceptionalities seems to have no such system in place, perhaps for three reasons: (a) it doesn't exist; (b) the existing systems in place have not caught up to current philosophies and/or (c) their child's needs are so unique the system can't exist and has to be custom-designed. I would beg to suggest that: (a) theoretically each child is unique and thereby could be deserving of a custom education, and thereby nothing is unique in custom educations being warranted for children with exceptionalities (yet from a practical standpoint, clearly children with exceptionalities offer extremely challenging situations for teachers because their differences are so multifaceted) and (b) that generalizations can and should be made in the special education field just as they are made in the regular education field and that, (c) it is imperative that a process to implement legislation must be instituted immediately. Implementing legislation should not take decades-- should not follow case studies of existing potential failures; implementing legislation should have its own course of action that is active rather than reactive.

Talking about findings.

My own biases are perhaps best disclosed in my own journal entry: *At the time of this writing, I am transcribing the second of five interviews of five unique mothers I have already interviewed (of six participants). These individuals have the wherewithal to insist upon the best for their children, perhaps born from motherly instincts, and they have been fueled by a passion that their children deserve not only educations, but the very best educations possible. Some of these parents have had to create the environment, itself, to develop a new academy, with new concepts centered around music and music education, and others have found this academy already in existence, borne from other mothers' passions and desires for the best. I am in no way associated with this academy at the time of writing this dissertation. I stumbled upon it in chance meeting (at a social engagement) with a founder of the academy. I was developing my topic at the time of that meeting, and I immediately knew I had found my potential participants when I met that individual. I had no idea at that time that such a place existed anywhere much less so close to where I had lived for so long, nor did I know how unique the learning environment is there and how impactful music and music education is to and for the students continuing their path of learning well into adulthood. I had no idea that themes would emerge and that the end of this stage of my own formal education would be fueled by my own life of teaching, learning, and performing music and by my own personal philosophy that many parents know their children best. I am documenting not just these parents' journeys, but "the Journey" (the historic one with a capital J) that came well before, yet is still relatively recent—given that it has come about in my own relatively short life of 50-something years.*

I have come to find that some motivated, intelligent parents will stop at perhaps almost nothing to provide the best educations for their children even if the society in which they live does not understand them or their children, didn't exist for them at the time of their child's formative years and may have miles to go before getting it "right." In that regard, there is no tradition when it comes to education, but a morphing development and perhaps a perspective that getting it right is not a pinnacle we attain, but (is a journey of) the very pursuit of striving to get it better, of understanding not only those who are conceived, but those who conceive, not only those who learn, but those who teach, not only those who are legislated, but those who legislate. I believe that our concepts of music education should not be limited by the traditions we have already created in this country, by what exists, and it should not be fueled by fear of its worth in terms of future endeavors, and it should be empowered by the worth of human spirit of those it enhances regardless of our various abilities, each of our own exceptional differences, and likenesses. This is but my own philosophy and the meaning and sense that I make of this present world of education for students with exceptionalities.

Purpose of human capital imposed by society.

I just have to interject some of my own states of consciousness. During the interview, I could sense things I thought about as this parent spoke. I remember thinking, "I hope the same thoughts (I'm having during the interview) come to me as I transcribe this so that I may write them down.

What I am thinking about right now (i.e., revisiting) is the concept of parents wanting their children to have a life of purpose. This seems to be something inherent in the meaning of living.... for all... Certainly for those without documented exceptionalities as well. But what about this world a child is thrust into? Does society have the ability, or rather, the right to assign what purpose a life embodies? Is the purpose of assigning purpose borne out of convenience, out of financial constraints, out of lack of time and/or planning, and if so, is this right? Is it legal? Is it moral? This parent talks about her son's gigs, proud of the praxis of doing, of having a sense of purpose, of being needed and/or of having constructive functions, social functions. Is this something inherent in all people, and whether it is or not, what happens to a society when one empowers others who lack the abilities to empower themselves? Certainly, historically, this occurred. The history (of not just education for students with exceptionalities) is one of force. Men forced mothers to abandon babies. Doctors forced women to abort. Husbands disowned families. Parents revolted. Parents forged a trail, insisted on what has become norm for today. But each period, perhaps, is marked by a sense of arrival. We have arrived to this juncture from all of that, and today is good. Today is just. But is it? What of today will be deemed unjust, inhumane, unethical, and immoral tomorrow? If we have never historically "arrived," then perhaps it would behoove us to look at today, today. Not tomorrow for what we didn't do. Perhaps, in order to enact change, we need to address, not yesterday's misgivings, but today's opportunities.

So today, does this exist? Are we imposing purpose on individuals with exceptionalities, forcing by the very nature of the system, a culture upon peoples who may not only be able to function at a different level than we are set up to "allow" and/or "create" and/or, at

least set up? Are we, essentially, setting up adults for a life with, if no meaning, then perhaps less meaning than they could have? And how? Perhaps... by measuring educational years for people with exceptionalities in physical terms that works for those without exceptionalities? Or, allowing an educational path to be determined by those individuals, some of whom their parents describe as ill-equipped to teach their children? Or, perhaps by allowing teachers' paradigms to generalize, and/or allowing systems of education to dictate whether pushing a broom is, at some point in a person's life, what constitutes to a meaningful job because it's something one can do today, and so tomorrow will and should be the same? I'm not suggesting this exists... but parents report that they will go to the ends of the earth to find something meaningful, something educational, something arts related, something dynamic for their grown children, their children who for a quarter of their children's lives had the parents there to navigate this system called IEPs, of finding the right mix of medical and educational opportunities for their child only to now, as this parent reports, realize that the stress not only doesn't go away, but morphs into a new reality: What will become of my child when I am gone? What will become of my child because he or she is no longer a child, but an adult, functioning in a system that believes they have arrived to an age in which they can not only sit around without typical peers, but digress? "My son's gig" denotes importance. Denotes value. Denotes purpose. Denotes growth. There's something very normal about that, and it essentially does not exist in many places in the world as we know it today.

Metacognition: Perceived ownership and effects of experience.

It's an interesting perspective. I went into this thinking of the IEP as the child's IEP. But here is parental ownership: "I had IEPs that were 4 hours long." Even I am perhaps forgetting not... the parent's role in this, but the parents experience in this and the parents perspective in this. In the process of securing a proper, just, and appropriate education for a child with exceptionalities, is enough consideration made, and/or is the perspective even being considered, of not just the role of the parent, but the experience of the parent? What do parents experience? When a parent describes an IEP meeting as "my IEP meeting" and it surprises me, I am moved by my own bias toward whose IEP meeting it is, and I feel moved to consider this from the vantage point of not myself, but the reality of the vantage point of the parent, stemming from the parent's experience, one that they have lived within a system, and one that I am not observing, but affording the opportunity for the parents to describe to me.

This is not a parent who happens to have a child with exceptionalities; this is a parent who has had a myriad of experiences of triumph, of struggle, of advocacy, of disappointment in the system, of frustration, of hopes, dreams, visions... This is not the same parent who started out this journey. This is a parent who has grown in and been affected by the very system set up to provide education and opportunity, and through whatever cause and/or effect has felt the need to advocate for her child for ensuring the best and most appropriate opportunities. Advocacy, itself, has many connotations, but in its purest sense, it should be welcomed, I believe, with open arms. Instead, it seems, the

parents have encountered a situation in which they perceive that they may be misunderstood. It must be so frustrating to have to ask for what you know your child needs and deserves. And, when this parent said that “When you walk in... and everybody tells you how much they love your kid,” I can’t help but wonder if there is a level of complacency on the part of all parents, including those whose children are (assumably) excelling in a system set up for their children without diagnoses. Are parents somehow jaded by being told, “Your child is so great”? I mean, if parents of children with exceptionalities have to fight so hard for what they believe their children need, how can we be so sure that all children are actually getting what they need? In a country where we worry about a decline and/or a disparity between “our” children’s competencies, should parents be demanding more and/or different approaches and services for all children? What ensures a balance of what is needed? Funding? Creative innovation?

Teachers experience affected by their experience: “Reality” of teacher challenges.

Teachers’ constraints, both personal abilities and biases and what they are allowed to do, and even opportunities afforded to them, including continuing education and technological tools, to adequate time to decompress and revitalize, are all factors that affect their abilities to teach. Are we considering the effect of experience on teachers? When we say, experienced teachers, we consider it from a positive vantage point. Teachers who have gleaned so much from experience that they are mature and seasoned; this seems to be a positive stance. But what are the effects of educational settings, the way education is set up... on teachers? Is what teachers experience day in and day out, changing them in negative ways as well as in potentially positive ways?

Why do we seem to accept that what has always been, the day-to-day “normalcy” is (1) the only way and (2) best way and that it wouldn’t affect those experiencing it in positive and negative ways?

Is evolution of thought and ability tracking with evolution of capability in education?

We are well into the 21st century, and yet classrooms are very much set up in the same exact ways as ever.... You may be thinking in terms of space, of desks, etc., but I am speaking in terms of teachers doing it all... one person who not only teaches but disciplines, organizes, preps, plans, grades—in much the same ways they have always done. Consider a comparison to, say, a physician conducting a surgery. Imagine the doctor calling the patient in, of doing the administrative paperwork, of prepping the patient, of cleaning the tools, putting a clean sheet on the table, of wheeling him or her around the hospital, of scrubbing up, of sharing the role of administering the anesthesia with another specialist, perhaps, but of executing the surgery, of sewing the patient up, of making sure the patient recovers, of getting the patient to his or her room, of cleaning the operating room, disinfecting the tools, you get it. One person. An expert in his or her field. How would that doctor, the one required to be everything and do everything be different than the doctors we know? How would the experience just described change that expert? How does experience change experienced teachers? How do experienced

teachers “deal with” the system they find themselves in to teach? How are they affecting parents’ visions and their students’ educations? How can the system be set up to enable teachers to be less defensive, more creative, more open to ideas, more likely to welcome input from parents?

It goes without saying that we all are affected by experiences; that is part of what living is. The question is: Are we complacent about what we believe experience can, could or should be? And, another question is: Are we truly aware of the effects of experience? If we are not, then we limit change that is directly proportional to limiting growth. If we cannot grow, we cannot change; and if we cannot change, we cannot grow. If we expect one person to do it all, we severely limit that person’s potential, and if we limit the potential of that person who is in direct contact with others, we limit the potential of all those with whom that person comes in contact. This is not about teachers and the environment, the system, they work in. Or is it?

In a modern age in which so much can be conceived and created, where the theoretical can become the reality, environments for working and for learning could be affected by new creative approaches. Although budgets may limit our ability to have teams of people in place allowing an expert to function in a school the way, say, hospitals function, just the consideration of new perspectives (of not just practices currently existing, but about our own potential complacency toward considering the potential for experience from the perspective of someone else and in new ways outside our own comfort zone and our own inherent biases) could be of value.

APPENDIX E: MOTHER'S CONCERN FOR THE FUTURE AND THE SOCIAL SYSTEM, AND RESEARCHER'S JOURNAL RESPONSES

(This is a direct quotation from a mother):

Music is of paramount importance, but why, (nervous laughter) why can't the rest of the program meet their needs? So basically when you turn 22, in [one state], it's 21 in other states, your special education entitlement ends, so all the supports and supports you were getting are just ripped out from under you. And then, if you're lucky enough to get funding, you, you move on to DDS, Department of Developmental Services. State funding—which is not an entitlement. It's, you know, "This is how many people qualify; this is how much money we have, and we're going to divide it up," and they don't care what happens to you, and they don't care what's a good match, what kind of program is a good match for you. So you might say, "My kid's interested in music, and I want him or her to do this," and they'll just... They will plug them into a program..."

[*But you think music is the key?*] Well, if you're musical. I mean. Whatever you're... I guess that was my point: that once you become an adult, and you have a disability, no one cares what your thing is, whatever your thing is. They just don't care. You're just warehoused, basically. You know, you're safe for 6 hours in the day, and um, you're going to live with mom and dad until they're dead, and that's all the funding we have for you.

During the transcription, I wrote this in my own journal:

Her point is that she can conceive her worst nightmare, that we could and may live in a society that doesn't care. If she has had to fight each step of the way, what could or will happen when she can't fight? If systems dictate, where is the personalization? If the system takes care of children and then drops them as young adults, a parent may be driven by tremendous emotion. I would argue that there are many people who care, but the system does not seem to be driven by individuals. Yet is it individuals like her who have slowly changed the educational system, and the medical system is evolving, as is the social system. However, it seems to only be driven by individuals willing to fight, capable to fight for each tiny cog in a wheel that is already in motion, but in what direction?

Perception that social system not set up for those on autism spectrum.

(This is a direct quotation from a mother):

See, historically, this funding, it used to be "Department of Mental Retardation." This is what this adult world was all about. And, if your IQ was below 70, you qualified. If your IQ was 70 ½, you got nothing, and you would sit on your parents' couch for the rest of your life and do nothing and have no services. And then all of this autism (nervous laughter) started to happen, so, they shifted for a change in the law, that it's based on need; it's not exclusively based on IQ. However, I feel like you have all of these people with autism who are entering the adult service system now, who don't... The model was built for adults with Down syndrome, adults with mental retardation, adults with

significant challenges, and now you have all of these adults with autism who, um, you know, have some splinter skills, you know, who maybe... could work a job, who could contribute to society, who maybe could do something meaningful. So the good news is that they're starting to get funding, but the bad news is that there's no... there's no program tailored to their needs. You're thrown in... like you'll be in a day program, and you're with 70 year men who are mentally retarded. Like, what do you have in common with them? Zero. So, you're warehoused all day, so that's the good news, is you're not sitting on your parents' couch; you're actually out of the house, but for what purpose? So, all your interests, you know... they don't care. This, this is why the program that [our son's] in [the postsecondary music academy] became an obsession for me, you know, like we're going to find a... you know, he's going to have the life of dignity and purpose, and I wrote about that on the blog this morning, that, you know, that everyone's so focused on, you know (nervous laughter) the, the school years and then they turn 22 and it's like, this is the rest of their lives. So, steering the ship from this point on is even more, you know, critical.

There used to be two models of what DDS would pay for. One is a group home, which is 24/7 staffing. You know, you're in a group home, and you have to live... you know, it's pretty um, restrictive. You know, you have to live by their rules, and again, I mean, if you're 22, and there's an opening in a group home and you get funding, they could put you in a group home with people, men in their 60s, 70s, you know, they're not looking (nervous laughter) for a good match. They're just, "Here's an opening. We're going to put you in." So there's that. Um, which he doesn't really need, and then there's this other model called "shared living," which is... it... it... I can't even find...like... There are agencies who provide it, and they have like a one paragraph (nervous laughter) description on their website...? So it's... I'd been even trying to explain to my family like what this means, you know. It's really hard to explain what it is because there's not really a good explanation out there. But essentially it means, yes, people sharing housing with someone in the community. So, ummmm, I mean, it could be a good thing. And this allegedly (is) the model that DDS wants to move everybody to (nervous laughter) because, you know, they don't want to pay for \$100,000/year group home for the rest of your life. They'd rather... pay half that, and have them be, you know, on the whole, they're moving toward de-institutionalizing and, you know, it's a very political/correct model of, you know, being integrated into the community, which all sounds great, if your kid is good with that. But you know, I have plenty of friends who have kids who are so severe that they can't, you know, that's not a good... you know... That's not going to work for them, ever.

So, that essentially, is the problem with adult services, is that, you know, with all of these people with autism are turning 22, and they're losing their special education funding, and they're being moved to these day programs which offer them basically nothing, and no enrichment, and no, you know.... So... if you're interested in music, or, you know, you say, "I want to do this," or "I want to, you know perform..." Let's say he wasn't at [this music academy], and I said them, "My son plays piano, and I want him to have a program where he can go into nursing homes and entertain and play piano," I mean, they would

just look at you, like, “Well, that’s not what we do.” You know? That’s not available, because it’s not an entitlement. Special education is, by law, and by definition supposed to be individualized and supposed to be catered to, you know, your vision statement of what you want. And adult services is like... (nervous laughter) You know, you’re just thrown into this pot so.... We need to work to change that. We’re endeavoring to change that. Because, you know, somebody like [our son], like I said, he has some skills. He could contribute. He could work. He could live independently. He is living independently—with support, but um, you know, there’s really... It’s black or white. There’s not a lot of grey.

My notes at this point in the transcription:

This parent keeps driving home this message: That parents spend time, energy, and resources navigating the system, and then, once all that parental energy has been expended for 21 to 22 years of that child’s life, the rest of the parents’ lives of that child’s grown life is spent being worried about the possibility of or actually being dropped by the system. From this parent’s perspective, that 21- or 22-year-old is thrust into a world that is not prepared financially and/or service-oriented to meet the needs of individuals, a world that this parent reports is legally bound to be individualized according to the vision statements of that person. This parent reports that the services are not there for intellectual stimulation, for the potential of growth, for meeting the hopes and dreams of that individual, and that 21-year-old may be placed in a home with other men or women who are potentially 50 or 60 years older than him or her with completely different abilities and disabilities, different exceptionalities. If the system essentially pays strangers who have been vetted and approved to basically foster these individuals in a “shared living,” situation, I wonder if the same system would pay parents to foster their own grown children and to be able to use that funding to provide opportunities of growth for dignified pursuits which they have identified as important to them and their children?

One parent closed out her blog interaction with these thoughts: (This is a direct quotation from a mother):

“How can schools find and foster the individual’s strengths? This quickly changes to “How can society and the Department of Developmental Services (DDS) find and foster individual’s strengths?” when your child turns 22.

Music as an interest, leisure skill, and even a vocation ought to be considered more seriously as an outlet for adults with disabilities. Unfortunately, opportunities to engage with music seem to disappear when leaving the school system.

People who don’t walk in our shoes have no idea of the enormous responsibility that comes with “steering the ship” toward a meaningful life for a child with a disability on the cusp of adulthood. We expend enormous energy during their school years, ensuring inclusion, academic rigor, SPED accountability. Yet upon turning 22, when the SPED entitlement abruptly ends, the danger of “falling off the cliff” looms larger than ever before. Now we have to worry about the quality of life for them as adults—for the rest of

their lives! Will they be warehoused in a one-size-fits-all day program that offers little in the way of intellectual stimulation, with a peer group of adults in their 70s who share diagnoses VERY different from your child's?

The adult services world is SO NOT ready for the tsunami of young adults on the autism spectrum, who possess unique splinter skills that could be harnessed for employment and independent living potential. But they won't be. Because the system is set up to serve a very different population—those with ID far more significant. And DDS is not interested in fostering the strengths of any individual in their care. Adult services are NOT an entitlement. If you're lucky enough to qualify at all, you get what you get. Mediocrity. Zero individualization. Warehoused. It's very bleak.

We can and need to do much better! It's incumbent that as a society, we recognize AND FUND programs that foster individual strengths and interests so a life of dignity and purpose can be achieved by all adults with disabilities. REAL lives. REAL interests. REAL skills. REAL purpose.”

My journal entry:

In reading over the comments on the blog, I realize these parents have rich histories and very busy present-day lives. These are not parents necessarily starved for a medium (such as a blog) to be heard and to interact with one another. In fact, none of them seem starved for that at all. They aren't sitting at home looking for a chance to figure something out. They are out making things happen, forging ahead in the field of whatever one might call it: education, medical applications, therapies, social events, and the myriad of ways of doing this thing one might call rearing a child—not just any child, but their own who seems to face challenges, and as one parent put it, “the least of which” is the disability or as I call it, exceptionality, itself. But they are interacting on the blog.

The challenge, it seems for every parent of every child is challenging status quo, not accepting that “the system” is necessarily all it should be for every or, for that matter, any child. The difference I see in these parents is that audacity to question, and the commonalities amongst them is that they seemed and seem to be driven to have sought and to seek the very best for their children despite the fact that it did not necessarily make them popular parents amongst teachers, other members of school systems, and oftentimes, doctors. Additionally, they still have the future of their grown children's quality of life at stake. But isn't this what every parent faces? If the system is what it is, (meaning imperfect and not necessarily adaptive and certainly not individualized) while they are here and alive and of the strength and willpower to advocate for their children, what will happen in the future? Are parents of children without diagnoses complacent and accepting that the present system fits their children's needs and that the future is assured for them as they grow into mature adults?

My own belief is that we can learn a great deal from parents such as this study's participants, not just for the good of and the future of children with exceptionalities, but as universal role models for all parents—for the energy, the visions, the hopes, and

passions of these select parents are not just inspirational, but noteworthy. That sounds trite and canned and full of bias; however, could anyone have imagined that the inclusion of children with dis-ability would lead this country out of a complacent and perhaps victimized mother-as-housewife stage into a women-of-power-and-vision-and-action movement (if it did)? Why did women and specifically these women, these doers, these never-settlers, these seekers of justice and visionaries of new methods unconstrained by present-day medical, educational, and therapeutic methods and practices, respond to my call for participants?

I embarked upon this research hoping that the visions of a few might disclose something that might help in the field of education and specifically music education, but what I have discovered is that, just as I suspected, these participants have much more to offer. What I am surprised by is that the parents' methods and visions for education hold potential for the future of all education, not just music education, and for all students, not just those with documented exceptionalities. Rather than seeking commonalities in classrooms, our system could be one of cherishing and nurturing differences, infusing education with music in creative ways, one that not just challenges, but ensures that teachers find creative strategies, embracing concepts that not only can teachers work for parents but with them in joint efforts that admonish the ease and comfort of teaching to "an average" and assuming roles of authority. These parents have each had to advocate, often utilizing legal means, to ensure the educations and care they believe their children deserve, even if it means starting a school, a camp, forcibly placing their children out of isolated corners and into the mainstream of not just classrooms, but life, itself. And as tired as they may have gotten and presently may get, they never give up for not only is their child's future at stake, but so are the futures of all the other children they have helped along the way. The instinctual wisdom and power of mothers come to the forefront when forced to face injustices and complacencies, not just for the future of one, but the future of all, not to alleviate difference, but to highlight exceptional qualities held by all beings with and without societally imposed labels.

It is true that parental participation and advocacy have helped create the very system that now mandates parental participation in IEP meetings, but what, literally and figuratively exists beyond these meetings? What values do parents hold for the educations of their children, and is the potential of the wisdom of parents best served, (and, likewise, is the potential of their children's educations, their future within a society that cuts off their education just as it seemingly begins for students whose early years are spent on socialization) by educational specialists who are limited by lack of time, lack of financial resources, and perhaps biases about parents, children's disabilities and/or giftedness, and who have the potential to make so much impact?

This parent who has done so much not only for her own child, but for many, many others, just as other parents have done... and this parent has driven home the concepts (a) that education, for all students, should be meaningful, that it should relate to having meaning and purpose for being learned; (b) that music can be used as a tool; (c) that education can be infused by music and the arts; (d) that how we view how to teach children can be

gleaned from what is working that motivates children to learn; (e) that parents matter and their advocacy can and does change lives; (f) that the status quo of what exists in a system such as an educational system does not have to be status quo. It can and perhaps should be changed if change reflects progress; (g) that medical interventions/therapies can be less stigmatized as being so clinical, and thereby making the person receiving therapies feel like a clinical patient if rather, therapy is infused into education. Education and therapy do not have to be conceived of and practiced as separate entities; (h) that how education and therapy make a person feel not only matters, but is perhaps directly proportional to the outcome of education and perhaps of therapy; (i) that we should focus on the positive traits of students, what they can do, and go from there; (j) education does not and should not have to be centered around remediation.

What I am most impressed with, what I am feeling, is that parental wisdom can and does change lives of not only those most closely related to them, but for others. Parental wisdom. These “trailblazers,” as [another participant] was called. Not all parents are equipped to blaze the trail, however, for whatever reason. So how does a parent confront a system of learned professionals if they feel a confrontation is necessary, if they believe the system is failing to serve their child, if they believe a system should and could incorporate new ideas, function from a new perspective?

One mother stated it this way:

As so, I have felt that I have really spent my whole life trying to find people who wanted to be around that part of him, because we have had to create a *world* for him, you know, in that way.

Capturing the essence of the advocate: A mission for perceived justice.

I should mention that this mother... is almost urgently trying to cover everything (all topics). I admire this about her. It's not that she has... an agenda, but that the agenda that is an omnipresent given from the first word to the last (of the interview) is urgently ... important. Her son's life is, of course, important. His livelihood, his well-being, the right thing for him at the right time, is important. It feels as if my interview with her is important business. She always responds right away, is ready to talk, has things to talk about, and has organized her thoughts. She needs to share. She wants to share. Getting her ideas, her concerns, out is important. This is what I admire. She has a motherly mission and that mission is to right the wrongs, to not accept the obvious as commonplace and norm, but to do and say and want the right things at the right times. This, to me, is noble. This is admirable. This comes across as a primal parental instinct at not only its best, but its most dire.

I see her as one who has faced stark realities that time is fleeting, that we don't choose what necessarily happens in the future... She has told me stories that make me realize that her advocacy is a necessary component in assuring her child gets what he needs and deserves. It all started when he was made unwelcome at a religious school. And, it started way before that, with getting a proper diagnosis. This parent clearly not only distrusts the system, but has had to learn to navigate the system. She doesn't take

anything for granted. And, it seems she has learned that she has to advocate, she cannot let her guard down, and that she will use every breath and every word she utters as not only important, but vital to her son's future. I would say most of us take a tremendous amount for granted by comparison.

I admire her and all her energy—all her words, and concern, and dedication. She is, in every sense of the word, a mother. She is passionate. She is committed, and she is strong, and, it seems, she will never give up saying, thinking, and doing what she believes she has to for her child, and she is living knowing that when she can no longer be the one to do this work, she has no idea who will carry the torch... not on her behalf, but on her son's behalf. This is ultimate parenting; ultimate mothering. The worrying, the critique are genuine and unfortunately, as she reports, a necessity. I am left wondering why it is a necessity—why it exists as a 21st century reality. Is it lack of funding, lack of continuity between services, is it problems caused by ignorance, incompetence, is it lack of foresight and vision? Certainly people care. So what is it? Why can't parents sleep at night knowing their children will have the best educations, the most individualized and pertinent educations... not available, but planned. There is a difference. This mother doesn't want the best that is available. She wants what is available to be the best. There is a difference, and I laud her for not only recognizing that, but working to make it happen.

APPENDIX F: RESEARCHER'S POSTSCRIPT

In response to the overwhelming reported propensity of students with exceptionalities being steered toward the vocational track:

So this seems to be an instance in which the system was attempting to steer an individual with exceptionalities to learn a skill, a trade, reserving intellectual pursuits to others. How many individuals throughout history have shown an acute interest in or aptitude toward music only to be steered away from music education, and why? Why would this young man's aptitude, interests, and intellectual pursuits be ignored in favor of learning a trade at this point in his development? Does this speak to society's generalizations about the potential of individuals with exceptionalities? Does this speak to society's generalizations about the field of music? And/or or, could, perhaps, the point at which educators and specialists are helping students find and develop a vocation be too soon for those with exceptionalities as compared to their peers without exceptionalities, and/or do students with exceptionalities need, require and/or deserve extra time to develop intellectually while or before training for a vocation? If a student is taking longer to learn certain skills, why does the educational system impose the same and/or similar time frames upon these students as their peers with average or above-average tracks? Could the same methods that are being used for teaching students with exceptionalities continue beyond what is traditionally accepted and presently in place for students with exceptionalities? Traditionally the education system in the United States, has provided education through high school, but what does tradition even mean? "Traditionally" students with exceptionalities were not taught at all until the 1960s, and only then due to parental advocacy and legal pursuits. "Traditionally" students with exceptionalities were eventually given the opportunity for education and placed in separate schools, until parents insisted upon other opportunities. The ways in which we teach students with exceptionalities is not traditional. These parents and those before them and countless others were and are making history. They have not been guided by tradition, they have created tradition, and in so doing, they have given consideration to the very fact that creating policies for education and educational reform is a science and an art clearly based upon parental wisdom, determination, fortitude, and investment in terms of time, money, and passion.

If it is taking students with exceptionalities much longer to develop some mental skills, why would a shift occur at such an early age, (or at the same age as peers without documented exceptionalities) to a more menial approach at this stage in the student's development? Both parents whose interviews are in the process of transcription have expressed an interest in continuing their sons' intellectual development beyond the arbitrarily accepted assigned age of 21 or 22, depending upon the state, and that is something they believe the education at [the post-secondary music academy] is providing. The students at this postsecondary academy are not just enhancing their social skills as one parent identified as the purpose of music therapy, but are continuing to

learn about and perform music from an intellectual, educational, and vocational approach. This music education is continuing well into adulthood. This music education is not reserved just for the gifted or those who have prior exposure to music education, but for all those interested in pursuing music education postsecondarily. Furthermore, the skills acquired through this postsecondary music and arts' education is valued and enjoyed by those without exceptionalities. This brings us to age-old philosophical questions of the value, worth, and purpose of music education and music, itself. When did music stop being valued as a science, relegated, instead in worth by conceptual measurements of entertainment and therapy? Does music exist to provide aesthetic enjoyment? (Reimer, 2003); is it praxial or "doing" in nature? (Elliott & Silverman, 2015); and/or should it be a highly intellectual endeavor?; and does it even make sense that, these concepts could or should avoid compartmentalization—that music, instead, provides an intricate combination of these and other attributes with potentials perhaps we have not yet imagined or attempted to measure?

My journal includes field notes of the meanings I am making of all this as the words enfold in transcriptions of the parents' interviews held on a digital recorder. These qualitative field notes I am taking may include observations and my own thoughts of the meanings and context of these parental experiences. These are the unspoken topics unheard of in quantitative methodology, one imbibed and limited by our own conceptions when developing such an instrument of data collection in the form of a quantitative survey. The potential for change is not necessarily only conceived, instituted, and born out of limitations we can test for and by what can be measured, but by what we feel and intuit based on others' knowledge, reason, experience, and the meanings they make of concepts in the world around them. Hence, this qualitative phenomenological approach is much more suited to the enfolding themes and remains unconstrained by preformulated questions.

I took the first and only participants interested in participating. They all happen to be mothers of sons whose exceptionalities are either autism or Williams syndrome and a cognitive impairment. The mothers have all had college educations from some of the best schools in the world. One has been a single mother all along and the others' have stayed married throughout the journey. One entire family has succumbed to various cancers while their child with exceptionalities remains healthy. The mothers in this study have given up careers and pursued new ones in order to ensure their child's education and resulting future is secure. Each of them describes their own advocacy and legal battles. They seem to be pursuing this project with me in what I believe may be another avenue: research. Advocacy, litigation, and research are three ways to be heard, three ways to have the potential to institute change, potential ways to leave legacies for their own children and those who follow. I don't believe these parents set out to change the system; I think each wanted a system in place that provided suitable and adequate educations for their children. Instead, they report that the professionals in the system, be it medical and/or educational, did not understand their child nor did it understand them. The system they hoped for, that they believed their child needed, didn't exist. I question whether these parents were, in fact, valued.

The people I have met, whom I have interviewed, have left me in awe of the magnitude and depth of parenting they have done. Imagine forging new paths! This is what these parents have done. And, at the core of these paths, however intertwined, complex, and unique they may be, at the core, is music education. When Winston Churchill stated, "Success is not final, failure is not fatal: It is the courage to continue that counts," he was facing a formidable and very real adversary in the face of Adolph Hitler and Nazi Germany. These parents have chosen, it seems, to have the courage to continue despite that fact that their adversary has had no face—for it wasn't, it seems, the faces of the individuals along the way who perhaps said ridiculous things and stood in the parents' ways of pursuing success for their children who were their adversaries, but, it seems, perhaps, it may have been the system, itself; additionally, these parents have continued pursuing success for their children despite the risk of failure inherent in all pursuits. Likewise, success in both examples embodies livelihood and perhaps requires a great amount of sacrifice, determination, and a long, hard course of action. All children function in the system in its current state, but for some, it seems, the system is truly in its infancy and the risk for failure is too great-- for each child matters, something, I believe good mothers know and will stop at nothing to ensure is valued. I believe that when parents are valued, they may be heard and not just listened to, that they may be an integral part of the process, not just dealt with as a problem. The problem does not, it seems, lie in the people needing education or the people insuring its merit and existence, but perhaps in the meanings, values, frequency, and timing of present-day methods and strategies and in the conscious or subconscious limitations imposed by those instituting these practices. Failure can occur from complacency; if we stop trying to institute needed change and if that change does not reflect individuals' rights and interests and new ideas presented by those who know them best and have their best interests at heart, we have failed those we choose to serve. The future of the legacy these six parents' advocacy and lifelong pursuits for not just the right of education they hold for their children and the placement of their children in a music academy, but the quality and value of that education; the ability to have the journey documented, lies in my hands as we (the participants and I) pursue this research together, and I am honored and deeply humbled by the tasks at hand. These are the thoughts I believe I should place in this, my journal of reflections in the phenomenographical endeavor.

As I transcribe this, I have to stop and talk about something I was thinking about during the interview. This parent is describing that making sure the laws were being followed, in her words: "Ultimately if the parent doesn't do it, then it's not going to happen." But one thing has come to the forefront of all of this: Some parents have been worried, on the other hand, that if they made too many waves, that it might be taken out on their child. [One participant] voiced this concern. She didn't want to make a lot of waves. I believe this must place parents in a sort of conundrum, or at least sets the stage for that. That must have the potential to create quite a bit of stress for parents, as well.

And here is another question: Do parents feel they are separate from the teachers and the experts? And, if so, why this perceived separation? What sets the stage for this to either happen or actually exist? Does it exist? What am I talking about? I'm referring to the

potential that parents may not feel part of a team. How many of these six parents have alluded to this even if they haven't voiced those exact words? Surely the majority, if not all. In my analysis, I have to consider that this is a theme: Many/some/most/all parents interviewed view their role as adversarial. Can/should this be addressed as to why this may exist? Surely it is to the benefit of the child, but is the stage set for this to be harmful to the parents, to the teachers, to the system and ultimately, the child? Could the stage be set for a different outcome entirely? Can we alleviate the necessity for parental advocacy by having a system that is, in itself, adversarial? Is the present system adversarial... or is it reacting only to fixing the problems parents demand are fixed? Has our system been borne from controversy, advocacy, ethics demanded to be adhered to by parents' insistence and legal battles? This is well beyond the scope of this study, but this study bears witness to the experiences parents not just encounter, but endure. And, parents seem to have only so much endurance and so the torch is passed amongst them, and between generations. Generations of torch bearers, of "trailblazers," of "warriors." Is our special education system set up in reaction to these wars, and is it inherently designed to perpetuate these wars? If so, is there a way to change that momentum, for the sake of the parents, for the sake of the teachers, for the sake of the faculty such as the special education directors and administration, and most importantly, for the sake of the students?

Parents are affected by their experiences, and I am, in turn affected by their descriptions of what they remember, their memories and their conceptions. I am trying to remain an open book. "Tell me what you have experienced and the meanings you make of it." Those experiences remain etched in their minds... or do they? Is what they remember most, how what happened made them feel? Is it the feelings that have ensured that they remember and is what they are remembering the entire situation? Surely it is from their own paradigm; that's what their memories are, thoughts of their worldviews. Are they biased into thinking if they had done nothing, their child would not have gotten what they needed, that their educations would have suffered?

Surely, their own biases exist, but history confirms that parental advocacy has been vital in shaping what we now call special education. And if, parents are fighting for basic necessities, where does this concept that these parents perceive of as the value of the arts, and music specifically, fit in? Is it left to the upper echelons of education, once all the fighting for bare essentials has taken place? Is that where the value of the arts exists, and if so, is that where it belongs? It is true that these participants are all parents of students pursuing a music-infused postsecondary education, so it should be expected that these parents would most likely hold the arts and the ways in which the arts affect their children in high regard. But what of the children, the offsprings now adult, out there who attended general music classes, who participated in chorus, who were somehow included and maybe positively affected by their experiences in music: Where are they now? Could they "be" more? Could we have done more, not just for them, but for all students by harnessing the power of music and music education these parents describe and their grown adult students are now thriving in?

I wasn't part of this special education system (as a parent). I am but a bystander, listening to the descriptions, and perhaps asking the core questions perhaps a bystander can do best: Why does what seems to exist, exist? Where did it come from? What are these parents' reported experiences, the reality of their lives so shaped by having a child I so eloquently deem "exceptional" for lack of a better word? And in listening to their journeys, I am moved and affected, and my emotion is nothing, absolutely nothing, compared to what they have forged through. I doubt that there will ever come a time when parents no longer feel the need to fight for their children. But can we do better? Can we, as a nation, as educators, as administrators, as leaders, do better? Can, if in realizing the parents' intentions, goals and motivation, and yes, experiences, can we do better than we are doing today? It may be pointed out that these are memories from long ago, but in talking with a young parent after her recent parent-teacher conference, I realize the stressors created by individuals called teachers with their own inherent biases, their own struggles with administration, their own limitations, (be they financial, administrative, time constraints, class size, standards, and/or personal ignorance and inherent limitations and the potential need to label, and/or the frustration of having to deal with children who are not a one-size-fit-all average,) well, these teacher stressors and biases can directly affect parental experience. So, what has changed in the years since these parent participants, some of whom wondered if this world would even educate their child, were young and their children were even younger? What has changed since these parents wondered just what the quality of education their children might receive would be? What has changed since one parent identified that children with exceptionalities were not being assessed in her school system, in her state and nation? What has changed? And what drives change? Is it the parents' role to identify and right the indemnities? And just how far do these observations, the identification of these indemnities go? Are they shared Do they make a difference for any others even in their same school or school system, much less their state or the country? These are questions that research like this doesn't answer, can't answer, will never, perhaps, answer. But they are questions that not only should, but must be asked. And if parents are asking in little voids called meetings, in individual schools, in individual towns and parishes and counties and states.... Yes little voids, my own bias, yes, but if parents are asking these questions in small individual sites, and leaders are either unaware or are on to topics perhaps traditionally classified as "bigger fish to fry," in reactionary rather than revolutionary fashion, who is ever going to ask: Is the education system purely reactionary in its development, and is it effective and serving all children, not just equally, but equitably?

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