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Chapter

Relationships and Resources: Supporting Exceptional Learners from Birth through Primary School

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Abstract

Bringing a child into your family is an emotional experience. New parents are excited to begin a new chapter with their new little ones but also apprehensive about what the future may bring. The hopes, joys, and anxieties of parenthood are unparalleled. When a child has any kind of special need, those emotions can be more pronounced and all-encompassing as parents and caregivers struggle to adjust to the unknown. This chapter will outline common milestones of young children, challenges experienced by parents and caregivers of young children with exceptionalities, and strategies and resources designed to support families on their journeys. The information is designed to be presented in a way to help set families and their little ones up for success. The content provided in this chapter is built on the premise that knowledge is power, that all children can learn, and that parent-professional partnerships are central to the growth of all learners.

Keywords: resources, partnerships, typically developing, atypically developing, child development, resources, challenges

1. Introduction

> *"Help a parent, and you've already helped the child." Johana Scot [1]*

All parents anticipate with excitement the upcoming birth of their soon-to-be baby. They dream about who the child will look like, who he/she will act like, and if their new baby will be an engineer, a ballerina, an athlete, or a nurse. Many times, when the parents are told that their child has or will have a disability, the wind is let out of the sails that give life to these dreams. New parents are apprehensive about what the future may bring. The hopes, joys, and anxiety that come with each new day can be more pronounced when their child has special needs.

This chapter will outline typical and atypical social/emotional, language/communication, fine/gross motor, and cognitive/academic development and discuss the common challenges experienced by parents and caregivers of young children with exceptionalities as well as strategies and resources designed to support families on their journeys. Each section will describe transition points for a child with special needs and provide strategies on how to help families make informed decisions

regarding major milestones within each time period. Resources will be provided to assist families and their child(ren) to reach their highest potential.

The content provided in this chapter is built on the premise that knowledge is power, that all children can learn, and that parent-professional partnerships are central to the growth of all learners.

2. Birth to age 3

"In the garden of humanity, every baby is a fresh new flower." Mridha [2]

Infants and toddlers are wonderful, miraculous, and exhausting. Each new day brings an odd mix of new discoveries and mind-numbing routines while attending to their every need. Caregivers have likely never been so amazed and exhausted in their lives. These new beings soak up every ounce of energy and love. Families are in awe of their new little ones and anxious about their development. Below, we outline typical and atypical developmental milestones for this period of time wherein exponential growth is the norm.

2.1 Social and emotional development

2.1.1 Typical

When a newborn comes home to a family, they typically require total care. Feeding, changing, and keeping them warm and dry consume the hours that make up each day. Children in this age span sleep a good portion of the day. They quiet down when they are picked up, turn toward voices, respond positively to touch, smile, recognize faces, and show pleasure when in a social situation [3]. Between 6 and 12 months, they display a few emotions, play peekaboo and simple games, comfort themselves, follow a few simple commands, and respond when they hear their name. Between 12 and 24 months, the typical child blossoms developmentally. The toddler will delight when they recognize him or herself in a picture and as they hug or kiss family members for greetings and goodbyes. One-year-olds will play alone for a few minutes and start saying no to many directions from caregivers [4, 5]. The 24- to 36-month-old toddler becomes more assertive and will let an adult know what he or she wants, which can be both humorous and tiring for the adult. He/she will watch other children play and will begin to join in and play near another child. This is known as "parallel play" [6]. Children this age prefer an ordered, more predictable routine, but they can adjust to change with minimum protest [7]. They want independence but need the security of their parents or caregiver, and they can become distressed if the caregiver becomes separated from them. During this age span, children begin to show empathy toward other children [7].

2.1.2 Atypical

When a baby or toddler has atypical social and emotional development, it is usually first noticed when the child does not smile or respond to their parent or caregiver. They may not imitate or show interest in adults or other children, which is unusual. Once they are toddlers, they may have extreme difficulty separating from their parents and waiting for a response or event to happen. They may not start interactions with others or respond to other children when they are spoken to. Children in this age span may show abnormal aggression or extreme passivity [8]. They may have rigidity about routines, and their sleep may be sporadic or

interrupted. The social and emotional aspects of atypical development are very hard on parents. Taking care of a baby or toddler who may not be sleeping well and who may not respond to you or interact well with family or peers can be overwhelming. Parents who are tired and get little positive reinforcement from their child experience high levels of stress. Developmental milestones in these situations are no longer taken for granted but are earned through blood, sweat, and tears.

2.2 Language and communication skills

2.2.1 Typical

Besides smiling and interacting with a parent, typically developing infants between 0 and 6 months will start cooing and exhibiting differentiated cries. They will show excitement by waving their arms and legs, much to the delight of their caregivers. Between 6 and 12 months of age, the coos turn into playful babbles that may start to sound like words as they near the 1-year mark [9]. They will shout loudly to get attention, show affection, and start to understand cause and effect (e.g., if I cry, then something will happen). Children in this age span start to repeat a sequence of syllables and may say, "Momma" and/or "Dada" [6], which is so exciting for many adults who have dreamed what that moment would be like once they become parents. Somewhere between 12 and 24 months, the child begins to recognize names of familiar people, understands "No," and tries to repeat words they have heard in conversation [10]. The "songs" they sing serve as wonderful entertainment and memory-building material. Young toddlers usually use between 10 and 20 different words by 18 months, and by the age of 2, they have a vocabulary of about 200 words. At this point, they can combine two words together. Many times, this two-word strand begins with "My ___! " These children can generally point to body parts, follow one-step directions, and repeat words over and over [10]. Older toddlers (around three) have a vocabulary of about 450 words, can answer "where" questions, talk to peers and adults, match four colors, and understand "big" and "little."

2.2.2 Atypical

From birth to age 3, atypical development may include limited facial expressions, not turning to sounds, not responding to their name, not using gestures, and/or lack of imitation. If the child between 12 and 18 months old has a vocabulary of less than 10 words, caregivers should seek professional assistance. A pediatrician is a good place to start. At 2, if the child does not have a vocabulary of 20–50 words and is not putting 2 words together, that is a concern. At 3, the child should have an interest in playing with other children and adults and use their language to communicate with others. At this point, they should have a vocabulary of about 100 words and should be stringing 2–3 words together (airplane in sky) [11].

2.3 Fine and gross motor skills

2.3.1 Typical

From birth to 6 months is a time where a baby will move their arms together and apart, bring their hands to their mouth, and possibly suck on a finger or fist. He or she may lift his or her head and shoulders off the floor when they are placed on his/her tummy. Between 6 and 12 months, the baby will sit up, start crawling and cruising around furniture, and start walking with hands held [12]. Typically

developing 6-month olds are working on sitting up with support. Around this same time, babies are attempting to roll over. As they reach 18 months, the child should be walking independently, and by 2 they should be running fairly well. At this same time, they should be able to walk up and down stairs while holding someone's hand. They can also point to pictures in a book. These interactions help build a bond between the baby and the caregiver. One welcome relief that comes around this time is the child's ability to hold his or her own cup or drink with minimal spilling. They are also able to scribble with a crayon to create "pictures." Between 2 and 3, children this age should be able to copy or make straight lines and circles with a writing utensil and string beads on yarn or string [10]. Around this age, the child should also be able to pedal a tricycle. This can give caregivers some extra exercise as they chase after their busy toddler.

2.3.2 Atypical

Concerns are noted when a young infant (around 3 months) is not attempting to hold its own head up for short periods of time. Better head control appears between 3 and 4 months, so if that is not happening, seek the advice of a pediatrician. If babies around 6 months of age are not attempting to sit up with support or make any attempt to roll over, there may be an underlying cause. If he or she is not using pincer grasp around to pick up small objects around 18 months of age, or he or she does not point to things using his pointer finger, these would be additional warning signs. If a child past 18 months of age does not use both hands during play, if their movements are shaky or stiff, and if they cannot imitate a caregiver drawing a vertical line, or walk independently, there may be an issue with either gross or fine motor skills. Anytime that skills regress is another reason to seek an evaluation [10, 13].

2.4 Cognitive skills

2.4.1 Typical

Infant/toddler cognitive development changes very quickly. Between 0 and 6 months, an infant can recognize faces, which is a cause for cheering among caregivers. At 6 months, they start to enjoy playing games like pat-a-cake and pop-up toys. Around 8 months, fear and separation anxiety may begin [3]. As the 12-month mark approaches, babies can imitate gestures and facial expressions, which is great fun. Babies will also begin to show affection and enjoy picture books around age 1 [3]. Between 1 and 2 years of age, the child will begin to understand words and commands and may even respond to them, imitate adults' actions and words, begin to want to do things independently, and will start to respond with words when requested to complete a task. They can also understand that an object hidden under a blanket is still there even though they cannot see it. This is called object permanence [14]. Between the ages of 2 and 3, the child learns to do several things: name some objects in a book, group objects by category, stack rings in order of size, put together simple puzzles, tell others what he/she is doing, count to three, and play pretend. All of the different skills children acquire each year are amazing!

2.4.2 Atypical

Warning signs that a difficulty may exist for a child under a year are having problems tracking objects, not responding to sounds, having little interest in

interactions with known adults, rigidity in routines, and fleeting eye contact with others. By 2 years, cause for concern would be if the child does not imitate other people, requires constant attention to stay with an activity, or does not understand common commands. By 3, the child should be interested in pretend play, know the function of common objects, no longer be mouthing toys, and play independently for short periods of time. If these events are not happening, caregivers should seek the advice of their pediatrician [10, 13].

2.5 Challenges and resources

One of the biggest challenges for parents of infants and toddlers with exceptionalities is getting a diagnosis. We know that a child with autism may have had up to eight wrong diagnoses before getting a correct autism diagnosis [15]. When a child is diagnosed or identified with a deficit, they are required to have an Individual Family Service Plan (IFSP). This plan is meant to identify services and supports for the child and their family. Services identified in the plan are provided at no cost to the family. Below are common considerations and challenges associated with this age span, suggested actions a caregiver can take to help address the concern, and resources caregivers can use to find more information (**Tables 1** and **2**):

Challenge	Action
Identifying the problem	Express concerns to pediatrician Get second and third opinions
Securing support/treatment/therapy for child	Connect with professional and parent organizations associated with your child's diagnosis (see Table 2)
Coping with emotional stress of having a child with a disability	Accept help from friends and family; establish a routine and build in time for your own interests. Join a parent support group and see a counselor if needed

Table 1.
Identifying and addressing diagnoses: challenges and actions.

Resources
Help Me Grow National Center: www.helpmegrow.national.org
Individual Family Service Plans: www.specialeducationguide.com
CDC's Milestone Tracker: check the app store appropriate for your device www.cdc.gov/ncbdd/actearly/milestone-app.html/milestones
International Resource: United Cerebral Palsy Association https://ucp.org/resource-guide/international-resources
Council for Exceptional Children Division of Early Childhood: www.dec-sped.org
Autism Society of America: www.autism-society.org
Issues Associated with Ages Zero to Three: www.zerotothree.org
Rights and Laws Associated with Special Education: www.wrightslaw.com
Center for Disease Control and Prevention (descriptions of milestones): https://www.cdc.gov/ncbddd/actearly/milestones/milestones-2mo.htm

Table 2.
Resources for infants and toddlers with special needs.

3. Preschool

"Children deserve to be loved and to know they are loved. They deserve to be cherished and to know they are valuable." Ramsey and Cruze [16]

Preschoolers are silly, energetic, inquisitive, and tiring. They are still completely dependent on caregivers for food, hygiene, and other day-to-day needs. Many parents and caregivers opt to send their children to preschool between the ages the ages between 3 and 4 to capitalize on their sponge-like thirst for knowledge. When the child developing normally, this can be a time of great excitement and provide them with opportunities to socialize. Parents of children with disabilities have these same hopes, but they are often tempered with hesitation about difficulties that may lie ahead.

3.1 Social and emotional development

3.1.1 Typical

Typically developing preschoolers are able to express likes and dislikes and developing their own personalities. They are able to talk about emotions rather than just display them. However, even though they can put words to their feelings, they may still display emotions in an exaggerated way. They laugh hysterically when they are feeling silly and can have complete meltdowns if they are angry or frustrated. It is not until they are a little older that they have better control over their emotions. Preschoolers are impulsive and likely to take whatever they want and have total disregard for things they want nothing to do with. It is difficult for even typically developing preschoolers to fully understand the consequences and cause-and-effect relationships of their behavior, although this is the period of time when they learn this skill, as the adults in their lives guide them through making appropriate behavior choices. Preschoolers are able to display empathy and cooperation [17]. They are very creative in their free play and ability to pretend. They may have difficulty distinguishing what is real from what is imaginary. Socially, preschoolers love making new friends. They move from isolated play to choosing to play with others. It becomes easier for kids toward the end of this age span to separate from their parents for short periods of time and have fun playing at school or with caregivers while their parents are away.

3.1.2 Atypical

Once a child reaches 3 years of age, if they do not play pretend or make-believe or play with other children or with toys it is a cause for concern. If they do not have an interest in others (friends or adults), if their emotional responses seem "flat," or if they do not match the antecedent (e.g., in a funny situation, the child becomes angry), then a developmental evaluation is in order. It is normal for children of this age not to have complete control over their emotions, but mismatched reactions or a lack of reaction to emotional stimuli can be cause for concern [10, 13].

3.2 Language and communication skills

3.2.1 Typical

Typically developing preschoolers are fine-tuning their listening skills, which is the foundation for learning to read. They can follow simple verbal directions and repeat simple songs they have learned. Children from the ages 3 to 5 use most speech sounds

correctly; they understand directional words such as "up," "around," and "behind"; and they use pronouns correctly. Rhyming is a very important skill acquired at this age. Preschoolers enjoy pretend reading and telling stories. Their propensity for talking sets the stage for their ability to read and write later on. They are able to articulate their wants and needs, and they are constantly adding new words to their vocabulary.

3.2.2 Atypical

If the 3-year-old drools regularly or has very unclear speech, then a speech evaluation is in order. At this age he/she should be speaking in clear sentences and should understand simple multistep directions. Be particularly concerned if the child does not make eye contact with his/her parents [18].

3.3 Fine and gross motor skills

3.3.1 Typical

The physical development of preschoolers is marked by increased coordination. Preschoolers can move both large and small muscle groups in meaningful and strategic ways. They can hop on one foot, kick a ball forward, and throw overhead. Their ability to hold writing instruments and aim small objects toward targets becomes more consistent and accurate between the ages of 3 and 5. Their hand-eye coordination also becomes more accurate [12].

3.3.2 Atypical

Developmental concerns should be noted if the child falls frequently while walking or does not run. Fine motor concerns should be explored if the child in this age range cannot eat independently using a spoon and cup or cannot hold a crayon [10, 13].

3.4 Cognitive and academic skills

3.4.1 Typical

Preschoolers are sponges when it comes to learning. One of the most exciting stages of development a caregiver will see during this time period is the child's ability to move from literal to representational or symbolic thinking. Somewhere between 3 and 4, children are able to use objects to represent other things and to pretend that something (like a horse or a fire truck) is present when it is not. Children at this age are able to begin categorizing objects, although they may only focus on one attribute of the object rather than take several attributes into consideration. Preschoolers are very egocentric, meaning that they see the world only through their own point of view [14]. The memory of a 3-year-old requires more recency than that of a 4-year-old.

3.4.2 Atypical

Atypical cognitive development in a preschooler would be if they cannot sort things by color, shape, or size, understand the concept of size such as which is smallest or largest, and do not know the primary colors red, yellow, and blue. As with all developmental ages, if a child ever loses skills they once had, it requires a trip to a physician to see if it is a concern [10, 13].

Challenge	Action
Identifying issue or concern Note: it may not be until children reach a school setting that parents and teachers recognize a delay or concern	Express concerns to pediatrician Get second and third opinions
Securing support/treatment/therapy/services for child	Connect with professional organizations associated with your child's diagnosis
Coping with emotional stress of having a child with a disability	Accept help from friends and family; establish a routine and build in time for your own interests and profession

Table 3.
Challenges and actions to identifying and treating diagnoses in preschool.

Resources
National Autism Association: http://nationalautismassociation.org/
The Council for Exceptional Children: https://www.cec.sped.org/
American Speech and Hearing Association: https://www.asha.org/
Interactive Autism Network: https://iancommunity.org/

Table 4.
Resources for preschool children with special needs.

3.5 Challenges and resources

Preschool lays the foundation for the remainder of a child's school journey. A positive start can set the stage for many happy and fulfilling experiences for everyone involved; a negative beginning can create a rocky road for all participants to travel on during future academic endeavors. When a child with a disability reaches 3 years of age, they will transition from an IFSP to an Individual Education Program (IEP) if they are eligible. This plan will identify goals and services for the child. All services are provided for the child free of charge. Below are common considerations and challenges associated with this age span, suggested actions a caregiver can take to help address the concern, and resources caregivers can use to find more information (**Tables 3** and **4**).

4. Primary school

> *"Parents with their words, attitudes, and actions possess the ability to bless or curse the identities of their children." Craig Hill [19]*

Five-year-old children are full of energy and enthusiasm. Typically developing children have a bubbling excitement for being "big" enough to go to "real" school. They have heard so much from their neighbors and siblings about what school days are like that many little ones are anxious to be a part of the official school-kid crowd. Dreams of bus rides, recess games, and eating in the cafeteria are only eclipsed by their parents' anxieties of how things will go. These anxieties can be exacerbated when special needs are present. Depending on the disability, the child's level of excitement can go from nonexistent to hyper-exaggerated. Students with intensive needs may not even be aware that a change is coming or have extreme difficulty adjusting to the change when it does. Those on the autism spectrum may perseverate

with excitement or stress on different aspects of issues related to school. The parents of these children have the same range of emotions and stressors as they face the myriad of decisions to be made as they enroll their children in primary school.

4.1 Social and emotional development

4.1.1 Typical

Socially and emotionally, typically developing children entering primary school have an interest in other children. They can share and make friends and begin to take "ownership" of their friends. They pay attention to rules and want their opinions to be listened to. Kindergarteners like to sing, dance, and act [10]. In the upper grades of primary school, typically developing students behave in a more independent manner, they are eager to please, and they demonstrate an understanding of knowing right from wrong. They constantly seek attention and approval from adults. They like to please friends and be like their friends [10].

4.1.2 Atypical

Students with exceptionalities at this age vary greatly in their social and emotional development. Those with severe cognitive delays may have difficulty forming relationships due to a variety of factors, such as language delays or lack of social skills such as inviting others to play or being aware of comfortable zones of proximity when meeting others. Students with special needs at this age may not be as independent as their peers when it comes to social play. They may have difficulty with turn-taking and following rules, which can lead to arguments, ostracism, and bullying. Their attempts to make friends can often be awkward and cause them to be stressed or anxious about social situations. These difficulties are a source of much angst for parents. It can be heartbreaking to see your child bullied or left out by other children. Friendships are such an integral part of life; it is devastating to think that your child may not be able to form these important bonds with other people [10, 13].

4.2 Language and communication skills

4.2.1 Typical

Typically developing children in primary school can clearly use language as a tool to communicate their needs. They understand the role of letters in learning to read and grow from non-readers to fluent readers and writers within this time frame. Typically developing learners in primary school add new words to their vocabularies constantly, learning between 540 and 11,260 a year [4]. This vocabulary acquisition opens new worlds for them in books, in conversations, and through their own writing. Primary-aged students are able to connect their life experiences to the stories they hear and read, and they like to talk and write about stories. In this stage, they move from learning to read to learning from reading.

4.2.2 Atypical

Students with disabilities often experience language delays [20]. Depending on the severity, this can affect their ability to learn to read and write, as well as their effectiveness in communicating with others using speech and text. Disabilities involving receptive and expressive language skills can cause significant gaps in

vocabulary acquisition. This causes a domino effect in their ability to understand new concepts or to discuss information and ideas in depth. Phonological awareness delays and deficiencies can affect a child's ability to manipulate isolated sounds in words, a key element of learning to read [21].

4.3 Fine and gross motor skills

4.3.1 Typical

Students entering kindergarten are usually fairly coordinated and spatially aware. As they grow throughout primary school, these skills are fine-tuned, and they develop the capacity to write neatly (utilizing fine motor skills) and participate in athletic endeavors (which utilize gross motor skills). Hand-eye coordination develops exponentially during this time frame. Children grow from barely being able to catch objects that are thrown to them to hitting balls with a bat during organized baseball and softball games.

4.3.2 Atypical

When a disability is present, this is yet another area that can be affected. Students may lack coordination and therefore have difficulty participating in play or physical education exercises. They may be non-ambulatory or need assistance with self-care tasks like brushing teeth, holding a writing tool, or typing. It is easy to see how lacking these skills can make a child stand out from their peers and cause both them and their parents a great deal of emotional distress. Along with the stress of not being able to perform these tasks at the same rate as their peers, children with atypical fine and gross motor development miss out on many of the benefits associated with physical play and learning through the repetitive action of tracing and writing with ease [10, 13].

4.4 Cognitive and academic skills

4.4.1 Typical

Typically developing primary school-aged children progress in their abilities to think logically and use reason. Early in this stage (around age 5), children are curious about everything. They constantly ask, "Why?" From kindergarten to third grade, their problem-solving skills improve. Memory and sequencing skills go from simple to complex as children move from mimicking simple directions to perform-ing complicated tasks from multistep directions they hear or read. They add to their repertoire of ways to learn by moving beyond observation, imitation, and repetition to reading, discussing, and reasoning in order to gain new information and think about more complex ideas. They understand spatial and directional vocabulary and concepts of time and that numbers represent amounts. Children in primary school typically move from being non-readers to being able to read primary chapter books by grade three. They should be able to solve basic mathematical and logic problems as well as extract information from content area texts.

4.4.2 Atypical

The cognitive and academic development of students with disabilities varies in its progression. Students with moderate or intensive cognitive delays are likely to have difficulty retaining new information as well as applying information to new

situations. Some students may have trouble accessing academic content due to physical barriers such as deafness or blindness. Students with autism may present exceptional skill in reciting information associated with a specific genre of information or topic of interest. For example, a child may be able to tell you everything there is to know about the solar system but may not be able to interact with their teachers or caregivers in depth like that about other topics. The primary-grade timeframe is also often the period of time when learning disabilities are identified. Students who are having difficulty with language-related issues may be at risk for reading difficulties. If a child has difficulty rhyming or manipulating sounds in words (e.g., "Take the /c/ off of cat and tell me what word you have"), intervention may be necessary. If the student has trouble with spelling or breaking down larger words, there may be a word-recognition learning disability present. In language comprehension, it may be that children (and parents) entered the school community thinking that everything was going to go smoothly, only to discover that learning does not come easily. Both of these situations bring various degrees of frustration and anxiety for both students and parents. If a child is not already identified, the process to assess, identify, and build the proper support network can be overwhelming. The relationships among all persons involved (the student, the caregiver, and the teachers) can become strained [10, 13].

4.5 Challenges and resources

All parents want their children to be in the best environment for learning in order to make this step a positive one. They wonder what kinds of options they have for schooling their exceptional child. What type of school to choose (private, public, full time, part time, etc.), what types of supplementary therapies and supports may be needed, and how to navigate the complicated process of securing those services through their child's school. If identification of a disability has taken place, or does take place during this time period, navigating that process can be trying. A child at this age will most likely be on an IEP and be receiving services through the school. Below are common considerations and challenges associated with this age span, suggested actions a caregiver can take to help address the concern, and resources caregivers can use to find more information (**Tables 5** and **6**).

4.6 Making connections

In each age range listed above, suggestions for how to help caregivers, family units, and the child with disabilities have been provided. Pulling these resources together and connecting agencies within the network and beyond can be a powerful strategy for maximizing support for all involved [22, 23]. Parents of children with disabilities interact with three primary categories of providers: medical, educational, and support services. When supporting units remain unconnected to any kind of network, they remain "bubbles" in the life of the family (see **Figure 1**). Each category of support is isolated and weak on its own. Within each of those bubbles, there can also be isolated components. For instance, the medical bubble could include doctors, mental health therapists, vision specialists, and home health workers. A family could be seeing multiple specialists who may not talk with each other and remain independent from one another. In the education bubble (e.g., teachers, therapists, tutors, principals), one could be seeing a general education and a special education teacher as well as a physical education, music, and art teacher. In the support services bubble (e.g., therapists, parent support groups, financial assistance and child care), a family could be connected with an occupational, physical, and speech therapist, parent support and/or disability-specific groups, as well as numerous social service agencies. It

Challenge	Action
Securing the proper types and amount of instruction and services	Meet with school team member first. Try to build a mutually respectful dialog about the situation and your child's needs. Speak with other parents who have been successful in securing services for their child. If you have difficulty working with the school, and you would like to secure the help of an advocate, you can find one in your state by searching here: http://www.yellowpagesforkids.com/
Supporting the student emotionally	Communicate with the mental health services and counseling department at the school. Pursue these services privately if need be
Coping with emotional stress of having a child with a disability	Accept help from friends and family; establish a routine and build in time for your own interests, and connect with professional organizations associated with your child's diagnosis
Difficulty learning to read	Formally state that you suspect a learning disability and that you would like the school to conduct an evaluation
Understanding the IEP process	Meet with the school's special education teacher or school psychologist. Find more information at www.understod.org

Table 5.
Navigating the process of choosing the best school for children with learning disabilities.

Resources
Understanding the Individualized Education Plan: www.understod.org
Ohio Center for Autism and Low Incidence: https://www.ocali.org
The National Center for Accessing the General Curriculum: https://ccrs.osepideasthatwork.org/resources/national-center-accessing-general-curriculum
National Center for Learning Disabilities: https://www.ncld.org/
Understood for Learning and Attention Issues: https://dyslexiaida.org/
International Dyslexia Association: https://dyslexiaida.org/

Table 6.
Resources for understanding action plans in schools.

is not unusual for these individuals to work on their own. They may not talk to each other and remain isolated, which can cause redundancy of service as well as unnecessary gaps in care. When the individual units and the components within the units are connected, they become a chain, much stronger and more effective in their support. **Figure 2** illustrates how connecting resources maximizes the strength of the overall network. When medical, education, and support services work together, the ultimate goal is to meet the needs of the individual with disabilities and their family.

Since it is not commonplace for agencies and/or providers to work together, a family with a child with a disability can supplant this phenomenon through organization and by keeping excellent notes. Starting a notebook with dividers for each area (education, medical, and support) of service can be very helpful. Every time a family sees a particular provider, they bring the notebook and update it. Verbally sharing the data or information in the notebook and providing copies to leave with the providers in order for them to get a full picture of what is happening help to streamline and strengthen a comprehensive support system. This can take place electronically or with paper notebooks. In the medical community, there are often medical portals where all of the medical information is shared within the medical system. This is generally not the case with the educational and support systems.
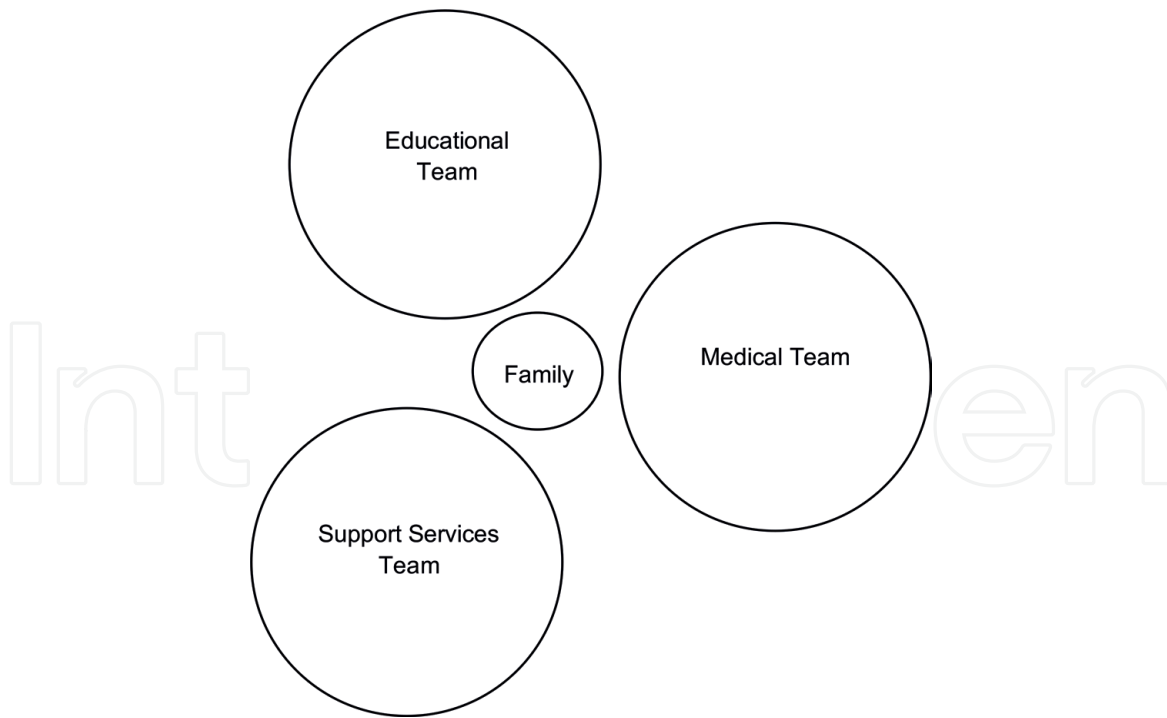
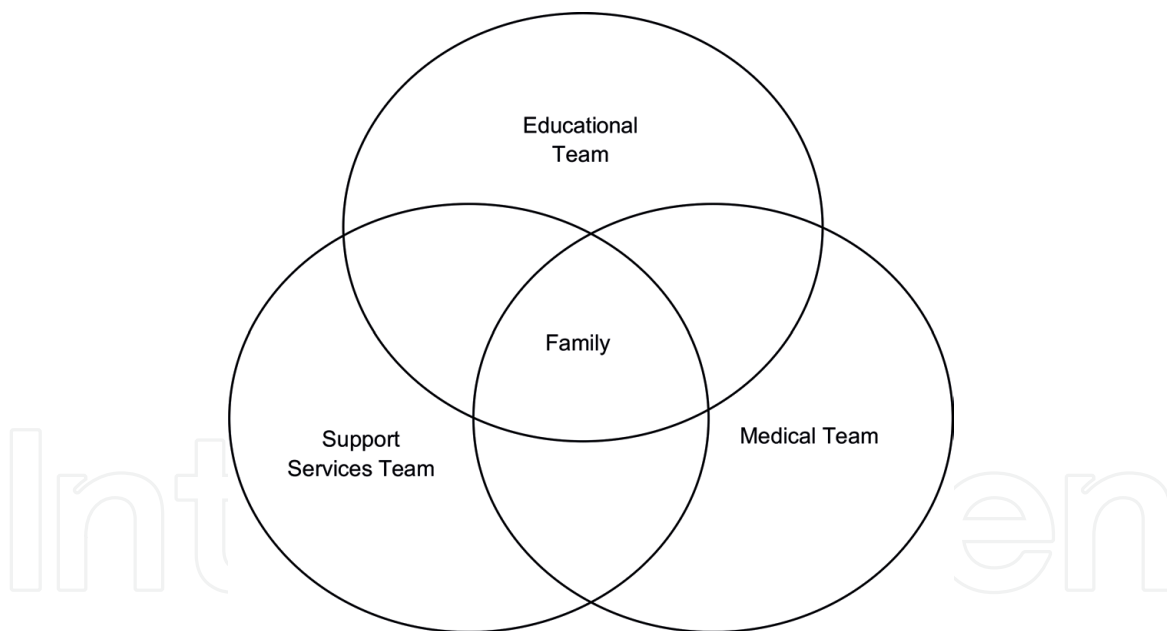**Figure 1.**
Isolated services model.

Figure 2.
Network chains model.

Providing a framework for all information to be shared benefits everyone involved. One of the greatest supports for families in navigating "systems" is parent-to-parent support. Pairing a parent up with someone who has gone through the system is very powerful and beneficial [22, 23].

The model illustrated below represents a typical approach to care for children with special needs and their families. Independent care units operate in isolation. Services are secured one by one, and professionals operate without knowledge of or interaction with the other agencies working with the families.

The model below illustrates a much more cohesive, efficient, and powerful approach to supporting children with special needs and their families. All service

providers communicate with each other and coordinate services. This cross-pollination strengthens the support for the child, the family, and the service providers. It minimizes redundancy and makes progress monitoring more efficient.

5. Summary

Parents of children with disabilities travel a different (not better or worse) path than most parents. Many parents of typical children take development for granted. Parents of children with disabilities are forced to be keenly aware of every developmental milestone and can experience a somewhat different appreciation for each newly acquired skill. Although many disabilities may be invisible to the general public, the child, and the family are very aware of their existence.

Sometimes, parents have to navigate the three systems (medical, educational, and support services) on their own. Resources are often plentiful, but finding them can be a challenge. By networking with other parents, parents of children with disabilities can break down common barriers. Most parents find that they acquire a new set of friends (parents of children with disabilities) out of the necessity of finding resources for their child with exceptionalities [24]. Once parents are aware of typical and atypical development, they can identify potential concerns and how to start the process to obtain resources to get providers to work together to meet the needs of the whole child and their family. Traveling on this sometimes-difficult journey with information and knowledge of how to get help is a win for the family and an even bigger win for the child.

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