Common supports for Parents of Children with Disabilities

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Common Supports for Parents of Children with Disabilities

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Abstract

Families with children with disabilities are all around us; our schools; our neighborhoods, our friends, even our own families. Researchers have invested time and energy in investigating issues that affect persons with disabilities, but few have allowed the expression of voices of the families with children with disabilities. This research delves into four main areas that families encounter regularly; stress, support, education and advocacy. It continues by examining these factors as they affect families with children with disabilities and also aims to investigate where they find resources and support around them. The culmination of this research investigation is a manual that describes the issues and challenges that novice families of children with disabilities should be cognizant of, in their quest for social, emotional, and professional support.
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Chapter 1

Introduction

The United States Census Bureau indicates of the 53.9 million school aged children (aged 5 to 17) in the U.S. civil noninstitutionalized population, about 2.8 million (5.2 percent) were reported to have a disability in 2010. IDEA (Sec. 300.8(c), 2004) defines the following categories of disabilities “mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, need special education and related services.” The above number of children that have disabilities is staggering. These children’s families have triumphs, challenges, heartaches and stress. The severity of the child’s disability multiplies the degree of challenges families experience. Disabilities may be different among the children in these families, but they need similar resources. For example, children with autism may need occupational therapy for sensory challenges. Children with multiple diagnoses may need physical therapy for ambulation concerns. A child with cerebral palsy may be struggling with ambulation and behavioral challenges. A child with Down Syndrome may need those same services and speech therapy to begin to work on verbal challenges. Although the diagnosis, children, families, and needs may be different, many resources they need are common.

Statement of Problem

Families with children with disabilities need support during various stages of their children’s development. The challenges include economic, social, emotional, educational and marital, legal, interpersonal and intrapersonal factors. As a result, parents of children with
disabilities greatly benefit from and need extensive supports. Types of support include physical, emotional, medical, or educational ones. Some parents naturally seek and find these supports through networking, information gathering through local and national service agencies, news, social media and word of mouth. However, many parents, especially novice parents of children with disabilities often fail to be aware of the need for and seek support. Finding supports can be challenging and time consuming, as parents may be facing the aforementioned challenges that prevent them or cause delay in seeking supports.

Fortunately, there are certain fundamental questions that are common to all parents with children with disabilities that parents can ask to seek help for bringing up their children with disabilities. These questions may help families get information about the issues that confront all parents with children with disabilities such as how to locate support from families that are experiencing the same issues, where the most useful resources are and how to advocate for their children to get the services they need. Studies show that support from various groups such as family, friends, professional entities and other support groups are necessary for the families to deal with different kinds of stress, have answers to questions they may have and get resources they need to help their children navigate successfully through their lives expectations and challenges (Kersh et. al, 2006; Warfield, 2005).

**Significance of Study**

It is important to provide parents of newly diagnosed children with disabilities with access to resources because most parents are unclear about what types of supports they need. Some parents begin to accrue that knowledge by default, as they continue to undergo lived in experiences with their children with disabilities. However, some parents may continue to be unaware even after their children’s age increase, due to various personal constraints such as
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extent of education, lack of net-working and lack of access. This results in an increase in the challenges posed due to the disability and increase in stress levels among family members.

In one study by Spann (2003) stated that, “Numerous parents noted that their level of knowledge and involvement had increased as their child grew older (p.235).” This points to a gap between the knowledge of novice parents and the knowledge among experienced parents who have sought and received support. Creating a bridge between experienced parents that have older children with disabilities and novice parents can facilitate the access to supports by novice parents. This research proposes that the bridging can be done through a creation of basic questions that those novice parents need to articulate in order to get appropriate services for their children. If novice parents have the right questions to ask, they are likely find more supports and as a result, feel more confident and efficient in addressing their children’s needs.

Purpose of the Study

The purpose of this study is to find out what parents know about existing resources and compile basic questions to assist novice parents to locate those resources while bringing up their children with disabilities. These resources include, but are not limited to, educational law, financial, support groups, strategies or interventions, waiver needs, or respite care. There is a need for families to have broad questions available to them to begin looking for support. Compiling these certain broad questions may benefit families that are in need of support or resources at the most crucial times in their children’s lives. These questions will help them acquire and utilize the most useful resources, locate places to get support from other families to reduce stress and advocate using the information they acquire.
Research Approach

The purpose of this qualitative study was to create basic questions that novice parents can ask to acquire support and resources in their community. In response to the research survey, a list that included the most important questions the experienced parents have asked, and the most useful information that they have received was compiled. Participants answered these questions via Survey Monkey™ regarding their experiences, successes, and challenges in raising children with disabilities. This information has yielded a set of possible questions that most or all parents of children with disabilities need to have answered in order to support their children with disabilities. The surveys were returned electronically and anonymously. The surveys were analyzed and checked for themes. The surveys kept in locked filing cabinet until the research has been completed, and then properly disposed after the research is complete. CITI and Nuts and Bolts training were completed, fulfilling two of the requirements to complete research on human subjects. See Appendix F for a copy of the CITI training. IRB approval has also been obtained. See Appendix E for a copy of the IRB approval. The surveys were analyzed and checked for themes and a set of possible questions for parents was created.

Definition of Terms

The following is a list of key terms that recur through this paper and their operational definitions:

Demand: “A demand is frequently defined as an external environment acting on an individual…”

Family Self Advocacy: Family Self Advocacy is families themselves personally seeking, finding and using information and resources to make educational and future plans work for the child and his/her family
Learning Disability: According to the DSM v, “the diagnosis requires persistent difficulties in reading, writing, arithmetic, or mathematical reasoning skills during formal years of schooling. Symptoms may include inaccurate or slow and effortful reading, poor written expression that lacks clarity, difficulties remembering number facts or inaccurate mathematical reasoning” (American Psychiatric Association, 2013).

Stress: “…Stress is defined as the relation of the external force to what it is applied to…”

Strain: “…Strain is the negative affect on the person or persons that are experiencing the stress” (Glidden, 1993, p.483).

Support group: “…Support groups are defined as a group of people that share the same experiences or concerns and may provide emotional or moral support to one another.”
Chapter 2

Literature Review

Families with children with disabilities need support during various times in their children’s lives because bringing up children with disabilities, supporting them economically, providing for their adequate education and training and ensuring their future success and independence are all challenging to families. Many families are fortunate enough to receive these supports from many members in their lives—from family, friends, coworkers, organizations, and people within their religious community. These members, however, cannot fully help novice parents as they begin their journey with their child with disabilities. Various reasons for this may be: parents may not know how to access these resources; they may not have access them in a timely manner; they may not adequately express what their needs are to service providers and they may not recognize the importance and priority of certain resources. Thus, supports may be inefficient and inadequate, instead of comprehensive, and appropriate to individual needs.

Furthermore, parents have to spend time, energy and resources searching for existing support systems, make connections with other, similar families and service providers and research for themselves in order find the information and resources then need. Additionally, once they find the resource they need it may be inaccessible to them due to location, matters pertaining to insurance or a long waiting list. This research endeavors to examine evidence in the literature regarding these issues with families of children with disabilities and to understand factors that govern support seeking by parents.

The following literature review will provide a brief overview of the laws that govern special education and rights of families with children with disabilities and elaborate on three
main issues that families with children with disabilities experience as they endeavor to find adequate supports to help their children. The first section will briefly describe the various options available to parents about healthcare. The second section outlines the laws related to individuals with disabilities. The third section of the review will examine published literature about stress and strains that families undergo. The fourth section details evidence in literature for the need for support from similar families and the last section elaborates on the need for skills that families should possess in order to advocate for their children.

**Healthcare**

Medicaid disability is a fund designed to help those who are living with a disability to meet their needs. There are three requirements to qualify; income, resource limits and meeting Indiana’s definition of disability. There are three major programs that Indiana offers; Care Select, traditional Medicaid and MED Works. Care Select provides care for chronic conditions and a few of those additional services are for preventative, home and hospital care and transportation. A member that qualifies for this can opt-out if they would like and transfer to traditional Medicaid. Traditional Medicaid provides for doctor visits, dental and vision care, surgeries and hospitalizations to name a few. Med Works helps those working with disabilities that are eligible that meet income and asset guidelines ("Getting Medicaid," n.d. Medicaid section).

Medicaid Waivers are very important to families with children with disabilities. The first question families of children with disabilities will ask a new family with similar needs is, “Are you signed up for Medicaid waiver?” These waivers provide a family with means to have their children with disabilities get involved in the community, build relationships within the
community, develop skills that will help them make decisions and be as independent as possible. There are to major waivers currently that a child can qualify for: the Community Integration and Habilitation Waiver (CIH) or the Family Supports Waiver (FSW). The CIH provides services so that family members can stay in their homes or live in other settings while living as independent as possible and maintaining community integration. The FSW provides supports for children to reside in their homes with their families and still attaining some limited services to help with that process of maintaining independence and community integration (What is Medicaid Waiver?,” n.d. What is Medicaid section, para 1).

**Special Education Laws**

There are three major laws that protect children with disabilities; American with Disabilities Act of 1990 (ADA), Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973.

**ADA:** According to the web resource ADA.gov “The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities and transportation. It also mandates the establishment of TDD/telephone relay services” (Americans with Disabilities Act, n.d.). The ADA protects individuals who have a disability from discrimination. This makes it the responsibility of the school to provide reasonable accommodations for their students and employees to be able to perform essential functions on the job.

**IDEA:** IDEA provides funding to state and local agencies for eligible children ages 3-21 with disabilities to guarantee a FAPE, special education and related services. This means that there is
a responsibility to provide a Free, Appropriate Public Education (FAPE) to children that are in
the special education program or enrolled in a job training program. IDEA requires that children
receive an Individualized Education Program (IEP) with specific guidelines on content and
requirements on meetings and participants in those meetings. IDEA requires written notice to
parents of any and all changes pertaining to identification, evaluation and placements. An
evaluation is required to check eligibility every 3 years ("Building a Legacy: IDEA 2004," n.d.
Welcome section).

Section 504: Section 504 prohibits discrimination from any programs or activities that receive
federal funds. This is a law that provides children with needs that are physical or mental and may
limit their life activities such as hearing, speaking, caring for oneself or performing a manual
task. If a child does not qualify for special education this law would help a child receive a service
that would allow them to complete a task such as writing. For example, if a child is in a car
accident and breaks his/her arm and cannot continue to write by themselves, this law provides
services so that he/she can continue to fulfill needed tasks in the classroom ("Overview of ADA,
IDEA and Section 504," 2009. Overview section, para 1).

Stress and Strain

In a further review of literature, three factors have stood out about support for families
with children with disabilities to reduce stress and strains in their daily lives. The first is the
degree of behavior problems and severity/type of disability a child may have. These families
with children with severe disabilities experience stress mainly because of the behavior problems
exhibited by their children. Warfield’s (2005) study focused on 51 families with children with
disabilities in two-earner homes while looking at how they share parenting and work
responsibilities. It found that if a child has more behavior problems, the parents report greater
stress than those that have fewer behavior problems. Similarly, in a study with 115 parents of children with intellectual disabilities between the ages of 36 and 60 months it was noted that these parents experience higher levels of stress than parents of typically developing children (Gerstein, Crnic, Blacher & Baker, 2009). Another study of 146 families with children of various diagnoses by Gupta (2007) found that parents with children with disabilities that have more severe behavior problems such as disruptive behaviors and developmental disabilities are linked with higher stress levels.

Second, studies have shown that spousal support is important to families with children with disabilities. One study indicated that both parents experience less stress if the spouse is supportive and that this improves parent functioning and lowers parental stress for both parents (Warfield, 2005). This study focused on two earner families and their parenting challenges while finding reliable child care and working. Correlations between stress, number of children, children with behavior problems and the roles of both the mothers and fathers in the caregiving roles and the stress for both were found. Warfield’s study concludes that there is a positive correlation between two factors relating to parental stress—whether they are satisfied with the size and helpfulness of their support group and parental well-being (2005). The relationship between husbands and wives has been shown in a study of 62 pairs of mothers and fathers to be more the perception of how the family is functioning and the support they are receiving outside of the family unit that lowers or increases stress levels (Dyson, 1997). 67 families, specifically the mothers, stated mothers feel better about their jobs as a parent when they receive support from their martial relationship (Kersh et. al, 2006).

Another study conducted with 134 mothers of children ages one through 36 months with no disabilities by Mulsow, Caldera, Pursley, Reifman and Huston (2002) concluded that a social
support network that includes other mothers who are facing or have overcome similar challenges might provide a resource base for how they coped with the stress, what strategies they used, and how it helps to reduce parenting stress during children’s toddler years. This study researched the correlation between the mother’s infant child and the amount of stress that she experienced. Researchers indicated that both mother and child temperament or personality, the satisfaction with their work or school choices and social support from a partner each perpetuated the amount of stress that the mother experienced in the first years of her child’s life.

One could extrapolate that adding the factor of having a child with a disability makes being a part of this social network even more important to that mother and her well-being. In the same study, it was found that having good relationships with one’s partner is associated with decreases in parental stress (Mulsow et al., 2002). This study continues to say that single parenthood predicts higher levels of stress due to the absence of that support from a partner. It concluded that, “a supportive partner is more likely to share the burden of caregiving better, perhaps compensating for the generally high levels of stress in these families” (p. 951). Finding support from friends, family, an organization or a support group in both times of increased stress and using this support to reduce stress is important to alleviate the presence of stress.

Stress is also associated with advocating for a child with disabilities. Research (Wang, Mannan, Poston, Turnbull & Summers, 2004) indicates that, “advocacy causes stress” (p.149). This study was conducted in three locations using 6 to 12 participants at each site. “Parents stated that they experienced a great amount of stress related to their advocacy activities” (p. 149). This statement mirrors parents thoughts on how it feels to deal with this constant battle that is calling providers, following up on commitments, writing letters, working with a school system and keeping up on records or appointments for that child on a regular basis. The study continued
to say that it is difficult on a family both physically and emotionally. Both of these factors cause stress that the family experiences, but the family feels it is necessary to continue to advocate for their child regardless of the price.

**Family Self Advocacy**

Support groups are defined as a group of people that share the same experiences or concerns and may provide emotional or moral support to one another. Support groups that special needs families attend are often linked with their child’s disability. There are several support groups available for members of the family, for example sibling support groups, grandparent or church support groups. Finding a support group can be a vital way to share both information and emotional connections to a family just like theirs.

In one study, 55 families of children with disabilities indicated that 68% of them sought general support from friends and 93% sought information and advice from families with similar diagnoses (Banach, 2010). It continued to say that 80% of those families sought information from other health professionals. This study strengthens the notion that general support from friends is important. However, specific support from families who have had the same experiences or support from professionals with knowledge is especially desired. Seligman and Darling studied 10 families (as cited in Dyson, 2010) and found that, a child’s family affects his/her development and in turn, the child has a special effect on his/her family as well. These relationships are constantly changing each other.

This indicates that families are affected in various ways, and some families have unique types of support of which others may be unaware. Heiman (2008) conducted another study among 121 parents who had a child with Asperger, Learning Disability (LD), or no diagnosis at
all were similar due to the need to be heard and share personal stories, feelings, frustrations, and expectations. Parents are able to gather intervention strategies and hope by expressing and sharing their experiences with others. In a third study, 105 families were interviewed and voiced the importance of support for parents (Hayden, 1996). This support included emotional support, developing coping skills and using their own strengths to face particular difficulties. This particular study was directed to the social workers that help families get resources. It was noted that resources need to be found on a family need basis and they must show a correlation between the most severe needs to a higher stress level and a higher need for the families unmet needs to be addressed quickly.

Research done by Trainor (2010) placed parents into different categories as they were acting as advocates for their children. She used the term, “disability expert” (p. 41) to describe a way of advocating that includes parents that attend workshops, meet with national experts, share information with their school professionals and participate in local support groups. They are able to use their membership in these support groups to get information, build attitudes, knowledge and skills about advocacy. If there are cultural or linguistic backgrounds that are similar, parents in this study believed they were able to make connections and learn of other services available for their child through support groups. Trainor’s study (2010) found the following, “Social relationships established through support groups and other affiliations afforded parents access to information and ways of approaching special education processes, often resulting in a more strategic approach to advocacy” (p.42). In research conducted by Wang et. al (2004) the study showed that parents benefit from expanding and enhancing their social support groups by participating in groups with children with disabilities similar to theirs, parent support organizations and professionals.
As evident in the above review of literature, a support group can give information to families and be a direct link to other families who are experiencing the same daily challenges, triumphs and stress or strains.

Types of support groups can range from family groups to sibling groups. Family groups are when the whole family may attend a weekend together to relieve stress, talk of common traits with other families or exchange stories. Sibling groups where children are taught to be able to voice the feelings they have about not being the child that gets the most attention or that it is ok to have feelings about their brother or sister. Different groups that are specific to a disability may have speakers to educate them or time to exchange resources or strategies that may have worked.

**Advocating In Education**

Being an advocate in education is finding and using information and resources to make educational plans work. Advocating for children with disabilities, in most cases is a job that parents are thrown into without access to published material on how to advocate for themselves and their families, without guidance and without prior knowledge about disabilities. These parents are expected to be advocates for their children. In order for parents to properly advocate for their children, they must know the specific procedures involved in seeking professional guidance for their child’s education, related laws and how these factors might affect their children’s development and education. Parents become advocates for their children because many children, particularly those with intellectual and developmental disabilities may be unable to advocate for themselves. A father’s words capture this sentiment best when he says speaking of advocating for his sons and participating in the study (Wang et al., p. 148):
Who will listen for those that cannot hear? Who will have vision for those that cannot see? Who will speak up for those who cannot speak? Who will stand up for those who cannot walk? And I volunteer to do that for my three sons and everybody else’s angel. That’s why I am here.

Educational professionals look up to these parents as if they are experts on their children, and they value the feedback that can be offered by such parents. Many parents are assertive and persistent while pointing out the children’s needs and working with others to develop and monitor educational goals for their children (Stoecklin, 94, p.5).

Another of these stressors for these families is education for their child with disabilities. The presence of a disability in a child brings a school and his/her family closer than his/her peers non-disabled family. The disability factor actually results in more frequent communication or contact between school and the children’s homes; this communication generally has negative overtones (Dyson, 2010). The study continues to say that the negative relationship with school systems is mainly from contact made regarding initial assessments, service delivery, labeling and treatment of the child (p.49). This stress can also be from the amount of time parents put into advocating for what their children need to obtaining pertinent information for their child or his/her disability.

Hess, Molina, and Kozleski (2006) conducted their study of twenty-seven parents or caregivers in hopes to create equal partnerships in families of children with disabilities and the education professionals. Their study stated that many parents report difficulty in obtaining information about existing services. A minority of parents reported extreme dissatisfaction with the available services, suggesting a continued need for more open communication and
collaboration in regards to their child’s education. In this same study, (Hess et al., p.153) reported that families want to play a role in their child’s education, but are unsure how to do so. Parents also stated that they needed general information and support in order to better understand their child’s special need and they sought ongoing specific communication around academics and behaviors. Parents discover that they are responsible for their child’s educational progress and that they are often times the only advocates for their child. The parents in this study also perceived their child’s learning disability as a difficulty that requires accommodations in order for their child to succeed. This study concluded that the need to assist families in learning to be advocates for their children through education, support and the use of family mentors lays at the most fundamental level. Families need to be given access to information about their child’s educational options and their rights in a language they can understand.

When families have this support and can locate resources for their child they can advocate actively for their child. In one study, Spann (2003) studied forty-five children with autism or other related pervasive developmental disabilities and stated that, “Numerous parents noted that their level of knowledge and their involvement had increased as their child grew older.”

In another study by Duquette, Fullarton, Orders, and Robertson-Grewal (2011), the findings from 17 birth mothers and their adolescents diagnosed with a learning disability were consistent that parents should learn how to advocate on behalf of the children. Advocating is a skill that noted above had shown to grow as the child gets older and the parents feel more knowledgeable. In another study of fifty-one parents of students who were receiving special services, Fish (2008) suggested that most parents take the initiative to educate themselves and that educating themselves on the IEP process and special education law helps the parent to
understand how the educational process works. When they know how the educational process works, they can be better advocates for their child.

Other researchers have gone so far as to identify the separate categories that each job or requirement fits for parents as they are advocating for their children. Stated above there are the disability experts but Trainor (2010) adds strategists, intuitive advocates and agents of change. Each of these labels can account for the different jobs or skills that a parent gains or uses on their journey as a parent of a child with a disability. Being a strategist means that you are aware of your rights by having a full understanding of “…special education documents, procedures and (your) parental rights in advocacy” (p.42). Parents that are “strategists” understand their role to help with decision making in referrals, evaluations, services, inclusion and accommodations for their child. When the parent is using the “intuitive advocate” role, the parent is using the benefit of being the best resource for this child or “knowing my child” (p. 40). In literature, it is repeated that professionals working with families in special education need to value and try to understand perspectives of the parent and the information they bring about their child in order to collaborate to best meet the needs of the child (Hess et. al, 2006; Fish, 2008, Stoner, 2005).

A “disability expert” is the parent that is using their knowledge that they have found through a variety of contexts to educate the professionals on their child. As stated above these parents seek more information about their son/daughter by going to workshops, meeting national experts, reading articles or books and then pass on to their child’s school professionals to help them in their knowledge of their child.

The “agents of change advocacy” is when parents feel that it is (Trainor, 2010) “… their mission to create easier paths for other parents of children with disabilities…” (p.44). These
parents see a goal to change something that has affected their family in order to make it better for another family behind them.

Summary

The review of the literature in the above areas has shown a connection between the issues presented; stress in families with children with disabilities, the need for a support group and the need for basic understanding of how to advocate for your child. Retsch et al. (2010) explains that parents experience unique challenges in raising their children with disabilities, and these challenges are often times the result of a “mismatch between the parent’s needs and the available resources (p.148)” or “mismatches in perspectives in educational practices” (Hess, 2006, p.150).

In the study by Duquette, Fullarton, Orders, and Robertson-Grewal (2011), the findings were consistent that parents should learn how to advocate on behalf of the children. This literature review has looked at the stress levels of families with children with disabilities and the levels of stress that are caused by several facets of their daily lives. If the system around these families can adequately fill each of these needs for support and services/resources, it can work to lower the demands, and the stress and strain that they experience. This study will identify what resources and supports some families who participated in this study have utilized to help their children with disabilities negotiate the system and create a manual where novice parents can find resources to navigate the educational process and find helpful, relevant information for themselves and their families.

Thus in view of key findings in the literature, the current study will address the following research questions:
• What are the existing local supports or resources for families of children with disabilities?
• What resources parents need to navigate the educational system successfully?

This study has created fundamental questions and resources for these parents to use as they begin their journey in a quest for support for their children, which may in turn help these novice parents be better advocates for their children.

Chapter 3

Methodology

Participants/Setting

As per IRB regulations, invitation letters to participate in the study were sent to families with children with disabilities through organizers of support groups or camps. The researcher sent the request to the organizers of various parent support groups, who in turn forwarded them to their group members. Twenty-one participants filled out the survey to participate in this study and all were parents of children with a wide range of disabilities ranging in ages ranging from 18 to 65 years. These parents participate in one of three groups; a special needs camp (Camp We Can, Rochester, IN), a parent support group (face to face or via Facebook) or have children that attend a special needs classroom.

Data Sources And Collection Procedures

The data sources in this study included individual surveys completed via Survey Monkey by the primary caregiver of a child with a disability. The research questions are:
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- What are the existing local supports or resources for families of children with disabilities?
- What resources parents need to navigate the educational system successfully?

Collection Procedures

The researcher conducted surveys using already assembled email lists from a mother’s support group and a special needs one day camp (Camp We Can, Rochester, IN) of which the co-investigator is a member. Co-investigator used emails and social media to further recruit participants with children with disabilities. See Appendices B/C for copies recruitment letters. The participation was voluntary and confidential and responses were coded. Co-investigator completed CITI trainings in preparation for this study. See Appendix F for certificates. The participants went to a link using Survey Monkey™ and answered the survey questions.

Research Questions

This one time survey was used to identify support systems that experienced parents have used to help their children with disabilities. These support systems include educational, financial, medical and therapeutic needs or strategies. This research will answer the following questions.

1. What resources do families of children with disabilities need to navigate the educational system successfully?

2. What are the existing local supports or resources for families of children with disabilities?

Data Analysis Procedures/Method

After responses to the survey were collected, they were screened for similar themes and issues. These themes and issues were analyzed and results were documented. Based on the
analysis of the results a manual for novice parents of children with disabilities was created that may help them ask the most beneficial questions to get the necessary supports for their child. The results have gleaned information on how many parents sought support and from what similar resources they may have received support.

Three themes have emerged from the results of this survey; Parents have a need for information regarding the laws and procedures in special education, a need for questions that they can ask professionals and a list of supports or resources that they can utilize. The first theme discovered is the need for information regarding laws and procedures in special education. This emerged from question number five and the low percentage of parents that indicated they have sought this particular resource. The higher percentages in the other areas, therapies and diagnosis indicate that parents have previously spent their time and energy seeking information. The second theme emerged from questions six and nine. Question six asks, “Where have you sought the most support?” Parents indicated that they most often utilized friends, other families and school, instead of using professionals to seek information. In question number nine parents were asked to share the most pivotal questions they have asked. They indicated they would ask questions that would be answered by their child’s doctors or therapists. In question seven, parents were asked to give advice on what resources they would offer to novice parents, therefore the last and final theme of a list of supports and resources was compiled.

Description of Special Project

First, a list of questions were created to see what information and support parents seek. The questions emerged from the survey responses submitted by participants and synthesis of literature. The survey information indicated areas of which experienced parents feel there is a need for the novice parent to know. The survey also indicated areas that families neglected to
seek information and could use given the right tools. Next, the researcher compiled a manual using the information that participants gave during the survey to analyze. Finally, a manual with basic questions that encompass a plethora of resources was constructed from the survey information. These questions can be used for a novice parent to ask or to use as a reference for answers to those questions. The researcher studied these areas to address the concerns and questions utilizing the resources available in the local area. The researcher has compiled a resource list that will both give the basic questions a novice parent needs to ask and attempt to answer the same questions to create a plethora of resources in one area.
Chapter 4

Results

Introduction

Parents of children with disabilities need support systems and resources as they journey through their lives with children with disabilities. Novice parents have more to learn from parents that are further in the journey with their children. The following results are from a survey conducted to see where parents found their support, what questions they asked and which resources they used. The purpose of this survey was to create a manual that novice parents can utilize to find information and support that is essential for the comprehensive systems of support that families with children with disabilities need.

Results are divided into sections by question to address common themes that have emerged through the parents completing this survey.

Demographic Information

19 parent participants with children with disabilities chose to go to the web link at Survey Monkey™ to complete this survey. The children with disabilities ranged in age from 3 years old to 24 years old. See Table 1 for detailed information. Disabilities of these children ranged greatly from hearing impairments to autism to mild cognitive delays to cerebral palsy to Down syndrome. See Table 1 for detailed information. Of the 19 participants, 15 have a current IEP. Two are not of school age and two are enrolled in home school programs.
Analysis of Survey Data

Question #1

What diagnosis does your child have that qualifies him/her for special education services?

Diagnoses for the children of parents participating in this survey ranged from autism, communication disorders, down syndrome, visual impairments, fetal alcohol syndrome, cerebral palsy and Attention Deficit disorder.

Question #2

What is the age of your child?

Parents in this survey indicated ages from 3 years old to 22 years of age.

Question #3

Does your child currently have an IEP (Individual Education Plan)?

15 parents indicated that their child had an IEP currently. Four parents indicated that their child did not have an IEP.

See Appendix H table 1 for details on this question.

The data collected in the first three questions was important to this study to show the range of both diagnoses and age of children in the survey because this survey was aimed at facilitating support seeking by new parents and understanding what experienced parent knew about supports needed. Thus, when looking at the age of the child, this indicates the number of years of experience the parent has in advocating, navigating the educational system and seeking professional help. The original goal of this survey was to use the experiences that parents have already had to help the novice parents earlier in their journey. However, the participants in the
study were a majority of younger parents. The question about having an Individualized Education Plan and the child’s age was a duplication of information. If their child was of school age, that is between 3-22 years old they indicated an IEP, therefore the question answer was duplicated. If the child was of school age, invariably the child was on an IEP. Three parents indicated their child was home schooled, and therefore did not have an IEP. Two participants in the study were no longer of school age. Their answer indicated that their child did not have an IEP. This information gives a better view of the participants in this study, in particular in understanding how many experienced parents took the survey and what their knowledge and access to supports were and how many novice parents responded to the survey and what supports they needed, or whether they were aware of the need for support services.

**Question #4**

Please describe your knowledge about your role in your child’s educational decision-making.

See Appendix H Table 2 for details on this question. Each table consists of all of the information submitted by the participant for each survey question. For the purposes of this research the information is in charts for quick reference next to the survey questions. If needed the information is located in Appendix H and the applicable table that corresponds to the survey question that further detailed information is needed.

The data responses in this question indicated two trends. The first trend was the fact that parents see themselves as knowledgeable, important, essential and substantial parts of the decision making process in education for their children. It shows that parents know they have a right to, “…be aware of the goals and outcomes of the IEPs (parent #3), that no decisions can be
made without my knowledge (parent #5) and that they have the right to be involved in the
decision making (parent #16).”

The second trend is the negative thoughts that were present in the responses about the
education of their children. Parents responded with:

“My role in my child's educational decision making is to keep fighting for what she
needs in order for her to learn in a safe environment, even if the schools don't always like it
(parent #4).”

“Our input is typically listened to, sometimes not (parent #11), “teachers constantly ask
me what I do for his behavior problems, but tell me little about what goes on in the classroom
with him (parent #14).”

“I usually felt like we were on the same page with the team in terms of eligibility (parent
#15).”

Each of these responses has a negative connotation due to words that participants used in
their responses such as, “telling me little or usually.” For example, one participant stated she/he
must fight for what they need. While another participant felt that she/he was usually listened to
or usually felt like they were on the same page, which shows that there are negative feelings in
the communication between home and school. These words support the study cited that states
that, “The presence of a child with a disability in the family actually results in more frequent
communication or contact between school and the children’s homes; this communication
generally has negative overtones” (Dyson, 2010).
The parents stated that they feel, “knowledgeable and essential,” in the education process. This is helpful to the production of this manual because parents know that they are expected to participate and that it is their right to participate in decision making for their children. However, the second trend of negative feedback and feelings that the participants voiced demonstrates that negative communication is frequent and adds to parent’s stress levels in dealing with the educational decisions of their children.

**Question #5**

In what areas have you sought information or resources for your son or daughter? Please indicate all that apply and describe where applicable: Diagnosis, Education Law, How to be an Advocate for your child, Parent Support Groups, Therapies, Waiver Services, Strategies, Medical, Financial.

See Chart 1 below titled “Percentage of Parent Responses” for a quick reference for the percentages of parents that chose each of the places where they sought information.

In this question, the data shows that families have sought the majority of their information in the areas of therapies, diagnosis and medical. In areas of educational law and advocating they have not sought as much information. 81 % sought information on diagnosis followed by therapies, medical information and parent support groups (63-69 %) with the middle percentages being in information sought for strategies and advocating with a tie at 37 %, and the lowest percentages at 18 % for educational law.

It is surprising that more information is not sought on how to be an advocate and educational law, as these are responsibilities that parents feel they are expected to accomplish.
and be good at. Parents seem to be busy researching areas regarding their child's diagnosis and medical needs rather than their educational needs.

Chart 1

Percentage of Parent Responses

- Diagnosis
- Educational Law
- Advocate for your child
- Parent Support Groups
- Therapies
- Waiver Services
- Strategies
- Medical
- Financial

Question #6

Where would you say that you have sought the most support? Indicate in order of where you have received the most support with a 1-6. Family, Friends, Professionals, Other families/parents with children with disabilities, Your child's school, Other (please specify).

The data in this question shows that a majority of families seek support from their families (chart #2). In retrospect, the researcher would have rephrased this question as families that have children with the same disabilities become friends and it may be that the data here was duplicated. This information correlates with the literature review statement that in one study, 55 families of children with disabilities indicated that 68% of them sought general support from friends. It does not correlate with that 93% that sought information and advice from families with
similar diagnoses (Banach, 2010). This survey indicated that responses were spread across both most and least support from friends and other families (chart 2-3). It is also interesting that family support is either a least or most sought place for support. The participants indicated either they do or do not get support from their family, there are not many responses in between. This question could be researched in further studies.

The data does show that family (see chart 2) and the child’s school (see chart 6) are also big supports for families which is contrasting to the responses in question four (see appendix H table 2) where the communication is often negative. This poses the question about whether schools are still able to play a supportive role even when some of the communication is negative. In further research, a question to examine would be “What or how does your child’s school support you?” Seven parents that answered not applicable (NA) in this study (see chart 5) indicated that they did not seek professional support? It is interesting that this area is not used more often by families, and it begs the question of why families don’t use the professionals more? In this question, professionals are defined as therapists, doctors or specialists.
**Chart 2**

**Support From Family**

![Bar chart showing support from family]

- 1 Most Support: 4
- 2 Support: 1
- 3 Support: 1
- 4 Support: 1
- 5 Support: 1
- 6 Least Support: 3
- N/A: 2

**Chart 3**

**Support From Friends**

![Bar chart showing support from friends]

- 1 Most Support: 1
- 2 Support: 2
- 3 Support: 2
- 4 Support: 2
- 5 Support: 2
- 6 Least Support: 3
- N/A: 0

Legend:
- Parent Response
Chart 4

Support From Other Families

Chart 5

Support From Professionals
Question #7

In addition to usual general care, parents have to provide, a much more intensive level of care, such as structuring their child’s daily routines, creating opportunities for socializing, daily activities, further education and providing companionship. How do you reach out in your community or above support systems to address the above needs for your child?
The responses for this question can be disaggregated into categories of practical or social ways a family reaches out to their community. Practical, for this survey, pertains to therapies, seeking help from therapists, resources, education or church services in the community. Social, for this survey, pertains to social settings, fundraising or educating others. Indicated under each response is a [P] for the word practical or an [S] for the word social to indicate which section the researcher placed the response for purpose of research on themes. Out of 12 responses social and practical were split with four (33%) responses each. Two (17%) participants indicated answers that had both social aspects and practical aspects. This survey question indicated families are seeking both activities in their communities that meet both their practical needs and their social needs (see Appendix H table 5).

**Question #8**

What advice or resources would you give a novice parent to address these needs?

Each response was analyzed for a theme and combined with responses that were similar to create the bullet points for a section of the handbook titled “Wisdom and Advice-From Parent to Parent.”

Participant #1 responded, “Do not stop until you get the answers you seek. Trust your instincts,” which corresponds to the first and second bullet on Words of Wisdom and Advice.

Participant #4 responded, “Take your time, what you know works for your child, do get them in therapy, but don’t expect it to fix everything. Nothing is a cure all, but to expect for you both to learn ways to cope with the life you’re given,” which corresponds to the third, fourth, and fifth bullets on Words of Wisdom and Advice.
Participant #5 responded, “Educate yourself. Search out your state’s or county’s resources and read the materials they give you. Don’t be afraid to ask questions or get clarification. Don’t be afraid to advocate for your child. Unfortunately, you aren’t there to make friends with the people who provide services for your child. Particularly in education, get involved and keep track.” Participant #19 said, “Ask and seek help in every area or concern.” Participant #16 added, “Keep asking until you get the support you need,” which corresponds to the sixth and seventh bullets on Words of Wisdom and Advice.

Participant #14 responded, “Be nice but persistent,” which corresponds to the eighth bullet on Words of Wisdom and Advice.

Participants #5 and #12 both responded, “Get involved in treatments and activities,” and “Get involved with education and keep track,” which corresponds to the ninth bullet on Words of Wisdom and Advice.

Participants #11 responded, “Call an organization like ASK or Easter Seals or ASI,” which responds to the tenth bullet on Words of Wisdom and Advice.

The eleventh through thirteenth bullet points on Words of Wisdom and Advice were a combination of several parents responses. “Get involved in treatments and activities,” was part of participant #12 response. Participant #13 commented to, “Research activities that most help your child’s needs.” Participant #15 commented, “Get creative online, use Facebook and Pinterest for ideas for activities and to get involved with more resources.”

(see Appendix H, table 6)
Question #9

As you have asked questions on your child’s journey what were three pivotal questions that were answered for you, your child or your family?

Each response was analyzed for a theme and combined with responses that were similar to create the points for a section of the handbook titled “Questions For__________.” Questions were then entitled under the pertinent section either questions for professionals in education or questions for doctors or therapists. The researcher has indicated a letter [E] for a question for Professionals in Education or a [DT] for the questions for Doctors or Therapists section. Of the seven responses, two responses can be questions asked of either the doctors/therapists or the education professionals. Several participants chose to leave this survey question blank. It is unknown to the researcher as to why this question was left blank.

Participants #1 and #13 responded with questions that could be asked to either the Professionals in Education or to Doctors or Specialists. Their questions were, “What will his future look like? What are the long term projections? What can I do to help her reach her greatest potential? What is best for my child?”

Participants #5 and #12 asked questions that a Professional in Education would answer. Their responses were, “Are we doing everything in our power to help this child, why does the gap between him and his peers keep widening? What available therapy options and what is mainstreaming at school.”

Participant #4 asked questions that a Doctors or Specialists would answer. That response read, “Will these behaviors always be this severe? Which therapies can you recommend? What are the chances my other children having this as well?”
One participant said, “There don’t seem to be answers to my questions about autism.”

**Summary**

Parents that participated in this survey knew that they were important to their child’s educational gains and career but their responses showed that there was a negative element to most of their answers. These words support the study cited that states that, “The presence of a child with a disability in the family actually results in more frequent communication or contact between school and the children’s homes; this communication generally has negative overtones” (Dyson, 2010).

Most of the information sought by the participants was for medical and diagnosis. This is material that is easy to gather on the internet at a variety of websites that support such work of parents. It remains surprising to the researcher that the parents did not seek more information about being an advocate, educational law or strategies for their child. This would be a good topic to further delve into; why do parents not search for strategies or ways to better advocate for their children with disabilities?

Where a family finds support was also surprising to the researcher. Why would it be separated between either families get a lot of support or no support from their family? This again, would be an interesting subject to further study. Could it be because there is a divide in acceptance to the child and his/her disability or is there some other reason for this response?

In the question about where and what supports families seek in their neighborhoods and communities it seems fitting that the responses would be split equally. The respondents equally need both practical and social support. The question that could be further researched would be where they were able to get those needs met for that support?
Review of Published Handbooks

Negotiating The Special Education Maze

This manual has plethora of strengths and would be a recommended reading by this researcher for parents who need more information on the special education maze. This manual is listed in reference section and in the manual as a more in depth look at this process and will answer many questions on this journey. It is broken up by chapters to identify the topic a parent may want to research for quick reference. This manual acknowledges the parent and school roles that exist. It even goes into great detail on the cycles that exist for both and how they differ slightly. Forms and examples are included to allow a parent to gather the appropriate information needed to be prepared for whatever stage they are addressing in the education process. It was written by a group of trainers of parent advocates that worked together to compile this information into a guide to be used for that training.

This manual also has weaknesses that include its length. It is a long book that a parent would likely not read in entirely rather only the chapter of his/her interest. The copyright for the manual that the reader obtained is 1997. This material is 14 years old.

The Right to Special Education in New Jersey A Guide for Advocates

This guide also has strengths that are noted by the researcher, the following are what the researcher noted as strengths. It includes a table of contents that can allow the parent to find the relevant information to his/her needs. The majority of this guide can be transferred to any school corporation, in any state, as it references national laws. It has valuable sections that can be generalized for any parent; request forms for various special education meetings, general tips and several definitions.
Weaknesses were also noted for this guide by the researcher. The most obvious is the fact that it was written for New Jersey schools. It references their Education Law Center and their Abbott Schools Initiative that are only relevant to their state. It is very lengthy and includes several sections that may not be relevant to every parent.

**Advocating for Young Children with Disabilities**

This quarterly resource was written to provide an overview of how families can be involved in advocacy for their children. A big strength for this resource is the in depth look into advocacy it provides. There are several resources in this manual that a novice parent could use to prepare for the education of their child. It provides information for the great lakes region with includes that state of Indiana.

A weakness noted in this resource is that it is focused only on the education part of raising a child with disabilities. It does not broach subjects such as therapies, support systems or other resources that a family with these challenges may need available to them.

**Parent to Parent; Heart to Heart**

This researcher’s manual addresses the above weaknesses of and strive to address other issues that these manuals have not. This study was compiled to allow parents to give other parents valuable information in their journey with their child with disabilities. The manuals examined did not have this piece. It will be a short manual, rather than lengthy and address subjects that parents have not already sought information on in another form. It includes valuable resources for them to use to ask questions of the professionals (doctors, therapists, teachers) in their child’s lives that other parents have asked. It is tailored to the areas in which parents feel they need more information and reflect issues that are pertinent to parents themselves. This
manual will provide a perspective from the parents to the parents. This manual provides resources relevant to our area in Indiana as well as statewide or national. I have addressed topics in my manual that parents have failed to seek support, but are essential for the comprehensive system of support that families with children with disabilities need.

One of the manuals above only covers one subject, this manual will cover several. This manual will be up-to-date and strive to provide helpful information in a variety of areas for appropriate questions to ask your professionals in education, films to watch for information to discuss and a helpful guide for parents to create a resource binder. All of these subjects are in clear and understandable language that parents can work with and benefit from.
Chapter 5

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Heart to Heart
Parent to Parent

Information for the Journey with Your Loved One with Disabilities

By Jennifer McCammon
If you are looking at this manual you are a professional; a teacher, therapist or school administrator, or you are a family member of a loved one that has a disability. The goal of this manual is to help families or your student with a disability. It was a culmination of a study completed using families that have loved ones with disabilities. The families and their answers were analyzed for themes. Their opinions, feelings and advice are within this manual to help those that are looking for more information on resources and support for these families.
I am currently a 3rd year first grade teacher at Pierceton Elementary in Pierceton Indiana. I have worked for my special education master’s degree while raising four children: one of them, Jaylen, with disabilities. Jaylen has developmental disabilities, cerebral palsy and disruptive behavior disorder. Through our journey, we have met several families that are struggling with the same issues of locating support and resources for our children. My goal is to provide this manual to families just like ours that need a starting point on their journey.

You were given this life because you are strong enough to live it.

Anonymous
Purpose of the Handbook

The purpose of this handbook is to offer a starting place for you, the reader, to locate a resource or support for you or your child. Within this manual, you will find practical questions to ask, locations for several websites to get more information on various subjects and advice directly from other parents just like you. If you are reading this and you are a professional, use it as a guide to help families that you encounter to offer this same information as needed.
Autobiography

I would like to offer my own experience as a way to explain day to day stress and strain that families who have children with disabilities undergo. By sharing, I hope to provide an insider’s perspective of the ups and downs in the daily lives, describe some of the challenges and how I negotiated them and the support systems that were in place that helped my family cope.

Imagine that you are a full-time mom, a full-time wife and a full-time person in your own; that person is me, my name is Jenni. I have a child with a disability. Her name is Jaylen. She is diagnosed with cerebral palsy and disruptive behavior disorder. She is one of my 4 wonderful children.

An ordinary day in the life of a family is never “normal.” There is the child that needs lunch money, the child that needs diapers for the babysitter, the quick trips to pick up milk and get the house payment paid all in the short time that you have between breakfast, work, dinner and bed.

There is not a normal family. We all have our challenges, but ours are different. We have regular challenges along with the challenges a child with a disability adds on top of that. You
know how it goes. You, the parent, get up in the morning, you bug the kids to get up out of bed, they lay there of course, go on to the next kid, wake them up and the morning continues. It continues with rounding up bags, permission slips, notes, after school activity bags, your mind goes a mile a minute. Imagine now that daily, as you are dealing with this regular routine, that your daughter is screaming at the top of her lungs about getting herself ready for school.


The caregiver, a stranger at first, who comes daily to bathe her and get her on the bus is running around with her, asking her questions about whether she wants to have oatmeal or toast first. More yelling. Loudly. More yelling.

After eating, she gets dressed and begins to walk around the house. Her off balance gait makes the toys on the floor from the other children a constant danger. She loses her balance. She yells. More yelling. More yelling. She gets up. She is angry. Now let’s get that coat on. She grunts and hits.

The other family members are moving around the house trying to get their belongings together, getting ready for their days while all of her noise continues.

Small spaces in the house. She’s tromping through again. Angry and loud.

She leaves the house to get on the bus. It’s quiet.

This is just the morning. It’s a constant battle. She needs constant attention. We cannot leave her alone. She has caregivers, therapists in and out weekly. After, a hard day at work, you will be faced with questions about how things are going, what improvements have there been
and what can we do to help. Appointments need to be kept, caregivers organized and toileting to be done.

But that’s just one day, one morning. What about the other 6 that are coming?

The routine of it all can drive your stress through the roof. This is just the regular routine. I didn’t even try to explain the days when it isn’t routine and the craziness that ensues.

Our family has gone a long road. If you are reading this you are either beginning that road or know someone that is on that road. In order for us to cope over the 15 years that our daughter has blessed us, we are finally in a “comfortable spot” with supports in place.

I have fought for those supports. I asked many a professional; a doctor, a therapist, whomever would listen-Where do we get help for our daughter, for us? For a long time we had only the therapists that visited our home, the school teacher or our family and friends to lean on. These were good supports. We still lacked. We didn’t know it would get better.

As the years passed, we learned about places in our community that had events that we could attend, we met other families and I began attending a Mother’s support group. Those ladies were my life line for a while. More time passed. At each developmental phase in our child’s life our family needed and had different types and levels of supports. This is what I would like to share with you, the reader, in this manual.

Now that “comfortable spot,” is the Medicaid waiver, which despite the long wait, has finally helped us out. We are not alone now. We have a team helping us with our daughter. We have a behaviorist, a case manager, caregivers and respite workers. We have a team that listens
to us; our worries, our joys and our challenges. They are here to help us get help and give us help and support. That’s why parents, you need to continue to ask for help. Be that voice for your child and your family! Keep asking! Keep believing that it will get better! Keep seeking people in your lives that will help, guide and support you!
Words of Wisdom and Advice

From a Parent Who Knows to a Parent Who Wants to Know

- Do not stop (searching, asking etc.) until you get the answers you seek.
- Trust your instincts.
- Take your time as you go through all of the process with your child. Remember that you know best what works for your child.
- Therapies will not fix everything.
- Nothing is a "cure all" for your child, but do expect that you will learn ways to cope with the life you’re given.
- Educate yourself. Use your state’s or county’s resources and read all the materials that they offer you.
- Ask questions! Get clarification! Don’t be afraid to ask more questions until you have what you need and you understand it. Continue to ask about every
area or concern you have until you get the help you seek.
• Be nice, but persistent when dealing with those you encounter on your journey.
• Get involved in your child’s education. You are not always going to be friends with the staff you encounter. Keep track of information, dates, calls, meetings etc.
• Use organizations that are available to you like ASK, Easter Seals and ASI.
• Research activities for your child that will help with his/her needs.
• Get involved early in your child’s treatment and in activities that include special needs kids.
• Get online! Search for activities in your community that will help with his/her needs.

These Words of Wisdom and Advice were collected during a study using 21 parent participants and their responses.
Questions for Professionals in Education

General Education/Special Education/Therapists

- What is mainstreaming and what does that look like for my child?
- What can we do to help my child reach his/her greatest potential in the classroom?
- This (strategy, environment etc.) may be great for other children, but what is best for my child?
- Can you explain why the gap for my child is widening between he and his peers if we are doing everything in our power to help this child?

These Questions for Professionals in Education were collected during a study using 21 parent participants and their responses.
Questions for Doctors or Specialists

- What does my child’s future look like? Can you give me an idea of long term projections that this time?
- What therapies should my child receive?
- If I have other children, what are the chances that they will have the same diagnosis?
- What can we do to help my child reach his/her greatest potential?
- Will the behaviors that my child is exhibiting always be so severe?

These Questions for Doctors and Specialists were collected during a study using 21 parent participants and their responses.
Common Supports for Parents of Children with Disabilities 53

QUESTIONS TO ASK IF YOU DON'T KNOW WHERE TO BEGIN

Note: The page numbers in the figure below correlate to page numbers in this handbook to ease your location of the information you are seeking.

Is my child enrolled in a program such as First Steps or education through the school? (pgs. 42-62)

Are there any programs in my community that I can enroll myself or my child for services or support? (pgs. 67-74)

Is my child up-to-date on medicaid waivers? (pg. 65)

Is my child enrolled in the right insurance program for us? Medicaid or Hoosier Healthwise? (pg. 63)
Americans With Disabilities Act of 1990 (ADA)

Type/Purpose--A civil rights law to prohibit discrimination solely on the basis of disability in employment, public services, and accommodations.

Who Is Protected?--Any individual with a disability who:

- has a physical or mental impairment that substantially limits one or more life activities;
- has a record of such an impairment;
- is regarded as having such an impairment. Further, the person must be qualified for the program, service, or job.

Who’s Responsibility Is it To Provide A Free, Appropriate Public Education (FAPE)?

- ADA protections apply to nonsectarian private schools, but not to organizations or entities controlled by religious organizations;
- ADA provides additional protection in combination with actions brought under Section 504 and IDEA. Reasonable accommodations are required for
eligible students with a disability to perform essential functions of the job. This applies to any part of the special education program that may be community-based and involve job training/placement.

Individuals With Disabilities Education Act (IDEA)

- Type/Purpose--An education act to provide federal financial assistance to State and local education agencies to guarantee special education and related services to eligible children with disabilities.

- Who Is Protected?--Children ages 3-21 who are determined by a multidisciplinary team to be eligible within one or more of 13 specific categories of disability and who need special education and related services. Categories include autism, deafness, deaf-blindness, hearing impairments, mental retardation, multiple disabilities, orthopedic impairments, other health impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairment.

- Responsibility To Provide A Free, Appropriate Public Education (FAPE)?--Yes. A FAPE is defined to mean special
education and related services. Special education means "specially designed instruction, at no cost to the parents, to meet the unique needs of the child with a disability...." Related services are provided if student's require them in order to benefit from specially designed instruction. States are required to ensure the provision of "full educational opportunity" to all children with disabilities.

- **IDEA requires the development of an Individualized Education Program (IEP) document with specific content and a required number of specific participants at an IEP meeting.**

- **Procedural Safeguards**--IDEA requires written notice to parents regarding identification, evaluation, and/or placement. Further, written notice must be made prior to any change in placement. The Act delineates the required components of the written notices.

- **Evaluation/Placement Procedures**--A comprehensive evaluation is required. A multidisciplinary team evaluates the child, and parental consent is required before an initial evaluation. IDEA requires that reevaluations be conducted at least every 3 years. A reevaluation is not required before a significant change in placement.
Section 504 of the Rehabilitation Act of 1973

Type/Purpose--A civil rights law to prohibit discrimination on the basis of disability in programs and activities, public and private, that receive federal financial assistance.

Who Is Protected?--Any person who

- has a physical or mental impairment that substantially limits one or more major life activities,
- (2) has a record of such an impairment, or (3) is regarded as having such an impairment. Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks.

- Responsibility To Provide A Free, Appropriate Public Education (FAPE)? --Yes. An "appropriate" education means an education comparable to that provided to students without disabilities. This may be defined as regular or special education services. Students can receive related services under Section 504 even if they are not provided any special education.

- Section 504 does require development of a plan, although this written document is not mandated. The Individualized
Education Program (IEP) of IDEA may be used for the Section 504 written plan. Many experts recommend that a group of persons knowledgeable about the students convene and specify the agreed-upon services.

- Information Lines to contact for further information
  
The ADA Information Line, 1-800-514-0301 (voice); 1-800-514-0383 (TDD).


  Obtained from
  http://www.kidsource.com/kidsource/content3/ada.idea.html

Smart IEPs

All children Can Learn!

Learning About SMART IEPs
S Specific
M Measurable
A Use Action Words
R Realistic and relevant
T Time-limited
Specific
• SMART IEPs have specific goals and objectives.
• Specific goals and objectives describe each behavior and skill that will be taught, and define each skill or behavior in ways that are observable and measurable.

**Measurable**
• SMART IEPs have measurable goals and objectives. Measurable goals and objectives allow you to assess the child’s progress. When you use measurable goals and objectives, you know when a goal is reached and when a skill is mastered. If you establish a goal to lose 25 pounds, you will use scales to measure your progress.

**Action Words**
• SMART IEPs use action words like: “The child will be able to . . .”

**Realistic and Relevant**
• SMART IEPs have realistic, relevant goals and objectives.
• SMART goals and objectives address the child’s unique needs that result from the child’s disability.
• SMART IEP goals are not based on district curricula, state or district tests, or other external standards.

**Time-limited**
• SMART IEP goals and objectives are time-limited. Time-limited goals and objectives enable you to monitor progress at regular intervals.

**Smart IEP Goals and Objectives**
Begin by analyzing your child’s present levels of performance. The present levels of performance describe “areas of need
arising from the child’s disability.” The present levels of performance tell you what the child knows and is able to do. Using information from the present levels of performance about what your child knows and is able to do, write a statement about what the child will learn and be able to do. Your SMART goal will focus on performance and observable behavior. Break the goal down into objectives that describe what the child will learn and be able to do. Focus on performance and observable behavior.

Q: So my child has been found eligible for special education. What next?

A: The next step is to write what is known as an Individualized Education Program—this is usually called an IEP. After a child is found eligible, a meeting must be held within 30 days to develop to the IEP.

Q: What is an Individualized Education Program?

A: An Individualized Education Program (IEP) is a written statement of the educational program designed to meet a child’s individual needs. Every child who receives special education services must have an IEP. The IEP has two general purposes:
(1) to set reasonable learning goals for your child; and
(2) to state the services that the school district will provide for your child.

Q: What type of information is included in an IEP?

A: According to the IDEA, your child’s IEP must include specific statements about your child that are listed below.

1. Present levels of educational performance
This statement describes how your child is currently doing in school. This includes how your child’s disability affects his or her involvement and progress in the general curriculum.

2. Annual goals, short-term objectives or benchmarks

The IEP must state annual goals for your child, meaning what you and the school team think he or she can reasonably accomplish in a year. This statement of annual goals includes individual steps that make up the goals (often called short-term objectives) or major milestones (often called benchmarks). The goals must relate to meeting the needs that result from your child’s disability. They must also help your son or daughter be involved in and progress in the general curriculum.

3. Special education and related services to be provided

The IEP must list the special education and related services to be provided to your child. This includes supplementary aids and services (such as a communication device). It also includes changes to the program or supports for school personnel that will be provided for your child.

4. Participation with nondisabled children

How much of the school day will your child be educated separately from nondisabled children or not participate in extracurricular or other nonacademic activities such as lunch or clubs? The IEP must include an explanation that answers this question.
5. Participation in state and district-wide assessments

Your state and district probably give tests of student achievement to children in certain grades or age groups. In order to participate in these tests, your child may need individual modifications or changes in how the tests are administered. The IEP team must decide what modifications your child needs and list them in the IEP. If your child will not be taking these tests, the IEP must include a statement as to why the tests are not appropriate for your child and how your child will be tested instead.

6. Dates and location

The IEP must state
(a) when services and modifications will begin;
(b) how often they will be provided;
(c) where they will be provided; and
(d) how long they will last.

7. Transition service needs

If your child is age 14 (or younger, if the IEP team determines it appropriate), the IEP must include a statement of his or her transition service needs. Transition planning will help your child move through school from grade to grade.

8. Transition services

If your child is age 16 (or younger, if determined appropriate by the IEP team), the IEP must include a statement of needed
transition services and, if appropriate, a statement of the interagency responsibilities or any needed linkages.

9. Measuring progress

The IEP must state how school personnel will measure your child’s progress toward the annual goals. It must also state how you, as parents, will be informed regularly of your child’s progress and whether that progress is enough to enable your child to achieve his or her goals by the end of the year.

It is very important that children with disabilities participate in the general curriculum as much as possible. That is, they should learn the same curriculum as nondisabled children do -- reading, math, science, social studies, and physical education.

In some cases, this curriculum may need to be adapted for your child to learn, but it should not be omitted altogether.

Participation in extracurricular activities and other nonacademic activities is also important. Your child’s IEP needs to be written with this in mind.

For example, what special education services will help your child participate in the general curriculum—in other words, to study what other students are studying? What special education services or supports will help your child take part in extracurricular activities such as school clubs or sports? When your child’s IEP is developed, an important part of the discussion will be how to help your child take part in regular classes and activities in the school.
Q: Who will schedule a meeting to develop my child's IEP? How will this be done?

A: The school staff will try to schedule the IEP meeting at a time that is convenient for all team members to attend.

If the school suggests a time that is impossible for you, explain your schedule and needs. It’s important that you attend this meeting and share your ideas about your child’s needs and strengths. Often, another time or date can be arranged.

However, if you cannot agree on a time or date, the school may hold the IEP meeting without you. In this event, the school must keep you informed, for example, by phone or mail.

Retrieved from :From Emotions to Advocacy  *The Special Education Survival Guide by Pam & Pete Wright*

http://www.fetaweb.com/01/faqs.iep.htm
Getting Medicaid

Medicaid Disability is a Medicaid aid category designed to serve individuals who are living with a disability. In general, to qualify for Medicaid under this category, individuals must meet three qualification criteria:

- income
- resource limits
- Indiana’s definition of disability.

Families who have children with disabilities are encouraged to apply for Medicaid to see if their child is eligible. Indiana has a few programs that serve its Medicaid members with disabilities;

- Care Select,
- Traditional Medicaid
- MED Works.

Traditional Medicaid, sometimes called Fee-for-Service (FFS) or Medicaid Disability, is a healthcare program that offers medical care such as doctor visits, prescription drugs, dental and vision care, family planning, mental health care, surgeries and hospitalizations to eligible individuals. Home and Community Based Services (HCBS) waiver members will be enrolled in traditional Medicaid.

MED Works is Indiana’s Medicaid program for working people with disabilities. To be eligible for MED Works, one must be aged 16-64 years, meet income and asset guidelines, have a
disability, and be working. Eligible members may incur a monthly premium, which is generally much lower than a spend-down (see page 2).

**Places to contact for further assistance:**

**County Office**
Families may apply in person at their local county office of the Division of Family Resources. To find a county office close by, click on the link below.

**For More Information**
Contact Family Voices Indiana, Indiana’s Family to Family Health Information Center, supporting families who have children with disabilities and special health care needs as they navigate systems and services. Visit www.fvindiana.org or call 317.944.8982.

Retrieved from www.fvindiana.org
What is a Medicaid Waiver?

The goals of Waiver services are to provide to the person meaningful and necessary services and supports, to respect the person's personal beliefs and customs, and to ensure that services are cost-effective. Specifically: Waivers for individuals with a developmental disability assist a person to:

- Become integrated in the community where he/she lives and works
- Develop social relationships in the person's home and work communities
- Develop skills to make decisions about how and where the person wants to live
- Be as independent as possible

Community Integration and Habilitation (CIH) Waiver CIH is a combination of the Autism and the Developmental Disability Waivers and provides services that enable persons to remain in their homes or in community settings and assists transitions from institutions into community settings. This is a needs-based waiver and is designed to provide supports for persons to gain and maintain optimum levels of independence and community integration while allowing flexibility in the provision of those supports.

Family Supports Waiver (FSW) Formerly the Support Services Waiver, the FSW is designed to provide limited, non-residential
supports to persons with developmental disabilities residing with their families, or in other settings with informal supports.

**How do I apply for a Family Supports Waiver?**

The Bureau of Developmental Disabilities Services District Offices can provide an application for the Family Supports Waiver as well as assist in researching additional services. Once it has been determined that an individual meets the criteria for a developmental disability, that individual will be placed on the appropriate waiver waiting lists. Once a waiver slot becomes available the individual will be offered a waiver placement.

*This is an example of the district of the author of this manual. To find your district simply go to [http://www.in.gov/fssa/files/BDDS.pdf](http://www.in.gov/fssa/files/BDDS.pdf) to look at the pdf of counties in the state of Indiana. Locate your county under one of the districts and this will be the office that you will need to contact for services for your child.*

**District 2**
100 W. South Street, Suite 100
South Bend, IN 46601-2435
Phone: 574-232-1412
Toll Free: 1-877-218-3059
Toll Free Fax: 1-855-455-4266
Counties: Cass, Elkhart, Fulton, Howard, Kosciusko, La Porte, Marshall, Miami, Saint Joseph, Tipton & Wabash
Obtained from Indiana Government website

http://www.in.gov/fssa/ddrs/4245.htm#Waiver
Local and National Organizations

About Special Kids
We are the place for families and professionals in Indiana to go to “ASK” questions about children with special needs and to access information and resources about a variety of topics such as health insurance, special education, community resources and medical homes. ASK is your connection to family support in the state of Indiana!

http://www.aboutspecialkids.org/ (This organization mentioned in survey by a parent)

*Arc, The and Easter Seals
Easter Seals Arc provides exceptional services to ensure all people with disabilities or special needs and their families have equal opportunities to live, learn, work and play in their communities. Several services are provided here from children and adults for a variety of needs ranging from adult living, medical rehabilitation, respite care and autism services.

http://www.easterseals.com/neindiana

(This organization mentioned in survey by a parent)
Autism Speaks

Autism Speaks, a national organization has grown into the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

http://www.autismspeaks.org/

*Anthony Wayne Services

People with Disabilities Thrive

The mission of AWS is to help children and adults with disabilities live as independently as possible, be included in the community and function at their maximum potential. Some of the services they provide Early Intervention, Day Services, Vocational and Residential.

https://www.awusa.com
*Bowen Center*

Bowen Center is committed to making a difference in the lives of those we serve. Our professional team of psychologists, psychiatrists, nurses, social workers, therapists and chemical dependency specialists, provides effective help with a full range of personal concerns.

http://www.bowencenter.org/index.html

*Cardinal Services of Indiana*

The mission of Cardinal Services is to support people with challenges or disabilities in reaching their personal goals. Founded in 1954, Cardinal Services is a community based not-for-profit striving to be the premier provider of services to people with disabilities and other needs. Cardinal provides day time work opportunities, adult job shadowing, group home settings and respite for families.

www.cardinalservices.org

*Camp Millhouse*

A Special Place for Special People

Nestled in a rustic clearing surrounded by 45 acres of woods is a special camp for special children and adults...that's where you'll find Camp Millhouse. Camp Millhouse is great experience from both families and their children with disabilities. Children and young adults get the full camp experience with the knowledge of their staff to accept all children with disabilities.

CAMP Millhouse http://www.campmillhouse.org/
**Camp-We-Can**

**CAMP-WE-CAN** has been in existence since 2003 and originated in Fulton County. This is a camp opportunity for children (K-HS completion) who have special needs. Modifications and adaptations are considered for each camper in order to maximize their experiences. Campers are asked to bring their personal adaptive items to use during their stay. Some of the activities offered previously include: convertible car rides, horseback riding, golf cart scavenger hunts, swimming, crafts – frames, flower pots, photo albums.

http://www.camp-we-can.com/

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**Centers for Disease Control and Prevention**

**CDC 24/7: Saving Lives. Protecting People.™**

**Centers for Disease Control and Prevention**

This national website has a plethora of information about all varieties of diseases. Browse this site and use the A-Z index to see what information it may have available on your child’s disability or disease.

Centers for Disease Control and Prevention
1600 Clifton Rd. Atlanta, GA 30333, USA
800-CDC-INFO (800-232-4636)
Contact CDC-INFO

http://www.cdc.gov
**First Steps**

To assure that all Indiana families with infants and toddlers experiencing developmental delays or disabilities have access to early intervention services close to home when they need them. Services they provide range from developmental therapy, vision, psychological, family support, health services and many more.

http://www.fsnci.org/index.htm

**From Emotions to Advocacy**

The Special Education Survival Guide by Pam & Pete Wright

This is a great website for information from a book by the same title. Easy to navigate and answers lots of questions about education and law. It also provides other sites to look into if you still need more information.

http://www.fetaweb.com/01/faqs.iep.htm

**HANDS in Autism**

**Hands in Autism**

**Interdisciplinary Training and Resource Center**

The Center provides innovative, research-based, and practical training and technical support to school staff, medical and service providers, primary caregivers, and individuals on the autism spectrum within
Indiana and globally based on the HANDS training model. The Center provides customizable live and online trainings, interactive workshops, onsite coaching and consultations, and intensive hands-on trainings for school personnel, health care providers, families, therapists and other caregivers. The HANDS in Autism® Center also focuses on identifying and meeting specific community needs as well as fostering: collaboration and networking across medical, school, family, and community settings; reciprocal sharing of information within and across communities; increased dissemination and awareness of resources and information; and increased training opportunities within, relevant to, and informed by the specific community.

https://handsinautism.iupui.edu/index.htm#.UwodBbRuSoU

Indiana Resource Center for Families with Special Needs

IN Source

1703 South Ironwood Drive, South Bend, Indiana 46613, (574) 234-7101 or (800) 332-4433, (574) 234-7279 (Fax)

A parent to parent organization that provides help with the complexities and challenges of raising a child with disabilities. This organization provides training in a variety of areas to help communities provide support to parents of children with disabilities.

insource@insource.org

*LAAN Support Group for Autism

LAAN wishes to provide information and support in and around Kosciusko County for all who care about people on the autism spectrum.

The facilitators of the group are representing area school districts, home school parents, and professional agencies who are all concerned with improving the lives of those affected by Autism.

*Lighthouse Autism Center*

This resource is a facility that offers ABA (Applied Behavior Analysis) to children in the Mishawaka, South Bend, Mishawaka, and Warsaw IN areas. They provide quality therapy to families while working together with you to create hope and positive change.

http://lighthouseautismcenter.com/together-we-can/lighthouse-autism-center-community-interest-meeting-warwick/

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National Dissemination Center for Children with Disabilities

This resource is a web site that offers first time parents information on a plethora of disabilities and ways to get involved in a support group. It contains many definitions, laws, how to know what to look for in your child, how to get into the early intervention steps and lots more.

http://nichcy.org/

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Self-Advocates of Indiana

Self-Advocates of Indiana (SAI) is a statewide advocacy organization that empowers people with intellectual and developmental disabilities. As self-advocates, we are citizens who speak out and
educate for equal rights, respect, and inclusion for all in the community. Self-advocacy is standing up for my rights, being in charge of my life, and bring treated with respect.

Self-Advocates of Indiana
107 N. Pennsylvania Street, Suite 800
Indianapolis, IN 46204
(317) 977-2375
1-800-382-9100

http://www.arcind.org/self-advocates-of-indiana/

*Sensory Critters

Fort Wayne Indiana has a retail store that offers gross motor, adaptive toys, ABA products, scooter boards, aroma, assistive technology and a huge list of many more. Check out the web site or the store, be prepared to look around a while, they have lots to play with and browse.

http://www.sensorycraver.com/

Teaching Parents Teaching Kids

Talking about sex and sexuality with your child with a disability: When, what, and why. This is a local expert that can be reached for a variety of behavior challenges with children with disabilities. To book a speaking engagement or inquire about autism/ABA services or sexuality education, contact me, Soarah Stein, at steinsarah@yahoo.com or 574-329-6856.

http://teachingparentsteachingkids.info/index.php?option=com_content&view=article&id=19&Itemid=18
**Turnstone**

Turnstone’s mission is to provide therapeutic, educational, wellness and recreational programs to empower people with disabilities. As the only not-for-profit organization within northeast Indiana that provides a full range of rehabilitative, educational, wellness, athletic and recreational programs and facilities to persons with physical disabilities and their families, Turnstone is creating possibilities.

http://turnstone.org/

*Several of these websites are programs that have a branch in our local area. They are part of national organizations. The sites provided, when applicable, are local Northeastern Indiana contact or the closest contact available.*
These movies are available by visiting your local movie rental store, library or online source such as You Tube™ or Netflix™.

Adam, 2009: This movie is about a teenager, Adam, with Asperger’s syndrome. He moves to a new apartment and begins a relationship with a upstairs neighbor Beth. The two begin a relationship that stretches them to accept one another.

After Thomas, 2006: This movie is about Thomas, a young boy with the challenges of autism. His father and mother are experiencing the obstacles that accompany raising a child with autism; temper tantrums, echolalia and not having social skills. They decide to get a dog and a friendship blossoms that begins to save their family. Based on a true story.

Black Balloon, The, 2008: This movie is about Charlie who is autistic. The challenges of accepting a sibling with autism can be tough. Will Thomas accept his brother, Charlie even though he steals his every opportunity? Will Thomas’ friend Jackie help the two be brother’s again?

Beautiful Mind, A 2001: Mr. Nash, a man who suffers from Schizophrenia, delusions, is a prodigy, is asked to help the federal government break a code. He breaks this code and heads through an adventure that tests his ability to deal with reality and love.

Boy Who Could Fly, The 1986: This movie is about Eric with autism. Two teenage neighbors deal with being orphaned (Eric) and moving to a new home (Milly) with a twist that one of them is believed to be autistic. Milly is fascinated with Eric, who believes he can fly and begins a friendship that will change Eric forever.

David’s Mother, 1994: This movie is about a single mother who struggles with raising her autistic son while fighting to keep him from an institution. Two beliefs are challenged to figure out what is best for David.

Fly Away, 2011: This movie is about a mother dealing with the challenges of her severely autistic daughter growing into her teenage years. She has to accept that loving her might mean letting go so that she can experience her world.

Forrest Gump, 1994: Forrest Gump, a man who grows from a boy to a man during the movie, is developmentally delayed, has mild cognitive abilities, and happens to be present at many historical events while continuing to reach for his true love, Jenny. Forrest grows and accepts in the ways of the world and the events that shape our American culture.
I Am Sam, 2001: Sam, a man, who is a moderately mentally handicapped, fights to keep his daughter. He struggles through a family law system that challenges his ability to raise his 7 year old.

Mind of Her Own, 2006: Inspired by a true story a young lady who deals with being dyslexic works her way through college and biomedical science as those around her tell her to work on less challenging ventures.

Miracle Worker, The 2000: Helen Keller, The Story of My Life, 1962: This movie is based on a true story of Helen Keller who lives with her family while adjusting to her deafness and blindness that she contracted through a disease at nineteen months. Her family seeks a caregiver, teacher and gets the remarkable Annie Sullivan and their lives are changed forever.

Mercury Rising, 1998: This movie is about a nine year old autistic savant boy is able to decipher top secret codes and becomes a target of assassins. He is appointed an FBI agent that works with him to keep him safe and develops a relationship in the process.

Molly, 1999: This movie is about a young man who becomes the guardian of his autistic, mentally handicapped sister. An experimental treatment helps her brain and his attitude.

Other Sister, 1999: This movie is about a young lady that is determined, even though she is mentally challenged to move out, go to college and have a relationship. Her family is protective and is not accepting of her abilities, therefore making her even more determined to make it out on her own.

Radio, 2003: This movie is about Radio, a young man, who is developmentally delayed and has mild cognitive abilities and frequently hangs out around the football field where he is befriended by the head coach. The transformation from a shy, insecure man into a man that becomes someone his community is proud of.

Rain Man, 1988: This movie is about the story of a man that discovers he has a younger brother, who is an autistic savant. They go on a trip together as the brother tries to figure out where their father’s wealth was left.

Riding the Bus with My Sister, 2005: This movie is about a woman who spends time with her developmental disabled sister after the death of their father.
Tips for Creating a Personal Binder

Assembling a binder will help you organize yourself and help you to be ready to address any concerns or questions you have about your child. The following are tips to get a binder started.

- Buy a large binder and a whole puncher
- Add a few photos of you, your child, or your family to the outsides to personalize it
- Place it in a safe and readily available location, next to your desk, computer or telephone
- Make lists of people to call, papers to return and check them regularly
- Make tabs and sections for
  - *Education*
  - *Medical*
  - *Therapies*
  - *Support/Other Families*
  - *Community/Organizations*
- In the *Education* section place the most recent:
  - IEP
  - Psychological reports
  - Progress reports or report cards
- Keep an up-to-date list of teachers, therapists, aides, administrative staff and any other staff that are in contact with your child
- In *Medical* section place the most recent reports:
  - Copies of medical records
  - Notes you take at appointments
  - Lists of medications (dosages, prescribing doctors)
  - Contact information of all specialists and doctors
- Take notes on conversations that you have with doctors, secretaries, case manager or insurance agents. Use these for follow up calls (for example- on 12/16 Name of person told me...or I spoke with...name of person about)
- Keep all contact information for therapists, teachers, doctors in the binder so when you need one you can locate it quickly

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<thead>
<tr>
<th>Name of Contact</th>
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<tr>
<td>Name of Organization/Office</td>
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<td>Phone Number</td>
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<tr>
<td>Address</td>
</tr>
<tr>
<td>Email Address/Website</td>
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<tr>
<td>Notes from Communication</td>
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Chapter 6:

Discussion & Reflection

Summary

This project investigated stress, education, and supports that families with children with disabilities navigate through during their journey. A literature review was conducted and the areas were considered as the survey questions were constructed. The handbook was created using the needs that were presented from the survey. It examined families with children with disabilities by conducting a needs assessment survey to address the areas in which families needed resources and information available to them. This survey was distributed through Survey Monkey™, was kept confidential and allowed for the creating of the handbook. Analyzing the families’ responses prompted the creating of the handbook that hopes to help families early in their journeys with their children with disabilities.

Reflection on Special Project

This project was a long process that this researcher continued to learn throughout the entire process. The most surprising part was the results that the needs assessment gleaned. The knowledge that this researcher thought she had on the subject was broadened by others’ thoughts and feelings as well. The APA format is a bit of challenge that continued to be monitored throughout the creation of the entire project.

Strengths & Weaknesses of the Project

This project has heart and was built for the love of families that have the same challenges and blessings that my family does. As a researcher, I wanted to learn more on this subject and I definitely did! My daughter having disabilities has blessed our family with both blessings and
challenges. Even some of the challenges have ended up being blessings. When you are in the middle of your journey as a parent with a child with disabilities you forget that others’ journeys are not the same. There are similarities, but there are differences as well. This project aimed to fill holes in information and resources that families need and it did just accomplish that. A weakness that this project has is in the survey questions about children and resources that families use, I, the researcher wanted to be detailed in where families were getting the help they needed, however, due to confidentiality that was difficult and was not approved.

In looking at the research data that was collected from this study the first piece that the researcher would have changed would have been the ability to use an “opt out” on a response on the survey generator. The ability for the participant to choose to not respond to the whole question caused information to be left out. In question #6 participants were able to choose from 1 to 6 which indicated in order of the most and least support they receive from 6 selections. Several participants did not use all the selections.

Another limitation was the omitting a question about stress in the parent survey that was created. This would have tied the literature review and the survey together. The researcher is learning during this process and now has understood why that would have been very helpful.

**Recommendations**

This handbook is recommended for families that are just beginning their journey with their children with a disability. It should be used as a reference for questions to be asked at appointments with professionals, key understandings about the education and to organize information that you acquire along the journey.
Improvements

This project was a needs assessment based survey that provided open ended questions to its participants. In giving open ended questions in the survey it was difficult to analyze themes. I would have changed answers from open ended to multiple choice answers to allow for easier disaggregation later in the study. I would have made sure that the engine I chose for the questionnaire would not allow for the skipping of questions. Several participants skipped several questions. When skipping questions the participants did not provide answers to the most crucial questions in the survey. It is not known why the participants would skip these questions in the survey, perhaps it took too much thought or time to generate an answer. The approval for this survey also stated that part of completing a survey had to leave the option to skip questions they did not wish to answer. As a novice researcher, I was not aware what this would complicate with my survey at the time. I learned very early into the survey that participants were skipping answers to the questions I thought would be the most pivotal to the study and handbook creation.

In choosing the freedom to skip any question in the survey, the survey had questions that several participants did not answer. The researcher has no information behind the reason for the participant to skip the question or part of the question.

Summary of Project

This project was a long process. It is hard to say in a few words what I have learned during this process. I have not completed a project like this before enrolling in my master’s program. It was difficult to see how all the preparation and work would translate into a finished project. It was scary initially as I have heard several students talk about this experience in a negative way. It is a challenge to continue to be optimistic and motivated for this long a period. I
was lucky to have a supportive family and friend base that were there for me when the
motivation was hard to locate or the stress and confusion took hold.
References


Appendices

Appendix A: Email to the principal

*Information withheld for privacy.*
Appendix B: Letter to potential participants
(this letter will be copied on the email from my principal to possible participants)

Dear Parents,

You are invited to participate in a study titled “Essential Questions for novice parents of children with disabilities must ask to get appropriate services/support.”

The purpose of the study is to learn about how parents of children with disabilities get the resources and services they need for their children.

In order to participate in the study, you will take an anonymous survey by clicking the given link. The survey may take about 30 minutes to complete.

You may choose not to take the survey. You will not be penalized if you choose not to complete it. You may skip any questions that you do not feel comfortable in answering. There is no direct benefit from you being in the study. However, your taking part may help parents in the future. The participation or lack of participation in this study will not affect your relationship with the school.

If you have any questions about the study, please directly contact Jennifer McCammon, Graduate Student, IPFW, or Rama Cousik, Assistant Professor, IPFW, via email at or via telephone at .

Thank you for your assistance in participating in my research study. If you would like to participate in the study, please go to the link below and complete the short survey attached.

Sincerely,

Jennifer McCammon

Graduate Student, IPFW
Appendix C: Facebook Post on Mom Support Group Page/Email Request
You are invited to participate in a study. The name of the study is Essential questions novice parents of children with disabilities must ask to get appropriate services/support.

The purpose of the study is to learn about how parents of children with disabilities get the resources and services they need for their children.

If you decide to participate, you will be sent a link to a survey and take it anonymously.

The survey may take approximately half an hour to complete. You may choose not to take the survey. You will not be penalized if you choose not to complete it. You may skip any questions that you do not feel comfortable in answering. There is no direct benefit to you for taking part in the study. However, your taking part may help parents in the future to get appropriate supports. The participation or lack of participation in this study will not affect your relationship with the support group. Thanks so much for your time.

If you have questions about the study, please contact the researchers at the following addresses and contact numbers:

Jennifer McCammon

Graduate Student, IPFW

Rama Cousik

Assistant Professor Special Education, IPFW

Professional Studies
Appendix D: Survey Questions

Survey Questions

1.) What diagnosis does your child have that qualifies him/her for special education services?

2.) What is the age of your child?

3.) Does your child currently have an IEP (Individual Education Plan)?

4.) Please describe your knowledge about your role in your child’s educational decision making.

5.) In what areas have you sought information or resources for your son or daughter?

Please indicate all that apply and describe where applicable:

☐ Diagnosis
☐ Education Law
☐ How to be an Advocate for your child
☐ Parent Support Groups
☐ Therapies
☐ Waiver Services
☐ Strategies
☐ Medical
☐ Financial

6.) Where would you say that you have sought the most support?

Indicate in order of where you have received the most support with a 1-6.

☐ Family
☐ Friends
☐ Professionals
☐ Other families/parents with children with disabilities
☐ Your child’s school
☐ Other (please specify)

7.) In addition to usual general care, parents have to provide, a much more intensive level of care, such as structuring their child’s daily routines, creating opportunities for socializing, daily activities, further education and providing companionship. How do you reach out in your community or above support systems to address the above needs for your child?
8.) What advice or resources would you give a novice parent to address these needs?

9.) As you have asked questions on your child’s journey what were three pivotal questions that were answered for you, your child or your family?
Appendix E: IRB

Purdue University
Human Research Protection Program
Institutional Review Boards

To: RAMA COUSIK
From: JEANNIE DICLEMENTI, Chair
Social Science IRB
Date: 11/11/2013

Committee Action: Exemption Granted
IRB Action Date: 11/11/2013
IRB Protocol #: 1310014163

Study Title: Essential questions novice parents of children with disabilities must ask to get appropriate services/support

The Institutional Review Board (IRB) has reviewed the above-referenced study application and has determined that it meets the criteria for exemption under 45 CFR 46.101(b)(2).

If you wish to make changes to this study, please refer to our guidance “Minor Changes Not Requiring Review” located on our website at http://www.irb.purdue.edu/policies.php. For changes requiring IRB review, please submit an Amendment to Approved Study form or Personnel Amendment to Study form, whichever is applicable, located on the forms page of our website www.irb.purdue.edu/forms.php. Please contact our office if you have any questions.

Below is a list of best practices that we request you use when conducting your research. The list contains both general items as well as those specific to the different exemption categories.

General
- To recruit from Purdue University classrooms, the instructor and all others associated with conduct of the course (e.g., teaching assistants) must not be present during announcement of the research opportunity or any recruitment activity. This may be accomplished by announcing, in advance, that class will either start later than usual or end earlier than usual so this activity may occur. It should be emphasized that attendance at the announcement and recruitment are voluntary and the student’s attendance and enrollment decision will not be shared with those administering the course.
- If students earn extra credit towards their course grade through participation in a research project conducted by someone other than the course instructor(s), such as in the example above, the students participation should only be shared with the course instructor(s) at the end of the semester.
Additionally, instructors who allow extra credit to be earned through participation in research must also provide an opportunity for students to earn comparable extra credit through a non-research activity requiring an amount of time and effort comparable to the research option.

- When conducting human subjects research at a non-Purdue college/university, investigators are urged to contact that institution’s IRB to determine requirements for conducting research at that institution.
- When human subjects research will be conducted in schools or places of business, investigators must obtain written permission from an appropriate authority within the organization. If the written permission was not submitted with the study application at the time of IRB review (e.g., the school would not issue the letter without proof of IRB approval, etc.), the investigator must submit the written permission to the IRB prior to engaging in the research activities (e.g., recruitment, study procedures, etc.). This is an institutional requirement.

Category 1
- When human subjects research will be conducted in schools or places of business, investigators must obtain written permission from an appropriate authority within the organization. If the written permission was not submitted with the study application at the time of IRB review (e.g., the school would not issue the letter without proof of IRB approval, etc.), the investigator must submit the written permission to the IRB prior to engaging in the research activities (e.g., recruitment, study procedures, etc.). This is an institutional requirement.

Categories 2 and 3
- Surveys and questionnaires should indicate
  - only participants 18 years of age and over are eligible to participate in the research; and
  - that participation is voluntary; and
  - that any questions may be skipped; and
  - include the investigator’s name and contact information.
- Investigators should explain to participants the amount of time required to participate. Additionally, they should explain to participants how confidentiality will be maintained or if it will not be maintained.
- When conducting focus group research, investigators cannot guarantee that all participants in the focus group will maintain the confidentiality of other group participants. The investigator should make participants aware of this potential for breach of confidentiality.
- When human subjects research will be conducted in schools or places of business, investigators must obtain written permission from an appropriate authority within the organization. If the written permission was not submitted with the study application at the time of IRB review (e.g., the school would not issue the letter without proof of IRB approval, etc.), the investigator must submit the written permission to the IRB prior to engaging in the research activities (e.g., recruitment, study procedures, etc.). This is an institutional requirement.

Category 6
- Surveys and data collection instruments should note that participation is voluntary.
- Surveys and data collection instruments should note that participants may skip any questions.
- When taste testing foods which are highly allergenic (e.g., peanuts, milk, etc.) investigators should disclose the possibility of a reaction to potential subjects.
Appendix F: CITI Human Research 2 Curriculum Completion Report

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)
HUMAN RESEARCH 2 CURRICULUM COMPLETION REPORT

Information withheld for privacy.

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid independent learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator
COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)
HUMAN RESEARCH 2 CURRICULUM COMPLETION REPORT
Printed on 12/02/2013

Information withheld for privacy.

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid independent learner. Published information and unauthorized use of the CITI Program course site is unethical and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator
Appendix G: Principal Letter

Information withheld for privacy.
Appendix G
Researcher’s Resume

Information withheld for privacy.
### Table 1 Responses for Questions #1-#3 in Parent Survey (Diagnosis, age and IEP)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Diagnosis</th>
<th>Age of Child in Years</th>
<th>IEP Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Autism, Mildly Mentally Handicapped, Communication Disorder</td>
<td>12</td>
<td>Yes</td>
</tr>
<tr>
<td>#2</td>
<td>Mitochondrial Myopathy</td>
<td>5</td>
<td>Yes</td>
</tr>
<tr>
<td>#3</td>
<td>Down Syndrome</td>
<td>5</td>
<td>Yes</td>
</tr>
<tr>
<td>#4</td>
<td>Autistic</td>
<td>7</td>
<td>Yes</td>
</tr>
<tr>
<td>#5</td>
<td>Autism, MMH, ADHD, Communication Disorder</td>
<td>12</td>
<td>Yes</td>
</tr>
<tr>
<td>#6</td>
<td>Cerebral Palsy</td>
<td>24</td>
<td>No</td>
</tr>
<tr>
<td>#7</td>
<td>ADHD</td>
<td>6</td>
<td>No</td>
</tr>
<tr>
<td>#8</td>
<td>Mild Cognitive</td>
<td>15</td>
<td>Yes</td>
</tr>
<tr>
<td>#9</td>
<td>Vision Impairment</td>
<td>7</td>
<td>Yes</td>
</tr>
<tr>
<td>#10</td>
<td>Multiple Disabilities</td>
<td>3</td>
<td>Yes</td>
</tr>
<tr>
<td>#11</td>
<td>Autism</td>
<td>9</td>
<td>Yes</td>
</tr>
<tr>
<td>#12</td>
<td>Development Delay</td>
<td>11</td>
<td>Yes</td>
</tr>
<tr>
<td>#13</td>
<td>FAS, ADHD, Distymia</td>
<td>11</td>
<td>No</td>
</tr>
<tr>
<td>#14</td>
<td>Down Syndrome</td>
<td>17</td>
<td>Yes</td>
</tr>
<tr>
<td>#15</td>
<td>Speech and Language impaired, Hard of Hearing, OHI</td>
<td>4</td>
<td>Yes</td>
</tr>
<tr>
<td>#16</td>
<td>OHI, ADD, LD in Writing</td>
<td>13</td>
<td>Yes</td>
</tr>
<tr>
<td>#17</td>
<td>Hearing Impaired</td>
<td>14</td>
<td>Yes</td>
</tr>
<tr>
<td>#18</td>
<td>Down Syndrome</td>
<td>23</td>
<td>No</td>
</tr>
<tr>
<td>#19</td>
<td>Autism, Speech Impairment</td>
<td>9</td>
<td>Yes</td>
</tr>
<tr>
<td>Participant #</td>
<td>Parent Response</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>-----------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#1</td>
<td>I know I am an essential partner in my child’s education team.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#2</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#3</td>
<td>As a parent your role is very important! Each parent needs to be aware of goals and outcome of the IEP.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#4</td>
<td>My role in my child’s education decision making is to keep fighting for what she needs in order to learn in a safe environment, even if the schools don’t always like it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#5</td>
<td>I am an equal and valuable part of the decision making process. No major decisions regarding my child’s education should be made without my prior consent or knowledge.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#6</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#7</td>
<td>He makes his own decisions, if he is able.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#8</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#9</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#10</td>
<td>Very knowledgeable, I was an OT before my son was born.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#11</td>
<td>I am part of all the IEP meetings. Our input is typically listened to, sometimes not.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#12</td>
<td>Attend case conference with educational team yearly, add input to direct teacher as needed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#13</td>
<td>She is unable to understand multiple instruction in a large classroom setting so she is currently being homeschooled.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#14</td>
<td>A lot. Teachers are constantly asking me what I do for his behavior problems, but tell me little about what goes on in the classroom with him.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#15</td>
<td>I usually felt like we were on the same page with the team in terms of eligibility.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#16</td>
<td>I have the right to be involved in all decisions made about my child’s education. The school must communicate with me yearly about educational goals and how they are meeting them.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#17</td>
<td>I make all school decisions for my child.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#18</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#19</td>
<td>I know that I have a substantial part in my son’s education.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 3 Responses to Parent Survey Question #5 (Where have you sought support)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Support from Family</th>
<th>Support from Friends</th>
<th>Support from Other Families</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parent Response</td>
<td>Parent Response</td>
<td>Parent Response</td>
</tr>
<tr>
<td>#1</td>
<td>5</td>
<td>#1</td>
<td>4</td>
</tr>
<tr>
<td>#2</td>
<td>NA</td>
<td>#2</td>
<td>NA</td>
</tr>
<tr>
<td>#3</td>
<td>NA</td>
<td>#3</td>
<td>NA</td>
</tr>
<tr>
<td>#4</td>
<td>1</td>
<td>#4</td>
<td>5</td>
</tr>
<tr>
<td>#5</td>
<td>1</td>
<td>#5</td>
<td>6</td>
</tr>
<tr>
<td>#6</td>
<td>NA</td>
<td>#6</td>
<td>NA</td>
</tr>
<tr>
<td>#7</td>
<td>1</td>
<td>#7</td>
<td>NA</td>
</tr>
<tr>
<td>#8</td>
<td>6</td>
<td>#8</td>
<td>3</td>
</tr>
<tr>
<td>#9</td>
<td>NA</td>
<td>#9</td>
<td>NA</td>
</tr>
<tr>
<td>#10</td>
<td>1</td>
<td>#10</td>
<td>NA</td>
</tr>
<tr>
<td>#11</td>
<td>6</td>
<td>#11</td>
<td>5</td>
</tr>
<tr>
<td>#12</td>
<td>NA</td>
<td>#12</td>
<td>4</td>
</tr>
<tr>
<td>#13</td>
<td>3</td>
<td>#13</td>
<td>5</td>
</tr>
<tr>
<td>#14</td>
<td>6</td>
<td>#14</td>
<td>NA</td>
</tr>
<tr>
<td>#15</td>
<td>NA</td>
<td>#15</td>
<td>NA</td>
</tr>
<tr>
<td>#16</td>
<td>4</td>
<td>#16</td>
<td>3</td>
</tr>
<tr>
<td>#17</td>
<td>3</td>
<td>#17</td>
<td>1</td>
</tr>
<tr>
<td>#18</td>
<td>1</td>
<td>#18</td>
<td>NA</td>
</tr>
<tr>
<td>#19</td>
<td>4</td>
<td>#19</td>
<td>5</td>
</tr>
<tr>
<td>Participant</td>
<td>Parent Response</td>
<td>Participant</td>
<td>Parent Response</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------</td>
<td>-------------</td>
<td>----------------</td>
</tr>
<tr>
<td>#1</td>
<td>3</td>
<td>#1</td>
<td>3</td>
</tr>
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<td>#2</td>
<td>NA</td>
<td>#2</td>
<td>NA</td>
</tr>
<tr>
<td>#3</td>
<td>NA</td>
<td>#3</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#4</td>
<td>2</td>
<td>#4</td>
<td>6</td>
</tr>
<tr>
<td>#5</td>
<td>3</td>
<td>#5</td>
<td>4</td>
</tr>
<tr>
<td>#6</td>
<td>NA</td>
<td>#6</td>
<td>NA</td>
</tr>
<tr>
<td>#7</td>
<td>NA</td>
<td>#7</td>
<td>NA</td>
</tr>
<tr>
<td>#8</td>
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</tr>
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<td>#9</td>
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</tr>
<tr>
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<td>2</td>
<td>#10</td>
<td>3</td>
</tr>
<tr>
<td>#11</td>
<td>1</td>
<td>#11</td>
<td>4</td>
</tr>
<tr>
<td>#12</td>
<td>NA</td>
<td>#12</td>
<td>6</td>
</tr>
<tr>
<td>#13</td>
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</tr>
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</tr>
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<td>#16</td>
<td>2</td>
<td>#16</td>
<td>1</td>
</tr>
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<td>#17</td>
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<td>#17</td>
<td>6</td>
</tr>
<tr>
<td>#18</td>
<td>3</td>
<td>#18</td>
<td>2</td>
</tr>
<tr>
<td>#19</td>
<td>2</td>
<td>#19</td>
<td>1</td>
</tr>
</tbody>
</table>
### Table 5 Responses of Parent Survey Question #7 (Where have you reached out to your community)

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Parent Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>I was a part of a parent support group for many years. [S]</td>
</tr>
<tr>
<td>#2</td>
<td>NA</td>
</tr>
<tr>
<td>#3</td>
<td>NA</td>
</tr>
<tr>
<td>#4</td>
<td>My child does not socialize with “normal” children, but one of her therapies has a weekly socialization group that is a wonderful outlet for her. Not only does she get to socialize with her peers, but she also gets the benefit of therapy as well. [SP]</td>
</tr>
<tr>
<td>#5</td>
<td>I really don’t anymore.</td>
</tr>
<tr>
<td>#6</td>
<td>NA</td>
</tr>
<tr>
<td>#7</td>
<td>NA</td>
</tr>
<tr>
<td>#8</td>
<td>NA</td>
</tr>
<tr>
<td>#9</td>
<td>NA</td>
</tr>
<tr>
<td>#10</td>
<td>NA</td>
</tr>
<tr>
<td>#11</td>
<td>We take our son to OT, social skills classes, and we see a behavior therapist. [P]</td>
</tr>
<tr>
<td>#12</td>
<td>Involve myself in fundraising for special needs nonprofits. [S]</td>
</tr>
<tr>
<td>#13</td>
<td>Therapeutic horseback riding, piano lessons, church activities, 4-H programs [P]</td>
</tr>
<tr>
<td>#14</td>
<td>I reached out in MI but to no avail. Here I was so deflated I only tried through churches and none had services but were willing to accept him as long as I accompanied him. MI was horrible. Anchor Bay area. [S]</td>
</tr>
<tr>
<td>#15</td>
<td>It’s really difficult when they’re young. I spent more than two years sheltering him, afraid of illness. It was necessary at the given time, but now I have a late start. I really haven’t found resources for a “kid like him” but as he gets older it has gotten easier. [P]</td>
</tr>
<tr>
<td>#16</td>
<td>I work with the school and my child to help support my child. [P]</td>
</tr>
<tr>
<td>#17</td>
<td>I like to ensure that my child is not treated differently. [S]</td>
</tr>
<tr>
<td>#18</td>
<td>NA</td>
</tr>
<tr>
<td>#19</td>
<td>I talk with a few parents, his aide, his teacher, therapists, and the principal. [SP]</td>
</tr>
<tr>
<td>Participant #</td>
<td>Parent Response</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>#1</td>
<td>Do not stop until you get the answers you seek. Trust your instincts.</td>
</tr>
<tr>
<td>#2</td>
<td>NA</td>
</tr>
<tr>
<td>#3</td>
<td>NA</td>
</tr>
<tr>
<td>#4</td>
<td>Take your time, what you know works for your child, Do get them in therapy, but don’t expect it to fix everything. Nothing is a cure all, but to expect for you both to learn ways to cope with the life you’re given.</td>
</tr>
<tr>
<td>#5</td>
<td>Educate yourself. Search out your state’s or county’s resources and read the materials they give you. Don’t be afraid to ask questions or to get clarification. Don’t be afraid to advocate for your child. Unfortunately, you aren’t there to make friends with the people who provide services for your child. Particularly in education, get involved and keep track.</td>
</tr>
<tr>
<td>#6</td>
<td>NA</td>
</tr>
<tr>
<td>#7</td>
<td>NA</td>
</tr>
<tr>
<td>#8</td>
<td>NA</td>
</tr>
<tr>
<td>#9</td>
<td>NA</td>
</tr>
<tr>
<td>#10</td>
<td>NA</td>
</tr>
<tr>
<td>#11</td>
<td>Call an organization like ASK or Easter Seals or ASI.</td>
</tr>
<tr>
<td>#12</td>
<td>Get involved early in treatment options and activities that include special needs kids.</td>
</tr>
<tr>
<td>#13</td>
<td>Research what activities are most help for your child’s needs</td>
</tr>
<tr>
<td>#14</td>
<td>Be nice but be persistent and call their lack of help for you, they give to poor families, but reject helping moms with five kids and one with Down Syndrome.</td>
</tr>
<tr>
<td>#15</td>
<td>That’s there’s a lot of creativity online. And support! Facebook has been a wonderful tool to find families with similar issues. Even things with pediastaff on Pinterest is a good place to look for ideas for at home work on goals. For instance, I searched something like “activities crossing midline” and found a few great activities. It’s tough living in a smaller town where there aren’t many resources but you can get creative online!</td>
</tr>
<tr>
<td>#16</td>
<td>Keep asking until you get the support you need. Learn the needs of your child and become the advocate for your child.</td>
</tr>
<tr>
<td>#17</td>
<td>Definitely a good school with an HI class like my sons.</td>
</tr>
<tr>
<td>#18</td>
<td>NA</td>
</tr>
<tr>
<td>#19</td>
<td>Ask and seek help in every area or concern.</td>
</tr>
<tr>
<td>Participant #</td>
<td>Parent Response</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>#1</td>
<td>What will his future look like? [E,DT]</td>
</tr>
<tr>
<td>#2</td>
<td>NA</td>
</tr>
<tr>
<td>#3</td>
<td>NA</td>
</tr>
<tr>
<td>#4</td>
<td>Will these behaviors always be so severe? Which therapies are recommended? [DT]</td>
</tr>
<tr>
<td></td>
<td>What are the chances my other children having this as well? [DT]</td>
</tr>
<tr>
<td>#5</td>
<td>If we are doing everything in our power to help this child, why does the gap between him and his peers keep widening? [E]</td>
</tr>
<tr>
<td>#6</td>
<td>NA</td>
</tr>
<tr>
<td>#7</td>
<td>NA</td>
</tr>
<tr>
<td>#8</td>
<td>NA</td>
</tr>
<tr>
<td>#9</td>
<td>NA</td>
</tr>
<tr>
<td>#10</td>
<td>NA</td>
</tr>
<tr>
<td>#11</td>
<td>There don’t seem to be answers to my questions about autism.</td>
</tr>
<tr>
<td>#12</td>
<td>Mainstreaming at school, available therapy options [E]</td>
</tr>
<tr>
<td>#13</td>
<td>What are the long term projections? What can we do to help her reach her greatest potential? That may be great for most children, what is best for her? [E,DT]</td>
</tr>
<tr>
<td>#14</td>
<td>NA</td>
</tr>
<tr>
<td>#15</td>
<td>NA</td>
</tr>
<tr>
<td>#16</td>
<td>NA</td>
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<td>NA</td>
</tr>
<tr>
<td>#19</td>
<td>NA</td>
</tr>
</tbody>
</table>