HELPING PARENTS COPE WITH CHILD DISABILITIES

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HELPING PARENTS COPE WITH CHILD DISABILITIES

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CHAPTER 1

INTRODUCTION

The increasing diagnosis of children with disabilities has a direct impact on families and teachers. Therefore, parents and teachers are adapting their life schedules to meet the needs of these children. Though teachers are learning new strategies in their continuing education, as to how to handle situations with all types of children, lots of parents are not developing these skills at the same pace. Many parents do not know what the most effective techniques are for helping or coping with their child’s newly discovered disability.

As parents face new challenges, they may be experiencing a variety of emotions. The shock of hearing their child is not “normal” is more then some can handle. When raising a child with exceptional need, parents are faced with a new type of lifestyle. For example, many parents struggle to find or keep their daycare providers. Some parents wrestle with being able to pay the bills, find adequate health care and keep their full time employment. Other parents worry about how to answer the questions that their children, friends and family may have.

In the past, children with exceptional needs were overlooked or pushed to the side and placed in different classrooms. Today every child is incorporated into the classroom and into everyday living. There is new research done everyday to help provide answers to questions about
disabilities, along with new strategies and techniques as to how to cope and work with children that have exceptional needs. This research is only a beginning to new findings that are sure to come.

Statement of the Problem

The problem to be addressed is “What are the most effective techniques that can be used when helping parents whose child has been diagnosed with a disability?”

Delimitations of the Research

The research will be conducted in and through the Karrmann Library at the University of Wisconsin-Platteville. Primary searches will be conducted via the Internet through EBSCO host with ERIC and Academic Search Elite as the primary sources. Key search topics included “help parents cope with child disability,” “parents with special education,” “disabilities at home,” and “effective techniques work with disabilities.”

Method of Approach

A review of literature on effective parent approaches, along with the examples of what parents of children with disabilities experience in everyday living, and a review of effective and ineffective approaches teachers use to help parents successfully parent children with disabilities will be conducted.
A second review of literature relating to research, studies, and evidence of effective coping techniques will also be held. The findings from this research will be summarized and recommendations made in this paper.
CHAPTER 2
REVIEW OF RELATED LITERATURE

Parents’ Reaction to Child Disability

“Mrs. Harrison sat at her daughter Ivy's annual individualized education plan (IEP) meeting and struggled to focus on the speech therapist while he discussed his report. Did he say that Ivy needed to work on social pragmatic skills? Mrs. Harrison did not realize that Ivy was having social problems. She seemed fine at home. While Mrs. Harrison pondered this new and worrisome information, she realized that Mrs. Jennings, Ivy's teacher, was asking her a question: Did she realize that Ivy had not been handing in her reading homework? Mrs. Harrison felt a sinking feeling. She had been so busy shuttling her sons back and forth to soccer practice that she had not been as vigilant as she should have been about Ivy's homework. Ivy needed so much help with her homework—she was so far behind the other third graders. Wasn't Ivy supposed to do her homework independently? Maybe she could ask Ivy's teacher to modify the homework. Wasn't that the teacher's responsibility? Could she ask for that? But by now, Mrs. Jennings was finished and the principal was speaking. They had to move along—their schedule included another meeting in 20 minutes. Mrs. Harrison felt a mixture of anger and frustration. Didn't anyone want to hear what she had to say (Whitbread, Bruder, Fleming, & Park, 2007, p. 6)?”

This is only one example of what a parent of a child with exceptional needs may go through every year. Researchers affirm, when parents first find out that their child has a disability; they go through a feeling of loss. Such as, “the loss of the child they expected to have, the loss of their dreams for their child’s future, the loss of their child’s quality of life, the loss of their way of life.” These losses change the parents’ way of thinking and they create adjustments in the parents and families lifestyles. This in result causes stress and pressure on family relationships. After the initial feeling of loss occurs, parents begin to go through the stages of grief. They feel shock, disbelief, anger, blame, guilt, sadness, and they start to question why it
happened to them and their child. Then they begin to panic and fear that they will not be able to handle their child’s situation or the questions their family and friends will have (Children with a disability. 2006).

Studies show that after parents begin to cope with their child’s disability, they still find parenting to be even more difficult, time consuming, and emotionally draining. These parents are faced with challenges first hand and learn quickly that doctor appointments, researching treatments, and meetings become the focus of their daily life. This type of parenting begins to affect their own emotional well-being. Some parents find themselves overwhelmed with the desire to find every solution that they can to help improve their child’s quality of life. Though their feeling of loss decrease overtime, parents still continue to have feelings of resentment, anger, sadness, and guilt as they navigate through the confusion of their child’s appointments and meetings and watch their friends plan simple outings with their children (Supporting the supporter. 2008).

Beyond the new feelings that parents have to deal with, they also begin to struggle with finding adequate resources and support for their child. Many parents have reported obstacles in finding and maintaining employment that is flexible and willing to work around their child’s meetings and appointments. When a child has emotional or behavioral disorders, it becomes difficult to locate trained childcare providers that can handle situations that may arise. Because finding sufficient childcare is difficult, many time parents enroll their child in daycare center where, when an issue
arises, the center then calls a parent at work and ask the parent to come and handle the situation that is occurring. Many times, once an incident like this has happened on more than one occasion the childcare providers asks the parents and child to leave their program. A study done by Portland State University states, “when compared to parents caring for children developing typically, studies of parents caring for children with developmental disabilities indicates that they are less likely to remain in paid employment and more likely to work part-time, to earn less money, and to reduce work hours (p. 79).” This is partly because once being asked to leave the childcare program, the parent now must take time off from work to either take care of their child or spend time looking for a new childcare provider. Furthermore, if parents do find adequate childcare with trained employees it often times creates larger expenses on the family’s bills, in result causing more stress on the family’s finances. Therefore, in some cases parents feel forced into quitting their job and staying home with their child until they enter school (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008).

Parent Coping Strategies

While parents work through the challenges they have with their child and the disability, they have to continue to work through their own issues of coping with the stress and the new unknown life they will have. In order for parents to relieve some stress in their life, they have to make sure they are continuing to devote time to others things in their life as well. Parents need
to make sure that they are sharing their feelings with one another or with someone who will listen and continue to listen as time goes on. They also need to make sure they are sharing daily tasks and that they are not trying to take on everything all on their own (Children with a disability, 2006). Most importantly, parents need to make sure they are taking personal time for themselves where they can continue to do things that they enjoy and love. If parents get caught in a world where they never take themselves into consideration, they will continue to feel overwhelmed and stress. For this reason, they should create a designated time to relax and relieve stress. A more relaxed person will in result create a more focused parent that in turn will benefit the child’s needs more (How to cope with having a special education child, 2008).

Parents should also reach out to others who understand what they are going through. First they should take into consideration the advice their doctors have provided them with. This may include resources around their living area that could provide them with assistance such as support groups (Pain, 1999). A study completed in Finland found, parents feel that information and acceptance, good family co-operation and social supports are some of the most productive elements for coping. All of they elements can be found in support groups. By joining a supportive group, parents become more familiar with the idea that they are not the only people going through this type of situation. Families start to find a sense of belonging knowing they are not alone (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). Support groups
also help families stay together. They do this by showing families how to work together as one unit to make a new “normal family.” Beyond this, in support groups parents begin to make new friends, they find new resources with new coping mechanism and strategies. They also become more familiar with advocacies around their area. It is by surrounding themselves with different resources and stress relievers, that parents are then best able to cope (Ohio Legal Rights Service, 2005).

Parents Helping Child

An article publicize by the Council for Exceptional Children emphasizes, when parents begin working with a child’s disability there are some things that they need to do to be best prepared themselves and their child. First, parents should become very familiar with the disability. They need to understand what the disability is and how it affects their child’s life (Council for Exceptional Children, 2008). Parents should make sure they understand the laws that cover their child’s disability and the rights they are their child have. Along with this, parents should become knowledgeable of the local services which are available and may be provided by the state (National Discrimination Center for Children with Disabilities, 2008). By knowing these things, parents are more capable of communicating with teachers, doctors, and their child. Next, parents need to keep in contact with their child’s teacher. The more they work together the more they can monitor the student’s behavior and in result create an instructional and behavioral
program that can be put into use both at school and at home (Council for Exceptional Children, 2008). Parents should also keep a journal of what their child does well. In doing this, they are keeping a positive outlook and they are able to keep track of what strategies helped their child succeed. Beyond this, the journal also makes for a great resource to look back on when the child feels like everything he or she does is unsuccessful.

Parents should also help their child become and stay organized. In most cases, children with exceptional needs struggle with organizational skills. Parents should make sure that they do not just buy their child organizational resources but that they show their child how to use them correctly. Another thing parents can do is help their child get involved in some form of an extra-curricular activity. This helps their child make new friends and it also gives the child something to work towards and excel at that is not always academic focused. Besides extra-curricular, getting a child involved with helping someone else is also a great thing parents can do. By helping another person, children with exceptional needs feel like they are being successful in something. It also makes them feel like they are not always the person who needs extra help.

Parents also need to make sure that they sit down with their child and make high but realistic expectations and goals. If the expectations and goals are set to low, the child begins to feel as if he or she is not capable of more or that he or she does not need to do anything more. However, when expectations and goals are constantly made too high, the child begins to feel
like a failure because he or she is consistently falling short of what is expected. When the child begins reaching for the goals and expectations, parents need to make sure they are teaching their child how to recognize when something is too difficult and they need help. Parents also need to teach their child how to then ask for help and not be ashamed that they asked for assistance (Council for Exceptional Children, 2008).

Moreover, parents should also include their child in the family decision making processes. By doing this, the child feels empowered and as if he or she has some say in what goes on in life. Parents can and should practice decision making with their child, for example, together the family could plan a trip away. Through this process, the child begins to feel a closer connection with his or her parents and with the family as a whole (Children with a disability. 2006). Going along with that, parents need to make sure that their child feels emotionally supported. Parents should praise their child on a regular basis for good actions or attempts at what they are doing. One great way parents can show emotional support is by spending quality time with their child and making sure that their child understands how important that time is to the parents (Cutter, Jaffe-Gill, & Benedictis, 2008).

Furthermore, parents also need to make sure they look into developing a financial plan for their child so that medical bills and living arrangements can be covered throughout their child’s life (Sullivan, 2007).
Teachers Helping Parents

Researchers have found that parents who have a better sense of well-being and a higher level of self-acceptance with their child’s disability are able to cope better and help their child more. Consequently, teachers need to help parents arrive at that place so that the parents can help their child more and in result, help the teacher more (Seltzer, Greenberg, Floyd, & Hong, 2004). This may be difficult but just as teachers know it is imprudent to generalize students as if they are all the alike; the same goes for generalizing parents. As much as the different types of special needs conditions vary, so do the parents of children with exceptional needs. All parents differ in the way that they approach situations and their concerns, along what they value and how they live socially and economically. Therefore, when teachers understanding what parents concerns are and where parents are coming from, teachers become more effective in working with those parents. In result, teachers are able to help parents get to a better place of coping and working with their child (Pretti-Frontczak, Giallourakis, & Janas, 2002).

When helping parents, there are some things teachers should never say. These things include phrases such as “let's wait and talk about that some other time, we cannot hire another person just for your child, we've spent too much time on this already, let's move on, and we don't think that is appropriate, but if you want it, we'll put it in the IEP.” All of these phrase make parents feel as if their child is unimportant and unworthy of the
teacher’s attention. This also undermines the parents and makes them feel as if what they think or have to say is just nonsense (Croyle, 2007, p. 26).

Instead, teachers should engage in regular communication with parents throughout the year and they should make sure that the communication is at the parents comfort level. Teachers should not use words that the parents are unable to understand. Things teachers should say things to parents such as, “what strategies have you found to work best with your child, are there things that you know about your child’s disability that you feel I should know, what resources do you feel help you the best, do you need assistance with your child’s disability, do you have any questions?” These phases show support and understanding that the child is important and so is what the parent has to say. Teachers should also encourage parent to ask questions and to express their feelings. Beyond this, teachers should know the resources and services available for assisting the child and or his or her parents so when parents ask questions that information can be provided in a timely matter.

In addition, teachers need to reinforce how important it is that parents take part in their child’s learning process. Teachers need to admit when they do not know the answer to a question that parents may have but that they will seek the answer out. This shows parents that it is okay not to always know the answer but that the teacher cares enough to find out. Most of all, teachers need to make sure they are responsive to parents. They need to make sure that they make the parents feel a sense of comfort when coming to them for
assistance. By doing this, parents will begin to work with the teacher more. 
This in result will create true team working for the best interest of the child 
(Healy, 2008).
CHAPTER 3

CONCLUSIONS AND RECOMMENDATIONS

Through a review of the literature, it becomes evident there are many struggles that parents who have children with exceptional needs must face. This research only skims the surface of what is a deep and complex pool of struggles that parents experience. Although, the research does show that regardless of how many different types of disabilities there are parents seem to identify with them all in a similar fashion. Parents go through a sense of loss and grief as if there was a death. Then as parents begin to cope, the sense of loss becomes less but of course it is brought out again in the feeling of being overwhelmed and frustrated when they struggle with everyday things like working with daycare providers, doctors, teachers and meetings.

The result of being frustrated and overwhelmed is why researchers say parents need to have time alone, routines and supporters. This is why support groups play such a large role in helping parents feel a sense of belonging. The support groups help parents pick up the pieces and keep moving on. They also provide advocacies for the parents so that they can get the help and understanding that they need about their child’s disability, in result, helping them cope with the disability for themselves.

It is with this understanding that parents are able to better provide for their child’s needs. Also, once parents are able to cope, they are then able to assist their child with things such as, getting involved, helping others,
reflecting positively and helping their child understand his or her own needs and how to get help for those needs.

As revealed in the story example at the beginning of this paper, teachers play a large role in this process and they need to be very responsive in helping parents. It is the teachers’ responsibility to make sure they do not offend parents but that they help them along the way by being a productive resource.

The increasing diagnosis of children with disabilities obviously has a direct impact on families and teachers. Therefore, the strategies found in this research paper are resourceful yet they are only the beginning of countless numbers of strategies that parents find useful in the everyday coping process.

As a professional, I understand that when I sit down with a parent in a conference I need to be supporting and comforting to them. I must show them that I am sincere about their child and what I am saying. I have to always keep reflecting on what they are feeling or what they may be going through. Hearing your child has a learning disability is a traumatizing experience. It isn’t one that can be scheduled in to a twenty minute meeting between classes. The meeting must allow parents time to think, reflect, and ask questions. Also, as a professional, if I have a student coming into my classroom with exceptional needs, I must remember to take what the parents have to say into consideration. After all, the parents work with their child everyday and they know what strategies work and do not work. Also, they may have a pattern down that works for the student at home that I could implement into my own
classroom. Finally, I need to make sure that I work hand and hand with the parents so we can become a great advocacy for the student. If we are working together, the student will recognize a similar pattern at home, as at school and this will help the student stay structured and focused. In result, the student will feel a sense of comfort in knowing what the expectations are and that he or she has lots of support through the process.
REFERENCES


