

# Chapter 21

## Better Understanding the Complex Academic, Mental Health and Health Needs of Children in the United States

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**Abstract** Using socio-cultural theory and an ecological perspective, this study utilized a case study format to explore how families and teachers understand children with complex academic, mental health, and health needs in the United States. These case studies were developed based on home and school observations and semi-structured interviews with the parents and teachers of two children with complex needs attending a primary school in the United States. Data analysis revealed that parents and teachers may understand a child's development differently because they become conscious of it at different times and construct meaning out of it in unique ways. For parents, the contexts and interactions surrounding their child's evaluation process greatly influenced their emotional response to, and understanding of, their child's development, primarily in terms of one developmental area. As a result, subtle yet important changes in other developmental areas went unnoticed or diminished in potential importance, making it difficult for parents to optimize potential outcomes through advocacy. For teachers, understandings of a child's development were framed by an existing personal teaching philosophy. The stronger and more complimentary the understandings of a child's development by both teachers and parents, the greater was the likelihood of developmental opportunities for the child. As the parent of a child with complex needs, this chapter also includes my own narrative as the lens through which I analyze the data.

### The Changing Ecology of Childhood in the United States

I remember with both clarity and intensity the day my daughter was diagnosed with a mental health disorder at 12 years of age. I can easily recall her words as she described in detail how she felt during periods of frantic elation and deep despair. The implied responsibility that came with her diagnosis weighed so heavily on me that I could hardly stand to leave the room. As I walked to our car, parked in the

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looming shadow of a former psychiatric institution in the Northeast United States, I felt completely distraught. Ten years earlier, my daughter had been identified as a young child with a developmental delay. Several years later, she would be diagnosed with a chronic illness. Somewhere in the span between these diagnoses, the essence of who she was and the context of our lives was somehow forgotten.

My experience with children with complex academic, mental health, and health needs is both personal and professional. As a mother and a teacher, I often lay awake at night thinking about the complex needs of my own child and my students. Over the years, some of the families I knew sought help for their child, with limited success. The professionals consulted were often knowledgeable about child development but not mental health. Alternatively, they were mental health specialists who were less knowledgeable about child development. Unfortunately, the complex and highly individual nature of children's strengths and areas of concern remained largely unaddressed in the well-intentioned programs and services available in this region of the United States.

As our children got older, concerns about language, cognitive, or motor development eventually became overshadowed by the increasingly complex relationship among their academic, mental health, and health needs. Some families, including my own family, had the resources to access further evaluation, attend meetings, and search for specialists. There were times when we felt empowered such as when an education, mental health, or health professional who understood a child's complex needs provided us with the hope that symptoms could be better managed. Still, there were times when even the most resourceful of us became disempowered.

According to Turnbull and Turnbull (2001), empowerment is considered critical for families to develop the motivation, knowledge, and skills necessary to take positive action on the part of their child. Empowerment occurs when there is a transaction between one or more individuals and the context in which we are taking action. Components include self-efficacy, perceived control, great expectations, energy, and persistence (Turnbull and Turnbull 2001). However, each component is informed by how each of us understands a child's unique development. This understanding influences, directly and/or indirectly, our transactions and contexts and provides a critical link to connect us with each other and the contexts in which supports and services may be provided. My experience has been that many families and teachers in the United States are often initially motivated to translate their understanding of a child's unique development into effective supports. However, when we do not have the resources, knowledge, or skills, either individually or collectively, to address a child's needs or if the home or school context is constraining, we can become overwhelmed (Turnbull and Turnbull 2001).

The challenges I faced were never just about my daughter. They were never just about my students. They were never just about my family or my students' families. No child, parent, or teacher exists in isolation. These challenges were, and continue to be, about the many subtleties and complexities of living and working with a child with complex needs while navigating the waters of the often highly fragmented and imposing education, mental health, and/or healthcare systems in the United States. The challenges that I faced, as well as those faced by other families and teachers,

were also impacted by a broader social context where understandings of children's academic, mental health, and health strengths and needs were created and where our children will "sink" or "swim" (Garbarino and Gaboury 1992).

## Exploring Child Development in Context

Exploring the development of children with complex academic, mental health, and health needs in the United States, and how it can be impacted by different contexts, is fundamental to an ecological orientation. This orientation is supported by the ecological theory (Bronfenbrenner 1979; Garbarino and Abramowitz 1992) as well as the theories of developmental contextualism (Lerner 1992), risk and resilience (Sameroff et al. 2000; Jenson and Fraser 2006), and developmental psychopathology (Sroufe 1997; Zeanah 2000). Although this "child in environment" perspective should lie at the heart of the "helping" professions in the United States, it can be difficult to realize.

It is estimated that one billion people have a disability, making this population the world's largest minority (United Nations 2014). In the United States, the number of children with disabilities represents 13% percent of the total school enrollment (NCES 2013). Recent estimates in the United States are that one in every five children is experiencing significant social and emotional difficulties (NIMHCM Foundation 2005) and that 30% of children have a chronic illness (Allen and Vessey 2004). These complex academic, mental health, and health needs can invariably interfere with a child's ability to succeed in US schools (Bronstein et al. 2012).

Significant discrepancies exist in the United States between the growing number of children with complex academic, mental health, and health needs that require additional supports and services and those that actually receive them (Lynn et al. 2003). The stakes appear to only get higher as children get older. In the United States, children with significant emotional and behavioral difficulties have the lowest grade point average and the highest dropout rates of all student demographics, including all disability categories (Wagner and Cameto 2004). When their health care needs are not adequately met, these children are also more likely to miss school because of illness (Grant and Brito 2010). As a mother and a teacher, I conducted this autoethnographic research to provide a rich description of some of the complexities such children and their families may face currently in the United States.

Viewing children with complex needs in the United States as part of the people and environments affecting them *is* complicated. To say a child *has* complex academic, mental health, and health needs places the problem primarily *within* the child. When we explore how a child *is* an individual *and* part of relationships *and* environments, responsibility for supporting development belongs to everyone. To explore how families and teachers in the United States may come to understand children with complex needs, I asked them the following questions: How do you understand a child's complex academic, mental health, and health needs? How does

this understanding inform your parenting and/or teaching practices? What do you think are some of the contexts and interactions that can influence a child's development?

### *The Community*

My study was conducted in a small, economically depressed city in the Northeast United States. At the time of this study, the primary school in this community served approximately 600 students from diverse socio-economic, racial, ethnic, religious, and linguistic backgrounds.

### *The Children*

**Matt** Matt is a 6-year-old boy who lives with his mother, Karen, and his 10-year-old sister, Jackie. Karen and their father, Steve, divorced several years ago. Both Karen and Steve have extended family living in this community. Matt was classified by his school as multiply disabled. His educational supports include special education services; occupational, physical, and speech therapy; adaptive physical education; a paraprofessional; and services from a teacher for the visually impaired. Matt also receives aqua therapy and hippotherapy outside the school. He utilizes the following adaptive equipment: wheelchair, walker, augmentative communication device, leg splints, adaptive scissors, gait trainer, and a "sippy" cup. Matt has been diagnosed with cerebral palsy, septo-optic dysplasia, and schizencephaly. Matt is considered to have complex needs because of his disability, chronic health issues, and periodic episodes of self-injurious behavior and "shutting down" in overstimulating environments.

**Timmy** Timmy is a 7-year-old boy who lives with his mother, Sue, step-father, Don, and younger brothers, David and Billy. Timmy has not seen his biological father in over 2 years. There is a family history of domestic violence. Timmy is in a special education classroom for students with significant emotional and behavioral issues. Timmy receives speech/language therapy and adaptive physical education services. He spends mornings in another classroom with his non-disabled peers. Over the years, Timmy has been diagnosed with attention deficit disorder, pervasive developmental disorder, oppositional defiant disorder, and bipolar disorder. He takes three psychotropic medications daily. Timmy is considered to have complex needs because of his disability, chronic dental health issues, and aggressive and non-compliant behaviors.

## Overview of the Study

This chapter is based on the extensive time that I spent with Matt's and Timmy's parents and teachers in both home and school settings. This autoethnography aims to highlight my role as a complete member researcher (Adler and Adler 1987). In this role, I was fully committed to, and immersed in, the groups I was studying as a member of mothers of children with complex academic, mental health, and health needs.

Following 5 months of home and school observations and multiple interviews with Matt's and Timmy's parents and teachers, I developed descriptive case studies as a first level of analysis. During a second level of data analysis, I engaged in the coding and interpretation of categories using an open and axial coding process adapted from Strauss and Corbin and based on the original process by Glaser & Strauss (Shank 2002). Using my own personal narrative to guide the data analysis process, two primary themes emerged.

## Understandings of Children with Complex Needs Differ Based on the Context and Interaction

One reason parents and teachers in the United States may come to understand a child with complex academic, mental health, and health needs differently, particularly when a child has complex academic, mental health, and health needs, is that they become conscious of it at different times and construct meaning out of it in different ways. For Matt's and Timmy's mothers, interactions with professionals during their evaluation process greatly influenced understandings of their child's development. For Matt's and Timmy's teachers, these understandings were greatly influenced by an existing teaching philosophy.

### *Parents' Understandings*

In the United States, when parents have concerns about their child's development, they may have their child evaluated by a professional to determine if he or she has a disability. Typically, professionals in the United States identify children with severe disabilities, like Matt, during infancy. Other children, like my daughter and Timmy, may be identified later due to milder exceptionalities or later onset. However, in the United States, regardless of the age of the child, an evaluation process is the gateway to special education supports and services (Turnbull et al. 2006). When families in the United States are told their child has a disability, they often enter the "world" of special education that has its own terminology, rules, settings, and

people. This can be a highly emotional process that also greatly informs their understandings (Graungaard and Skov 2007).

**Matt's Mother** Born with congenital disabilities, Matt's evaluation process began in this community in the United States shortly after his birth. Matt received three medical diagnoses and had two surgeries before he was a year old. The first surgery, which opened his skull to decrease pressure on his brain, was life threatening. Whether or not to have this surgery was very traumatic for Karen because Matt's life was at risk either way. Most of his early years were spent in one of nine doctor's offices or receiving physical and occupational therapy services. While doctors closely monitored Matt's medical conditions, therapists intensively supported his physical development, including muscle tone, strengthening and coordination. These services later expanded to include speech therapy and special education services.

Matt's evaluation process was highly emotional for his mother Karen. The baby she thought would be born healthy had a severe disability and needed life-threatening surgery. Karen was also in the early stages of a divorce. Through his evaluation process, Karen came to understand the primary cause of Matt's disability as medical/physical. This understanding was further shaped by Matt's physical and occupational therapists with whom she developed very close relationships. Karen described,

I mean I trusted these people. They came into my home. They were just really nice. They just basically helped me through it, like getting his wheelchair, his orthotics, his hand splint. I mean they guided me through all of it.

Karen's understanding of Matt's development primarily in medical/physical terms also influenced the allocation of family resources. For example, Karen purchased a different vehicle specifically so she could transport Matt's wheelchair. Recently, she also began the time-consuming process of transferring Matt's out-of-school therapy services from one program for children with developmental disabilities in the United States to another so that he could receive additional services. Maintaining Matt's intensive therapy schedule also consumed much of Karen's time and energy. Her understandings also influenced how she set goals for him and viewed progress. Karen believed Matt was making great progress in his motor skills. She hoped that someday he would walk.

**Timmy's Mother** During the first few years of his life, Timmy moved several times within this region in the United States with his mother; had two step-fathers, several step-sisters, and two brothers; witnessed domestic violence; and was the victim of sexual abuse. Timmy's initial evaluations revealed severe emotional and behavioral needs, and he attended a special education preschool specifically for young children with challenging behaviors.

Timmy's evaluation process was highly emotional for his mother. Sue was coping with her own trauma, coping with Timmy's challenging behaviors, and caring for her three young children. Through this evaluation process, she came to understand his development as emotionally and behaviorally disordered. This understanding was further shaped by a psychiatrist who diagnosed Timmy with Bipolar

Disorder at age five. Sue explained, “I don’t care what anybody says, there is no fixing him. He is Bipolar.”

Sue’s current understandings of Timmy’s development also influenced the allocation of family resources. Replacing the household items that were broken during Timmy’s behavioral outbursts and filling three psychiatric medications for him was expensive. Although it created financial hardship, Sue had a cell phone so his teacher could easily contact her and kept a well-maintained car in case she had to get to his school quickly. Coping with Timmy’s behavior and communicating with school personnel consumed much of Sue’s time and energy.

Sue’s understanding of Timmy’s needs as primarily emotional and behavioral also influenced how she set goals for him and viewed progress. Sue thought that Timmy was becoming less aggressive. She hoped his behavior would stabilize enough that he could continue living in her home and eventually graduate from school.

My daughter’s evaluation process was a highly emotional time for me. I had four children under the age of 5 years. My daughter had difficulties eating and sleeping. She cried a great deal of the time and reacted negatively when touched. The evaluation process indicated that she had significant sensory processing issues. My understanding was further shaped by the occupational therapist that conducted her evaluation and suggested sensory activities as a way to help regulate her behavior. My understandings of my daughter’s needs as primarily sensory also influenced the allocation of family resources. I purchased books on sensory processing and sensory toys and joined a support group for parents of children with sensory processing disorders.

## *Teachers’ Understandings*

When a child with a disability in the United States receives special education services, an individualized education program (IEP) is developed around their educational performance and goals, appropriate programs and/or services, and how progress will be measured (IDEA 2004). For teachers, this program was greatly informed by an existing teaching philosophy.

**Matt’s Classroom Teacher: Mrs. Williams** Mrs. Williams’ teaching philosophy was that children in schools in the United States are unique and bring different strengths to school. Her role is to open the door for learning and model the acceptance of all students’ backgrounds and abilities. Mrs. Williams believed Matt benefited from being included in her classroom. She explained,

The students were fighting over who got to ride in the elevator in the school with him and push his wheelchair, so I had to come up with a system for the children to take turns using our class list of names.

Mrs. Williams believed that opportunities for her students to participate in classroom activities are very important. She described, “I try to have at least two

classroom learning centers a day that Matt can do like computers because he loves that.” Mrs. Williams also thought it was important to have high expectations. She explained, “Maybe because I have high expectations for his learning is why Matt is blossoming so.” Mrs. Williams believed Matt was making great progress this year at school from being with peers. “Seeing what his peers are doing, he wants to do it too.”

**Matt’s Special Education Teacher: Ms. Stone** Mrs. Stone’s philosophy was that children in schools in the United States should not be expected to do things in the same way, time, or pace. When she worked with Matt, she presented him with different activities such as identifying numbers 1–5, the letters in his name, colored blocks, and books.

Mrs. Stone thought it was important to provide clear expectations and try different strategies. She believed Matt’s challenging behavior of biting his thumb was purposeful. When Matt started biting his thumb, she and Mrs. Williams ignored it. Next, they put him in the classroom “think chair” as a time out. Lastly, they went back to ignoring it. Mrs. Stone explained, “He wants a reaction from me; he knows.” Mrs. Stone believed Matt had come “leaps and bounds” since the beginning of the school year.

**Timmy’s Special Education Teacher: Mrs. Connelly** Mrs. Connelly believed that students in schools in the United States with emotional and behavioral disorders need consistency. She believed it was important to offer students an educational program where they learned appropriate behavior. Mrs. Connelly believed that the lives of her students were often unpredictable, and they cycled through difficult times. She explained,

They can do fabulous work, and they can completely bottom out, whether it is something going on within them, a genetic kind of thing, or something going on at home. For whatever reason, these kids bottom out, and when they do, they need a supportive environment.

Mrs. Connelly thought she had a clear idea of what each of her students needed to be successful. She described being aware of educational theories suggesting that school programs should become more fluid but didn’t see that as realistic for her students, many of whom had been in abusive situations.

Mrs. Connelly believed that Timmy had the skills but just didn’t use them. She believed he knew how to interact with peers but was reluctant to do so. She thought his language skills were good when he chose to exhibit them. She believed he comprehended what she was saying but just didn’t want to put in the effort. Mrs. Connelly recognized that Timmy’s past experiences created challenges for him but felt he was responsible for his behavior. She believed Timmy had made a lot of progress this year.

**Timmy’s General Education Classroom Teacher: Mrs. Gaston** Timmy spent mornings in Mrs. Gaston’s classroom with his non-disabled peers. She described her teaching philosophy as strongly guided by her experiences as a parent in the United States with two sons with Autism. Mrs. Gaston explained,



I see children with disabilities in my classroom a little differently than somebody who hasn't had that experience. By watching my own children develop, the biggest thing I have learned is to look for what precipitated the behavior.

Mrs. Gaston structured students' mornings into different learning centers where they were expected to work quietly and independently. It was also important for her to have center activities done in a certain order and fashion.

Mrs. Gaston understood Timmy's behaviors as attention seeking because when she ignored his early attempts to get her attention, he eventually stopped the behavior. In spite of her efforts to ignore his behaviors, however, Mrs. Gaston believed Timmy detracted from other students' learning. She described, I will be honest with you. It is work reading with Timmy every day. I have had to change who he comes to reading group with because he is a detriment to the other kids in the group.

Like Timmy and Matt's teachers, my daughter's teacher, Ms. Masterson's, philosophy framed her understanding of her development. This teaching philosophy was based on the belief that children in schools in the United States need to work at their own pace. Ms. Masterson believed that my daughter had all of the necessary skills to be successful in her school; they were just delayed. She felt her classroom was just the right environment to support my daughter's development. It was her belief that, in time, my daughter would outgrow her developmental needs and no longer need special education or related services.

### *The Contexts and Interactions in Which a Child Develops in the United States Can Create Risks and/or Opportunities*

Some children with complex academic, mental health, and health needs in the United States may be provided with more developmental opportunities than others. Although few children in the United States escape risk completely, the accumulation of risk can jeopardize development particularly in the absence of enough compensatory forces (Garbarino and Abramowitz 1992). By exploring the people and places in these children's lives in the United States, we can begin to view the impact on their development, depending on the degree to which each child was offered material, emotional, and social encouragement compatible with their needs and capacities in this context (Garbarino and Abramowitz 1992).

**Matt** Matt's developmental risk was more the result of his own biology than his immediate environment in the United States. For the most part, Matt's home life was very stable. He also developed positive reciprocal relationships with extended family. However, as a single mother working in customer service in the United States, Karen couldn't financially meet Matt's needs without additional support from a federally funded government program for children with developmental disabilities. This program provided funding for Matt's equipment such as his wheelchair, assistive technology, and augmentative communication and to pay for medical

appointments. As a result, this program played an integral role in creating developmental opportunities for children such as Matt in the United States.

Development is also enhanced when children in the United States are able to observe differences in their own dyadic experiences because a third party is present (Garbarino and Abramowitz 1992). Jackie support Matt's development as a third party to the mother-son dyad through a positive reciprocal relationship that expanded his capacity to play, work and love (Bronfenbrenner 1979). Additionally, Matt's relationships with his extended family, teachers, and therapists also created additional developmental opportunities by providing him with a more comprehensive support system. His mother, Karen, was an effective advocate for Matt not only in her ability to obtain supports and services to meet his unique academic, mental health, and health needs but by closely monitoring his providers to ensure he was given a level of material, emotional, and social encouragement that was compatible with these needs in this context. To be an effective advocate for Matt, however, Karen expended a tremendous amount of time and energy meeting his needs. As a result, there were times when Karen was physically and emotionally vulnerable, which also created developmental risk for him.

As a customer service representative in the United States, Karen was able to flex her work hours to be compatible with Matt's therapy schedule, and this created developmental opportunities for him. Karen's work schedule, however, was set by her employer in advance and could not accommodate any last minute schedule changes for her. In order to flex her work hours to match Matt's therapy schedule, Karen worked some evenings and Sundays. This provided fewer opportunities for her to focus on Matt and Jackie's schoolwork and Matt's therapeutic activities, potentially increasing their developmental risk. A customer service position in the United States provided Karen with little or no job security and few opportunities for economic advancement. Any reduction in government funding at the federal or state level, under consideration at the time of this study, could lead to a decrease in the number and/or quality of Matt's programs and services and increase his developmental risk.

It was also through a federally funded government program that Karen had access to an individual that provided on-going coordination for Matt's special education supports and services. Karen described Matt's service coordinator as an integral component in her ability to effectively advocate for Matt. As Matt ages, he will need different equipment and activities. If Karen continues to receive support in her advocacy efforts, Matt should experience developmental opportunities. If Karen does not receive enough support or if she is unable to maintain strong relationships between contexts (due to, e.g., illness), she could be at risk for exhaustion. The long-term neglect of Karen's own needs may eventually create risk for Matt.

**Timmy** Timmy experienced several different family contexts in the United States as a young child, at least two of which were abusive. He also faced biological vulnerability due to a family history of bipolar disorder. This created additional developmental risk for him. Unlike Matt, Timmy experienced an accumulation of risk in this community without adequate compensatory forces. One reason why was that

his mother, Sue, was also the victim of physical and emotional abuse. As a result, her decreased sense of empowerment diminished her ability to offer Timmy the material, emotional, or social supports compatible with his developmental needs and capacities in this context. For example, Timmy was very active yet lived in what is considered in this community in the United States as a small home that was shared with four other family members. His mother, Sue, had an authoritarian parenting style that provided few opportunities for positive reciprocal interactions in the mother–son dyad. Timmy and his brothers also had to compete for limited family resources. In addition, Timmy did not receive any special education supports or services outside of the school setting.

Timmy experienced a great deal of developmental risk. Like many young children who live with poverty in the United States, Timmy often had limited access to what would be considered in his community to be safe environments that supported exploration, stimulated his learning, and provided opportunities for warm, responsive interactions with adults (Erwin 1996). As a mother and a full-time college student in the United States, Sue had no personal income and a busy schedule that allowed for little flexibility. When there was an unexpected expense or when she had to change her schedule to meet the needs of her family, Sue experienced increased stress that usually resulted in increased conflict with Timmy. Sue considered herself an advocate for Timmy, but the effectiveness of her advocacy was periodically compromised by feelings of powerlessness that started long before Timmy but continued to limit her ability to effect change in either Timmy’s home or school setting in this community.

My daughter experienced both developmental opportunity and risk. As a young child in the United States, she lived in a neighborhood where she had access to safe environments and positive reciprocal relationships with both peers and adults. For the first 5 years of her life, I was her full-time caregiver. As a result, I was able to flex my time to be compatible with her therapy schedule, provide therapeutic activities in our home, and attend meetings with professionals at school. This created a developmental opportunity for her. When I became a full-time teacher and a graduate student at a university in this same community, there were times when I was unable to maintain strong relationships between these contexts. Like Karen and Sue, I expended a tremendous amount of time and energy meeting my daughter’s complex academic, mental health, and health needs. As a result, there were times when I was physically and emotionally vulnerable, which also created developmental risks for her.

## **A Child's Evaluation Process Can Be a Very Emotional Experience for Parents**

As mothers in the United States, Sue, Karen, and I were greatly influenced by the contexts and interactions that surrounded our children's evaluations. While the reason for the referral, timing, and location of each child's evaluation was different, it was a highly emotional experience for all of us. Whether the reason for referral was a speech, motor, or social and emotional concerns or the child was preschool age, an infant, or a toddler, part of what made this experience emotional was our level of vulnerability. For Karen, this vulnerability stemmed from being a single mother of a medically fragile child and having little knowledge of congenital disabilities. For Sue, this vulnerability stemmed from being the victim of domestic violence, a single mother of three children, and having little knowledge of mental health disorders. For me, this vulnerability stemmed from being the mother of four young children with very little knowledge of sensory processing disorders. Although access to resources may provide a buffer for a parent's level of vulnerability, the evaluation process for children with complex academic, mental health, and health needs remains a highly emotional and influential time for families in the United States.

As mothers of children with complex academic, mental health, and health needs, our interactions with professionals during their evaluation process also varied, based primarily on our level of participation. Karen and I had high degrees of participation in our children's evaluations and questioned neither the process nor the outcome. We observed all their evaluations, completed forms and questionnaires, and spoke directly with evaluators. Sue also participated in Timmy's evaluation process but did not directly observe all evaluations, completed most forms, and had fewer opportunities to speak with evaluators. She did, however, privately question both the evaluation process and its outcome. In contrast to Karen and me, who believed our participation could positively impact our children's experiences during the evaluation process, Sue believed her potential impact was limited. This limited her participation, possibly in response to the stigma attached to Timmy's psychiatric diagnosis and the severity of his externalizing behaviors. Through a unique set of contexts and interactions involved in the evaluation process, each of us came to understand our child's development as delayed, primarily in terms of one developmental area.

For young children with disabilities in the United States, clinical approaches based on diagnostic/prescriptive and behavioral models of intervention continue to be dominant. Based on these models, discrete areas of deficit are identified for remediation guided by a set of distinct professional competencies for therapeutic intervention (Erwin 1996). For example, in the United States, speech therapists typically evaluate and remediate speech–language difficulties, occupational therapists evaluate and remediate fine motor and sensory difficulties, physical therapists evaluate and remediate gross motor difficulties, and special education teachers and psychologists evaluate and remediate cognitive difficulties and challenging behaviors. Based on these diagnostic/prescriptive and behavioral models, evaluations are

the gateway to special education services in the United States. For our children, such evaluations drove decisions about the type, number, and frequency of special education services, parent priorities, and educational placement. Periodic reviews of each child's strengths and needs informed this decision-making process but not with the same degree of impact.

According to Graungaard and Skov (2007), it is critical that professionals in the United States offer possibilities for taking action to parents of children with complex academic, mental health, and health needs. For Karen, the professionals in this community provided her with viable options for taking action to support Matt's academics and health but not necessarily his mental health. For Sue, the professionals in this community provided her with one viable option for taking action to support his mental health needs but not necessarily to address his unique academic and health needs. The professionals in this community provided me with viable options to address my daughter's sensory processing issues but not necessarily to address her unique academic, mental health, or health needs.

For the professionals involved in our children's evaluations, the context of the evaluation process framed their interactions. In contrast, as mothers of children with complex academic, mental health, and health needs, the interactions during the evaluation process framed our context. As mothers of children with complex needs, not only were our interactions with the professionals in this community disability-specific, but we were greatly impacted by the degree to which these individuals helped us identify possibilities for taking positive action on our children's behalf. When a child's disability was identified in a cognitive, speech–language, sensory, or motor developmental domain, possibilities for taking positive action were evident, and our interactions with professionals were viewed as supportive. For example, when my daughter exhibited sensory issues, I viewed her occupational therapist as supportive when she provided ideas for specific sensory activities that we could do at home. When Matt exhibited difficulties with motor development, Karen viewed the physical therapist as supportive when she provided muscle strengthening exercises they could do at home and a hand splint to wear while doing them. It is important to note, however, that neither therapist considered in their assessment framework the possibility of a mental health component to our children's behavior. When Timmy exhibited significant social and emotional difficulties, Sue did not find the mental health professionals in this community very supportive. It is also important to note that these professionals did not appear to have considered the potential of an academic or chronic health component to his behavior.

## **Implications for Parent Advocacy**

Using an ecological perspective, as parents of children with complex academic, mental health, and health needs in the United States, it is important that we are able to understand their unique development and note specific developmental changes and how they occur (Benn and Garbarino 1992). If we understand our children's

development primarily in terms of one developmental area, we may not fully recognize the inherent complexities necessary to optimize their potential outcomes (Benn and Garbarino 1992). As a result, subtle yet important changes in other developmental areas may go unnoticed or diminished in potential importance and may impact our advocacy. So, although children such as ours may have very different complex needs, we might miss subtle, yet important, changes in our children's development that can impact both individual and collective parent advocacy efforts in the United States.

If Karen understands Matt's development primarily in terms of his physical development, she may not recognize subtle, yet important, changes in his social, emotional, or language development. As a result, she may not advocate for additional strategies or services such as re-programming his augmentative communication device to increase his opportunities for social interaction or positive behavior supports, which could optimize Matt's potential outcomes.

If Sue understands Timmy's development primarily in terms of his social and emotional development, she may not recognize subtle, yet important, changes in his fine motor skills or academics. As a result, she may not advocate for additional strategies or services, such as those provided by the school's occupational therapist or reading specialist, which may help optimize Timmy's potential outcomes.

If I understand my daughter's development primarily in terms of her sensory processing, I may not recognize subtle, yet important, changes in her academics, mental health, or health. As a result, I may not advocate for additional strategies or services that might help optimize my daughter's potential outcomes.

## **Implications for Home–School Partnerships**

Through different experiences and interactions, parents and teachers in the United States develop an understanding of children with complex academic, mental health, and health needs. How such children's development is understood can either strengthen or weaken the relationship between the home and school setting, further impacting each child's development.

Some parents of children with complex academic, mental health, and health needs in the United States may not develop close relationships with teachers who understand their child's development in substantially different ways than they do. In addition, some teachers of such children may not develop close relationships with parents who have a different understanding than they do. In the United States, when understandings of a child's development are similar, as they were for Matt and my daughter, the home–school partnership can be strengthened. When these understandings are different, as they were for Timmy, the home–school partnership can be weakened. The stronger and more complementary the linkages between home and school in communities in the United States, the more powerful is the influence on a child's development (Garbarino and Abramowitz 1992). For Matt and my daughter, a strong and complimentary home–school link created additional

developmental opportunities. As a child whose link between home and school was neither solid nor complementary, this link created additional developmental risk for Timmy.

## **Conclusion**

Families and teachers of children with complex academic, mental health, and health needs in the United States are often initially motivated to translate their understanding of a child's development into effective supports. Some families, however, have access to more resources than others, and some home and school settings have more constraints than others. When parents do not have the knowledge, resources, or skills to access effective supports or if the home or community context is constraining, they can feel overwhelmed or disempowered.

In the United States, when a child's disability is identified as cognitive, speech/language, sensory, or motor, possibilities for taking action may be more evident, and parents might consider their interactions with professionals supportive. Karen and I were overwhelmed at times, but the possibility of taking positive action on behalf of our children offered us hope. When a child's disability is identified as primarily as a mental health issue and there are aggressive behaviors, the possibility of taking action may be less evident and interactions with professionals deemed less supportive. Sue was overwhelmed at times and, without the possibility of taking positive action, was not offered hope.

Ultimately, we must ask ourselves whether we are offering all parents and teachers of children with complex academic, mental health, and health needs in the United States possibilities for taking positive action on behalf of such children and, in turn, offering them hope. Among the most dynamic aspects of a parent-teacher relationship is the ability to move beyond our individual and collective limitations, see the possibilities for taking positive action, and offer each other hope. As a parent and a teacher of children with complex academic, mental health, and health needs, I believe that it is only when we are offered possibilities for taking positive action and hope that we are able to offer them to our children and students and provide them what may be their most important developmental opportunities.

## **Lessons Learned and Next Steps**

This study fills a gap in the literature on young children with complex academic, mental health, and health needs by exploring the experiences of families and teachers in the United States. First, we learned that understandings of a child's development can be constructed very differently, depending on the person and the context. This has important implications for the ways in which observation and evaluation can be used to better capture the complex interactions among developmental

domains by including multiple settings and interactions. Secondly, we learned that family, teacher, and caregiver relationships greatly impact a child's learning and development. This has important implications for closer examination of the current emphasis on academics in the broader context of an interrelationship of care that fosters interprofessional collaboration and strengthens home–school partnerships for children with complex academic, mental health, and health needs. Since many families and other school professionals may not be aware of, or are unsure how to respond to, a child's complex academic, mental health, or health needs, we also learned that there is an urgent need for more targeted family training and professional development for school staff. Lastly, we learned about the importance of gaining a much clearer picture of the number of young children with complex academic, mental health, and health needs and the nature of them. This has important implications for the types of supports and services that will help children with complex needs achieve optimal outcomes in inclusive settings.

## References

- Adler, P. A., & Adler, P. (1987). The past and the future of ethnography. *Journal of Contemporary Ethnography*, 16(1), 4–24.
- Allen, P. J., & Vessey, J. A. (2004). Does family involvement and psychosocial support influence coping in teenage patients who have congenital disease. *Pediatric Nursing*. Retrieved from [goliath.ecnext.com](http://goliath.ecnext.com), 4 Apr 2014.
- Benn, J., & Garbarino, J. (1992). The developing child in a changing environment. In J. Garbarino (Ed.), *Children and families in the social environment* (pp. 99–130). New York: Aldine De Gruyer.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Bronstein, L., Anderson, E., Terwilliger, S., & Sager, M. (2012). Evaluating a model of school-based health and social services: An interdisciplinary community-university collaboration. *Children & Schools*, 34(3), 155–166.
- Erwin, E. J. (1996). *Putting children first*. Baltimore: Paul H. Brookes Publishing.
- Garbarino, J., & Abramowitz, R. (1992). The ecology of human development. In J. Garbarino (Ed.), *Children and families in the social environment* (pp. 11–33). New York: Aldine De Gruyer.
- Garbarino, J., & Gaboury, M. T. (1992). An introduction. In J. Garbarino (Ed.), *Children and families in the social environment* (pp. 1–10). New York: Aldine De Gruyer.
- Grant, R., & Brito, A. (2010). *Chronic illness and school performance: A literature review focusing on asthma and mental health conditions*. New York: A Children's Health Fund Monograph.
- Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33(3), 296–307.
- Individuals with Disabilities Education Improvement Act. (2004). Washington, DC: U.S. Government Printing Office.
- Jenson, J. M., & Fraser, M. W. (2006). *Social policy for children and families*. Thousand Oaks: Sage Publications.
- Lerner, R. (1992). *Developmental systems theory: An integrative approach*. Thousand Oaks: Sage Publications.



- Lynn, C. J., McKay, M. M., & Atkins, M. S. (2003). School social work: Meeting the mental health needs of students through collaboration with teachers. *Children & Schools, 25*(4), 197–209.
- National Center for Education Statistics. (2013). Retrieved on September 30, 2014, from <http://nces.ed.gov/fastfacts/display.asp?id=64>
- National Institute for Mental Health Care Management. (2005). *Mental health: An overview of key considerations for health system stakeholders*. Washington, DC: National Institute for Healthcare Management Foundation.
- Sameroff, A., Lewis, M., & Miller, S. (2000). *Handbook of developmental psychopathology*. New York: Plenum.
- Shank, G. (2002). *Qualitative research: A personal skills approach*. Columbus: Merrill Prentice Hall.
- Sroufe, L. A. (1997). Psychopathology as outcome of development. *Development and Psychopathology, 9*, 251–268.
- Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals and exceptionality: A special partnership for collaborating for empowerment*. Upper Saddle River: Prentice Hall.
- Turnbull, A. P., Turnbull, H. P., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality*. Upper Saddle River: Pearson Education, Inc.
- United Nations Enable. (2014). Retrieved on September 30, 2014, from <http://www.un.org/disabilities/default.asp?id=18>
- Wagner, M., & Cameto, R. (2004). *The characteristics, experiences, and outcomes of youth with emotional disturbances*. Minneapolis: National Center on Secondary Education and Transition NLTS2 Data Brief. Retrieved April 1, 2008, from <http://www.ncset.org/publications/print-source.asp?id+1687>
- Zeanah, C. H. (2000). *Handbook of infant mental health*. New York: The Guilford Press.