Challenges to Collaboration, Inclusion and Best Practices within the Special Education Community

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Abstract

This manuscript identifies the challenges of children with special needs and their families. This text further highlights the complexity of integrating children with intellectual differences into inclusive settings. Furthermore, the author incorporates the teamwork and collaboration principles and practices of the Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC, 1990). In keeping with the Council's principles, the most important aspect of the Council's mission and goals is to work across systems to meet the needs of children and families (DEC 2009). These principles focus on the importance of parent involvement, collaboration and interdisciplinary approaches to services. Lastly, this paper examines inclusion, advocacy and support for parents while reflectively examining a study (Scott-Croff, 2017) that details the perspectives of parents and pediatricians caring for children on the autism spectrum.

Key Terms: Early intervention, special education, parents, inclusion, children, teamwork, advocacy and autism spectrum disorder.

The Barriers to Collaboration, Inclusion, Teamwork within the Context of the Special Education Community

This article highlights:

1) the history of inclusion
2) the impact of inclusion and the least restrictive environment principles on services for children with special needs
3) the role of advocacy in special education
4) the role of parents pertaining to advocacy and the history of special education
5) support services provided to children and families
6) the influence of early intensive behavior interventions (EIBI) on children's development
7) the importance of collaboration among parents and service providers
8) examining a qualitative study on the perspectives of parents and pediatricians
9) research methods
10) recommendations
11) results and discussion questions

Defining the term Inclusion and its Role in the Realm of Special Instruction

Since the early seventies, inclusion in early childhood and special education settings has become the hallmark of best practices for young children with special needs (Yell, Rogers & Rogers, 1998). The research of Bacon and Causton-Theoharis (2013) defines inclusion as supportive programming for children with intellectual differences into mainstream settings. Bredekamp

(1993) also notes inclusion is as a programmatic approach that carefully integrates children with special needs into more inclusive settings. Her research connotes, inclusive settings that meet the needs of children with varied intellectual, social and emotional needs (Bredekamp, 1993). Integrated settings include children with varied learning styles. Moreover, inclusive settings promote the least restrictive environment (LRE) for children. A least restrictive environment is a setting that maximizes the needs of a child diagnosed with a developmental disability by providing the least restrictive environment for them to learn in. Whenever children are educated and integrated into educational settings with typically developing children (Bredekamp, 1997). These environments maximize children's abilities opposed to disabilities. Researchers Schwartz, Sandall, Odom, Horn and Bechman (2002) indicated the need for diverse programming that supports inclusion. The researchers go on to say that each program's approach to inclusion varies. Services offered to children and families may not meet the needs of all children or families. The complex needs of families warrant a diverse approach to service implementation (Torreno, 2012). Researchers Howard, Williams and Lepper (2010) indicates the need for empirically based services for children, personalized services across the continuum of children's needs, a culturally sensitive approach to service implementation, empowerment of parents, collaboration with other experts and advocacy for parents and children.

Advocacy

Advocacy serves as a catalyst to ensuring programs provide high quality services for children with special needs and their families (Heward, 2009). The research of Heward (2009) posits, advocacy is the ability to advance a cause (Bacon, & Causton-Theoharis, 2013). Advocacy often helps further the needs and causes of marginalized populations. Activism has been the bedrock of the early childhood special education community (Bredelkamp, 1997). Bacon and Causton-Theoharis (2013) notes advocacy has led to modifications in funding structures to support children with special needs. Parents are continually thrust into the role of advocates due to the challenges they face within the special education system. It is time we protect the rights of children and their families (Autism Speaks, 2013). Many advocacy groups and coalitions that serve the needs of children with special needs were developed by the parents of children with special needs. These groups were borne out of desperation, fear and anxiety and displeasure with the current support offered to parents (Smith, 2003). The research of Smith (2003) indicates advocacy groups adhere to the following tenets to support their work: (1) they identify the goals and objective of the cause; (2) they develop a strategy to eradicate the challenges; (3) they consider the perspectives of all individuals involved; (4) they exercise emotional intelligence during tense conversations; (4) they become well versed regarding the needs of families; (5) they use a strength based approach to advocate for the needs of others and lastly, resolve all concerns in a matter that is acceptable for all parties (Hess, Molina, & Kozleski, 2006).). The forwarding paragraph on stress describes the support required by families of children with special needs. The paragraph typifies the challenges that consume families of children with special needs. The research of Howard, Williams and Lepper (2010) children's abilities as well as a families' needs are uniquely different. Support of families is contingent upon quality interaction, services, education provided to families and a full spectrum of services and placement options.

Support for Families

Stress. Bacon and Causton-Theoharis (2013) posits, parents are dealing with multiple stress factors, lack of finances, and lack of adequate services and support (Bacon & Causton-Theoharis, 2013). Parents must balance the developmental needs of their children with their housing and fiscal needs. Parents may have other children to care for as well as deal with shame centered on their children's diagnosis, leading to additional stress. Researchers Bacon and Causton-Theoharis (2013) stipulate, parents experience feelings of hopelessness, anxiety, depression, shame, bewilderment and fear around their children's diagnosis. Parents are often challenged by the special education system and the daunting process to obtain services (Autism Speaks, 2013).

The research of Dettmer, Thurston and Dyck (2002) and Gallagher, Malone, and Ladner (2009) details parents' frustration during service provision meetings. According to their research, parents expressed confusion and challenges with the technical language used during the evaluation process. Parents then go on to say they were also overwhelmed by the amount of people in attendance at the hearing. The researchers asserted parents were overwhelmed by the terms utilized during the meetings. As noted by the researchers, service providers often utilize "expertise speak". Expertise speak is a language unto itself (U.S. Department of Education, 2010). It is terms, idioms and terminology utilized by experts in the field. These terms are unfamiliar to parents (Hess, Molina, & Kozleski, 2006. As detailed by the research of Dettmer et al (2002) and Ladner (2009), when this occurs, parents feel alienated during the service coordination meetings. Many reported they were relieved once the meeting was over. The researchers noted, parents felt ill equipped to attend service meetings alone. Parents also stated they found it very difficult to advocate successfully for their children. They further recounted, feeling inept when services for their children were denied. Parent's experience with anxiety, depression and confusion after attending these meetings show the disconnect, they feel when experts are the only ones with appropriate knowledge to advocate (Dettmer, Thurston & Dyck, 2006).

Educating Others. The research of Hess, Molina and Kozleski notes, parents, reported that learning the language utilized during special education service planning meeting was beneficial to them. Parents, the researchers also noted, encouraged and learned from each other (Hess, Molina & Kozleski, 2006). Parents rely on each other's experiences to assist them through the service planning process. Furthermore, Bacon and Causton -Theoharis, (2013) indicates that parents are the primary teachers of their children. Parents they go on to state, teaching other parents about their rights as parents and the rights of their children was invaluable to their self-esteem as parents. Parents taught each other about resources and services available to their children. The researchers detailed this was very important for parents. As they indicated, parents experience cultural differences, feelings of isolation, uncomfortableness and feeling misunderstood during the evaluation process.

Moreover, the research of Anderson, Chitwood, Hayden and Takemoto (2008) posits parents are conflicted, frustrated and perplexed by the decision's schools make regarding the education of their children. The research of Kendall and Taylor (2016) asserts parents enter into service agreements with providers that barely address the needs of their young children. However, parents that the research reported, felt compelled to sign off on the service plans. Their research goes on to say, parents signed under duress, fearful if they didn't; their children would not receive any services at all. Taylor's research further indicates 40% of the children eligible for services in public schools do not receive them. The services offered, the researcher indicates did not meet the needs of their children. The qualitative study of Scott-Croff (2017) detailed the perspective of parents with a child diagnosed with autism, one parent noted, "my child has a social and communication disorder, how can an hour and a half of speech per week address his needs."

The needs of families caring for children with special needs are multilayered (Scull, & Winkler, 2011). These challenges include but are not limited to; (1) access to services; (2) understanding their children's service plans; (3) managing the needs of their children; (4) stress associated with caring for a child with special needs and (5) educating others about their children's needs. The research of Dettmer, Thurston and Dyck, N. (2002) and Heward (2009) concurs and further noted, parent's needs are as diverse as their children. Families of children with special needs experience unique challenges (Torreno, 2012). As it relates to services; service provisions for children with special needs can be difficult for parents to navigate. Toreno (2012) noted the challenges of parents of children with special needs include: (1) identifying appropriate service providers; (2) developing a service schedule that are aligned with their children's needs; and (3) service plans that ideally support the needs of children and families. The research of Dettmer, Thurston, and Dyck (2002) and Heward (2009) indicates service plans must include the following: (1) flexible parent support programs; (2) participatory planning with parents; (3); transparency in language and interactions with families; (4) diverse service provisions; and (4) consideration for families. Parent support programs as indicated by the researchers fail to support the individualized needs of families; specifically working families.

As it relates to participatory planning with parents, the research indicates the majority of planning takes place without parents (Smith, 2003). The planning process as identified by the researchers requires transparency. Parents are often unable to decode the language utilized in service planning meetings, yet they often fail to speak up due to their embarrassment (Smith, 2003). Diverse service provisions require interpreters, and services that meet the ethnic and cultural backgrounds of the families served (Smith, 2003). Well thought-out planning requires time and allows parents to actively participate (Forest, 2018, Reiman, Beck, Cappola, and Engiles, 2010). Heward (2009) details the significance of supporting parents of children with special needs. Heward (2009) noted that parents of children with special needs are continually working to meet the vast needs of their children. Heward's (2009) research further indicates parents are challenged by the following: (1) the needs of their children, service plan revisions and monetary challenges; (2) management of children's service provisions; (3) stress factors Service Needs. The service provisions for children with intellectual differences are great, yet the services offered to families are often scaled back due to school budget cuts and fiscal challenges (Heward, 2009). Often times, children may not receive the cadre of services they need due to: (1) fiscal challenges of the district; (2) lack of staff to implement services; and (3) too many children to serve (Heward, 2009). In school year 2015–16, the percentage (out of total public-school enrollment) of students ages 3–21 served under IDEA differed by race/ethnicity. The percentage of students served under IDEA was highest for those who were American Indian/Alaska Native (17 percent), followed by those who were Black (16 percent), White (14 percent), of Two or more races (13 percent), Hispanic and Pacific Islander (both at 12 percent), and Asian (7 percent).

Management of Children's Service Provisions. Special education service providers experience higher turnover, thereby creating challenges with implementation of services and managing the multiple needs of the children served by the district. The research of Cohen, Dickerson, and Forbes, 2014) notes there are more than twenty thousand served in New York City alone. Currently there are too few programs meeting the service requirements of children with autism (National Autistic Society, 2016). Harlem New York houses the only program that specifically served children with autism exclusively (National Autism Center, 2009). There is an alarming rate of increased diagnosis of autism across the country, yet parents continue to struggle to identify appropriate schools and programming to support their children (National Autism Center, 2009). Parents manage many processes to obtain the unique services their children with special needs require. This includes but is not limited to; the legal proceedings, the administrative procedures, the school administrators, teachers, specialist and their children. As supported by the Division of Early Childhood principles parents must work across systems to meet the needs of their children. This creates a culture of collaboration and commitment. Parents are the first and best advocates for their children. It is essential for parents to work alongside teachers, service providers and advocacy groups to ensure their perspectives are part of the planning and implementation of services for their children. (Anderson, Chitwood, Hayden & Takemoto, 2010).

Stress

The research of Myers, Mackintosh and Goin-Kochel (2009) highlights the stress attributed to caring for a child diagnosed with autism. These stress levels have been outlined in studies in the United States and the United Kingdom (Mugno, 2007). The researchers captured the stress associated with caring for a child with autism has impacted parents' mental health, physical appearance and their overall quality of life. The factors associated with a parent's stress: (1) financial challenges such as the cost of caring for a child with a disability; evaluations, medications and specialized program; (2) the struggles related to day to day care of a child with special needs; (3) strained relations with families and social isolation (Myers, Mackintosh and Goin-Kochel, 2009).

Collaboration and Teamwork

The research of the National Association for the Education of Young Children (NAEYC, 2013) developmentally appropriate and evidenced based practices are the hallmarks to quality care for children in early childhood settings. These tenets paved the way to best practices for young children (Copple & Bredekamp, 2009). To create an atmosphere of collaboration and teamwork, their research details requires authenticity and intentionality. Moreover, the research of NAEYC outlines, respectful and collaborative processes must include parents, teachers and administrators. NAEYC details each group must understand each other and work well together. According to NAEYC (2013) this work must include: (1) support engagement and inclusivity; (2) promoting respectful interactions; (3) diversity, equity and actively listening to understand each other's thoughts, perspectives and need; (4) resilience during challenging times; (5) coping skills; and (5) honest reflection. The research from the Division of Early Childhood concurs and notes, inclusion matters and leads to best practices that impact the overall health, social and emotional development of children with special needs. Partnering with families and collaborating with service provides yield positive results for children. They

Procedures

The author of this paper reviewed the several studies that detail the needs of children with special needs. These studies also captured the unique needs of families as well as the many challenges families encounter. The author utilized the data of a qualitative study (Scott-Croff, 2017) that detailed the lived experiences of parents of children diagnosed with autism. The researchers study also highlighted the perspective of a group of pediatricians caring for children diagnosed with autism. The literature further reviewed the parents' experiences with school-based support teams, experiences with program models, related service providers and pediatricians. The review of the literature identified a gap in knowledge regarding the impact of a diagnosis of autism spectrum disorder from the perspective of parents and pediatricians. The research surmised pediatricians have limited time and resources to complete further testing of children with special needs. As indicated by the principles of the Division of Early Childhood inclusion benefits all and is an essential process in children with special needs growth and development. Collaboration is essential to meet the needs of children with special needs. The parent perspective is necessary to ensure appropriate planning (Anderson, Chitwood, Hayden & Takemoto, 2010).

Research Questions

Based on the preceding review of the literature. The following research questions were posed:

1. What are the challenges and concerns for families seeking support with special education services?
2. What role does inclusion have in planning for children with intellectual differences?
3. Are parents justly given an opportunity to participate and a substantive role in service planning meetings?

Methods

The author reviewed the literature associated with the needs of children with special needs. The author noted the challenges of families with children diagnosed with autism. This aided in identifying what impact knowledge has upon parents' ability to participate in in service planning for their children. According to the research of Scull and Winkler (2011) and Forest (2018) state that parents indicated their limited or lack of knowledge upon their children's initial diagnosis and very little knowledge related to effective treatment. Their study also highlighted parents' limited knowledge impacted their ability to effectively plan and participate in service planning meeting.

Results

The studies of Almansour, Alzahrani, Algeffari, and Alhomaidan (2013); Gallagher, Malone, and Ladner, 2009); Odom, and Soukakou, 2011); Reiman, Beck, Coppola, and Engiles, 2010); and

Schwartz, Sandall, Odom, Horn, and Beckman, 2002) each captures the challenges, the anger, ambivalence, shame and apprehension parents experienced during their journey for access, equity, collaboration to obtain the most inclusive settings for their children with special needs. The researchers also noted parents' relationships with school-based support teams, private and public-school systems were challenging. These systems, the families stated, while designed to support families, often served as a hindrance. The researchers highlight the frustration, anger, bitterness, lack of transparency and limited communication with service providers and school officials. Moreover, each study captures the trials, tribulations, challenges, barriers and needs of families and children with special needs. As indicated in Table 1, of the study conducted by Scott-Croff (2017), the researcher's study noted the lived experiences of parents and pediatricians. The study highlights as indicated by the data, parents had little to no experience at the onset of their children's diagnosis of autism. In addition, pediatricians who are at the onset of diagnosis lacked training, knowledge and time to direct parents beyond the initial diagnosis. The tables (1.1, 1.2, 1.3, 1.4, 1.5 & 1.6) outlines the results. The research of the Division of Early Childhood indicates the importance of the collaboration. This study details the lack thereof for families and children.

Discussion

The considerable needs of children with special needs and their families indicates it is essential to exercise patience with families, recognize the strengths of parents and begin to partner with families. Partnering with parents during service coordination, the diagnostic and evaluation process is important. Parents of children with special needs often report of contentious meetings, animosity toward service providers and lack luster support. Parents requires allies not enemies. Parents are met with divisive interactions during planning meetings with little resources. It is important for families to experience respectful and supportive communication. Parents require support on all levels. Communication, collaboration, education and actively listening are the primary approaches required to effective planning for children with special needs. An additional aspect to supporting parents is actively listening and eliciting the voice of parents. Retrench antiquated that limit funding and services for families. Polices lastly, a respectful and inclusive tone is one of the most important elements to planning for the needs of children (Heward, 2009). The long-term goal of the Division of Early Childhood is to continue to engage stakeholders to enhance the quality of programs to meet the needs of child and families with special needs. The goal is also to raise awareness and advocacy efforts to support children. Working in collaboration across systems as identified in the mission of the Division of Early Childhood will help accomplish this.

Conclusion

The principles of the Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC, 2016) reports inclusion, collaboration and teamwork are required for a successful approach to supporting children and families. Parents, after continued challenges with the special education system, have become advocates for their children. Parents enter meetings with limited knowledge of special education law. They attend meetings with a lot of apprehension. There is considerable skepticism by parents to believe that a meeting with five to seven school-based support team members using related to terminology and one ill equipped parent will yield positive outcomes for parents or more importantly allow them to successfully challenge a school-based support team with years of experience (Schwartz, Sandall, Odom, & Beckman, 2002).

Parents reported a limited understanding of the special education and evaluation process. Parents must become an active voice for their children. Parents are often thrust into an environment with different expectations, diverse settings and complex terminology. Parents want settings for their children that are inclusive, culturally responsive and intellectually diverse. As the author details the need for understanding and support for parents, she also suggests that parents attend any and all training made available to them as a parent. If parents are able to financially, investing in their own professional development to enrich the lives of their children it is suggested (Hess, Molina & Kozleski, 2006).

Many agencies will prorate training for parents if they request it. This yields positive results for parents. Parents not only begin to understand the terminology utilized by the experts, the many caveats to services but parents attending training helps parents become formidable advocates for their children at service planning meetings (Smith, 2003).

Reiman, Beck, Coppola, and Engiles (2010**)** study examined the literature related to the progression of inclusion and concludes “parents-school communication, relationships and collaborative planning form the foundation upon which student-centered educational plans are built”. It is important for school officials to understand; parents are the primary teachers of their children. They are cognizant of their children’s needs. This knowledge must be given its proper respect. Parents must be met with an inclusive tone. Parents must not only have a seat at the planning table, but they must be supported, acknowledged and encouraged to participate. Perfunctory participation must stop. Too often parents are invited to meeting but the decisions have already been made. Enough is enough. When an inclusive tone is employed, this yields respectful, remarkable experiences for parents. It gives parents hope. Hope for a better future for their children and the strength to fight another day (Bacon, & Causton-Theoharis, 2013). Family centered practices, an evidence-based approach and continued collaboration will assist in developing positive outcomes for families (Blackman, 1967).

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About the Author

Cecilia Scott-Croff has more than twenty-five years of experience in the fields of early childcare, special education, and advocacy. She is a leader in these fields having secured major city, state, and federal funding of over 5 million dollars for the programs she has served, obtained its national accreditation, managed multiple funding streams, and worked closely with at risk families. Cecilia has worked as a teacher, coordinator, special education itinerate supervisor, parent advocate, director, adjunct professor, higher education administrator, and staff developer throughout her career. She is a level 3 credentialed trainer with the New York State Association of the Education of Young Children, a New York State certified special educator, early childhood educator and administrator, and holds the New York State Certified Professional Administrator Credential (CPAC) and three teaching licenses with the New York City Department of Education.

Cecilia serves as the Executive Director of the Early Childhood Center at Borough of Manhattan Community College. She is the Chair of the Child Care Council at City University of New York (CUNY). She is currently a board member of “It Takes a Village”, the National Coalition of Campus Children’s Center, a member of the Professional Development Institutes (DI) at CUNY’s Leadership Initiative, a member of the New York State Association for the Education of Young Children, Region 3 and Chair of the Adhoc Committee for the Child Care Access Means Parents in School Committee assembled by the National Association for Campus Children’s Centers. Cecilia has two graduate degrees, one in Early Childhood Education and the other in Administration and Supervision. She has also completed the Leadership Development Institute with the National Black Americans Council. Cecilia has a doctorate in Executive Leadership at St. John Fisher College and is working toward the Board-Certified Behavior Analyst (BCBA) certification at Hunter College.

Table 1.1 Definition of Terms utilized in the field of Special Education (Scott-Croff, 2017)

Terms	Definitions
Inclusion	Is identified as a program model that is inclusive of children with exceptional as well as children who are typically developing. An inclusive setting is an environment that is designed to meet the developmental needs of children with intellectual differences and typically developing children. Typically developing children are children who meet their developmental milestones on target. Programming implemented to meet the needs of children with special needs into a mainstream setting and the least restrictive environment (LRE) Heward (2009).
Individualized Family Service Plan	Is formulated to detail the services awarded to a child with special needs. The plan itself is for children between zero and threes of age (Heward, 2009).
Individual Education Plan (IEP)	Plan a plan developed for children attending a public-school setting awarded services by the committee on special education (Autism Speaks; Heward, 2009).
Least Restrictive Environment	This describes an environment that affords children the opportunity to excel in school under the least amount of restrictions (Heward, 2009).
Service Providers	These providers are identified providers such as speech and language pathologist, occupational (Heward, 2009).
Related services	Refers to services provided to meet the needs of children with exceptionalities. These services include: (1) special education; (2) speech and language services; (3) occupational therapy; and physical therapy (Heward, 2009).
Inclusive Environment	The surrounding or conditions in which children with identified disabilities and typically developing children are educated altogether (IDEA, 2004)

Individuals with Disabilities Act (IDEA)	A special education law that protects the rights of children with disabilities (U.S. Department of Education, 2010).

Table 1.2 Summation of the Review of the Literature (Scott-Croff, 2017)

Study	**Summation**
Almansour et al. (2013)	Highlights the stress and the challenges parents encounter face while caring for a child with special needs.
Bacon et al. (2013)	Underscores the barriers for families seeking inclusive environments for their children with special needs.
Scott-Croff (2017)	A dissertation study details the perspectives of parents and pediatricians on knowledge of parents and practitioners at the onset of a child's diagnosis of autism
Gallagher et al. (2009)	Their research emphasizes the viewpoints and perspectives surrounding children with disabilities
Kendall and Taylor (2016)	Research notes the importance of transition planning for children under two. Consistent, timely communication and planning the researchers note are the hallmark to smooth transition to special education.
Odom et al. (2011)	The researchers study describes inclusive services as well as the progression of inclusion within the last twenty-five years
Schwartz et al. (2002)	research provides an alternative to services when school-based settings fails to meet the needs of the child
Reiman et al. (2010)	offers suggestions for improvement in services

Table 1.3 details the demographic information relating to the parent participants (Scott-Croff, 2017)

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
Age	26	38	32	27	41
Number of Children	1	5	3	1	2
Birth order of the child diagnosed with autism	First	First Fourth	Third	First	Second
Age child was diagnosed with autism	15 months	2 years 3 years	2 years	2 years	2
School environment of child with autism	Public	Public	Public	Public	Public
Type of treatment option chosen for child with autism	Early intervention, applied behavioral analysis services, speech, and occupational therapy	Early intervention, applied behavioral analysis	Early intervention, applied behavior analysis	Speech, occupational therapy, special instruction, applied behavior analysis	Speech, occupational therapy, special instruction, applied behavior analysis
Borough of Residence	Queens	Westchester	Bronx	Bronx	Yonkers
Level of education of parent	Associate degree, working on undergrad. degree	Master's degree	Associate degree	Associate degree, attending an undergrad. Program	High School

Ethnicity	Latina	Black	Ivory Coast (Cameroon)	Asian	White
Marital status	Not married	Married	Married	Married	Married
Occupation	Homemaker	Speech Pathologist	Homemaker	Homemaker	Business Owner

Table 1.4 details the demographic information relating to the pediatrician participants (Scott-Croff, 2017)

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5
Age	56	56	67	54	70
Gender	Male	Female	Male	Female	Male
Ethnicity	White	White	White	White	White
Number years in practice	25	20	35	24	30
Location	Hartsdale	3-Croton Harmon	Croton Harmon	White Plains	Hartsdale
Size	200	300	350	3,000	5,000
Ethnicity of parents served	80% White 15% Black 5% Hispanic	White Hispanic African American	White	80% White 15% Black 5% Hispanic	80% White 15% Black 5% Hispanic
Number of courses taken or training completed relating to children with autism	2-year fellowship	3-4 courses		Ongoing	2 years
Number of children in practice identified with autism	10	20	350	450	40-50

Practice setting: Hospital/Private/Urban/ Suburban	Private	Private	Suburban	Private	Private/ Suburban
Office Hours	9-6, 9-2	9-6	9-5	9-5, 9-12	9-5

Table 1.5 Pediatrician Participant Interview Questions Table (Scott-Croff, 2017)

Question	Pediatrician 1	Pediatrician 2	Pediatrician 3	Pediatrician 4	Pediatrician 5
Please tell me a little about yourself and your experience working with families of children with disabilities.	Pediatrician, private practice Fellowship, Kennedy Center 2-year residency Worked for Early Intervention in the Bronx	Pediatrician in private practice Took a few courses many years ago	Developmental pediatrician who has worked continuously with children with disabilities; started out in the 70s; in the beginning years, the practice included about 20% children with special needs; 15 years ago, 80%; 5 years ago, practice moved to 100% developmental	Pediatrician, private practice; was a nurse prior to becoming a physician She has taken several courses and her training is ongoing	Completed a Fellowship at Kennedy Center many years ago
Please describe your first experience caring for a child with autism.	1988, 1991	Many years ago, child is in 10th grade now; 20 years practicing accumulated a lot of children; the child	Fifty years ago, worked with special needs kids; the autistic children, at that time, had a classical description, with minimal	First experience was in residency; the children seen were very ill. The majority stimmed and had self-harming	In residency, as a youngster, a young man with atypical behavior and features of autism

		described earlier went through Early Intervention, and he ended up seeing a developmental pediatrician and neurologist	delays, multiple atypical behavior, and repetitive behaviors, and were treated with psychopathologic agents available at the time	behavior. Described it as overwhelming	was fascinated with the subway. Probably today would be classified as having Asperger's. Then he carried a diagnosis of mild mental retardation
What resources are available for your families?	Special school with an emphasis on the needs of children with autism	Early Intervention, a state supported agency for families of children with developmental delays	Autism speaks, an advocacy, research and referral agency for scientist, parents and children. ."	Board of Cooperative Educational Services (BOCES): an organization that support children's academic learning and progress Westchester Jewish Community Center A nonprofit that services the Westchester Community and the special needs community	An agency that is instrumental in ensuring the educational needs of children are met
Are you familiar with any programs to support parents	"No, but I would try to send them to family therapy; but it's difficult to	"I am not aware of any official programs. I know there are some on	"Autism Speaks"	"Westchester Jewish Community Service"	"Not specifically; either a center or a place in Westchester

caring for a child with autism?	know which ones accept insurance or private pay or what costs are involved. I tend to say the Westchester Jewish Community Center Service.”	the Internet. Some groups, parents’ kind of talk to each other, try to support each other.”			called Westchester Child Development Center”
What is your process for diagnosing a child with autism?	Hesitant to diagnose before the age of 3. Ask parents questions during the screening process related to symptoms of autism as well as language. Completes a screening tool used for to identify children with autism. Lastly, pediatricians refers any children with speech and language concerns to early intervention.	Refers to early intervention and then to a developmental pediatrician if additional follow up is required. Pediatrician has a system for screening of young children beginning at 6 months, and 6-month intervals thereafter.	Starts with a developmental history, completes a physical and mental health examination. Clinician stated he does not use any developmental tools or check list during his process. As per his responses, the children he works with have already been evaluated and diagnosed.	Explained diagnosis is a straightforward process, however pediatrician 4 stated they work with developmental specialist with advanced training in autism and neurologists to confirm their diagnosis. They also use the M-CHAT reversions 1 and 2 and proceed to further testing.	Pediatrician process is not formal and was based upon his knowledge of working with children over the years.
Can you tell me about any development	Modified Checklist for Autism in Toddlers (M-	Modified Checklist for Autism in	None, children were prescreened by	Modified Checklist for Autism in	Informal methods based on education,

al screening instruments used with families to detect autism?	CHAT) Communication and Symbolic Behavior Scale Development Profile (CSBC-DP) Pediatric Symptom Checklist (PSC) assesses for social problems	Toddlers (M-CHAT)	others before referred to him	Toddlers(M-CHAT)	knowledge and experience

Table 1.6 Parent Participant Interview Questions (Scott-Croff, 2017)

Question	Parent 1	Parent 2	Parent 3	Parent 4	Parent 5
Please tell me a little about yourself and your family.	Resides in Queens	Resides in the Bronx	Resides in the Bronx	Resides in Westchester	Resides in Westchester
Can you describe for me how you found out your child had autism?	Early intervention diagnosis	Early intervention diagnosis	Early intervention diagnosis	Early intervention diagnosis	Early intervention diagnosis
What was one of the first things you did upon finding out about your child's diagnosis?	Cried	Very upset	Blamed myself	Got a second opinion	Cried for days
Who did you seek support from?	Pediatrician Early intervention	Pediatrician Early intervention therapist School	School social worker Therapist	I did not have much support Early intervention Researched	Researched on Internet
Have you participated in any parent support programs?	Special Education Parent Teachers' Association (SEPTA)	No	No	No, I tried to create a group for parents	Local advocacy agencies, but no parent group joined
Can you describe the treatment intervention programs your child has participated in?	ABA	ABA	ABA	ABA Therapies	ABA