

## LITERATURE REVIEW

### Families with Special Needs Children and Stress: Research Review

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#### **Abstract**

*This research review provides a synthesis of articles that analyse the impact of the educational system on families with special needs children and the potential ways that these families can be empowered and equipped. The articles selected focus on research participants and schools found in North America and Great Britain, in order to give the research consumer a corresponding picture of the impact of stress on Canadian families with special needs children. The assessment of the research articles illustrates that the educational system does create high levels of stress for families with special needs children. However, teachers can use empathy, compassion, and mutual understanding to help empower families with special needs children. There are also practical tools, such as instructing parents in teaching skills to assist their children, which can be used to equip these families and help them to reduce their stress levels exacerbated by the educational system. Further study should be done to look at changing teacher attitudes toward special needs students, and at learning more about how the stress of a special needs child specifically affects fathers and other male caregivers, non-special needs siblings, and non-middle class families.*

#### **Background and Research Process**

The Office of the Auditor General – Manitoba (2012) reported that between the 2000-2001 and 2009-2010 school years, special needs enrolment in Manitoba increased by 86%, going up from 3,850 students to 7,156 students (p. 249). Special needs students are growing in numbers in Manitoba schools, and various organizations and individuals are attempting to discover the most effective ways to address the educational needs of these students (VanWalleghem & Lutfiyya, 2013). However, schools must also not forget the family as a whole unit and the potential influences that a special needs child can have on parents and siblings. Schools need to identify and acknowledge that stress caused by special needs children's educational needs and experiences affects the entire family unit. As well, educators need to figure out the best ways to support these parents and their children in order to minimize the effects of stress, empower the family unit, and equip them to succeed in the educational system and in their overall daily lives.

All parents have desires and aspirations for their youngsters' lives, but parents with special needs children have a harder time meeting these goals (Hanvey, 2002; Janus, Kopechanski, Cameron, & Hughes, 2007; Morinaka, 2012; Reio & Fornes, 2011). Parents take on many responsibilities with raising a special needs child, such as caring for the child's physical requirements because of disability, helping the special needs child to create and maintain relationships, and creating a place in the community for the special needs child to belong (Hanvey, 2002). Special needs families often experience higher levels of stress than non-disabled families (Gottfried & McGene, 2013). These higher stress levels are created by various factors that influence a special needs family. Special needs families are often in a lower income bracket due to the need for one parent to become the primary caregiver of the special needs child (Hanvey, 2002; Moriwaka, 2012). When that aspect is compounded with the high financial necessities for a special needs child, the situation can create even greater stress for the family

unit (Hanvey, 2002). Families with special needs children also experience higher levels of breakdown in the family unit, resulting in divorce and single parenting (Daire, Dominguez, Carlson & Case-Pease, 2014; Hanvey, 2014). These various factors intensify anxiety levels, creating a situation in which high numbers of parents with special needs children report being discouraged, stressed out, and exhausted (Gottfried & McGene, 2013; Hanvey, 2002; Reio & Fornes, 2011). This has a spill-over effect on the family as a whole unit and influences the health and well-being of all family members (Gottfried & McGene, 2013; Hanvey, 2002; Orfus & Howe, 2008; Van Haren & Fiedler, 2008). The health of the family depends on the well-being of the entire household unit (Orfus & Howe, 2008).

For this paper, definitions have been established to create a cohesive understanding of the research topics studied. Special needs are defined as including all students who require specialized programming or services to benefit from elementary and secondary education (The Auditor General's Report on Special Needs Education, 2012; VanWalleghem & Lutfiyya, 2013). The term *special needs families* refers to families who have at least one special needs child as a part of the family unit. Stress is described as being related to the impact of a special needs child; the chronic, long lasting periods of time that stress is maintained; and how that stress affects other aspects of family life or family members in potentially negative ways (Beck & Hastings, 2004). Empowerment is explained as the result of helping families to gain control over the events in their lives, and imparting abilities to aid them in getting what they want and need to raise a special needs child (Van Haren & Fiedler, 2008). Parent education can be defined as "providing parents with specific knowledge and systematic activities with the goal of promoting the development and competence of their children" (Reio & Fornes, 2011, p. 55).

This paper acknowledges that all sources of stress for special needs families are important. Special needs families require support and skills to deal with these stressors. It is important to the special needs family unit that these areas of need are addressed and that assistance is given. However, as well, this paper seeks to create a better understanding of how the schooling process creates stress for special needs families. Once a better understanding is gained of how educational systems may create stress, that information can be used as a springboard to research ways that schools can empower special needs families, and what practical tools can be implemented to aid special needs families with their anxieties.

To provide an overview of this professional research, first an introductory paper was written to initiate the research process for this review. That paper identified an interest in supporting families with special needs children in the educational system (Ott, 2015). Using the ideas in the paper as a starting point, Internet searches were done to locate information that fit the topic, employing Brandon University's access to the ERIC database and Google Scholar. As research was refined, specific categories were created for investigation, which included examining the potential sources of stress for special needs families, and how schools could potentially help these parents. Searches were done by using key phrases such as "special needs families and stress," "parents of special needs children," "school impact on stress of special needs families," and "special needs children and the effects on siblings." Research was limited to articles found within the last 15 years, in an attempt to keep them as chronologically relevant as possible. Research was also limited to studies that occurred in North America and European countries (particularly Great Britain), since these countries have educational systems most common to Canada's. Analyses of the data collected at this point were done, and from this juncture the Internet search was widened to include "perceptions of special needs families," "empowering special needs families," and "supporting special needs families in education." Thirteen articles were found that best fit the parameters of the starting position paper. As well, information garnered from the class text, *Interpreting Education Research: An Introduction for Consumers of Research* (4th ed.) by Hittleman and Simon (2006), was used to create guidelines of what constituted reliable and valid research sources (e.g., pp. 123-133, 137-138). Article reviews were written on a weekly basis, and the chapters from the text were read and analysed so as to achieve a better understanding of the research elaborated in the articles. The articles were

assessed and reassessed in order to develop a better understanding of the research information and results. Articles were studied multiple times and then put in clusters based on their common themes. The categories created were intended to answer the questions set out at the beginning of the research process. Sections were reread and analysed to make sure that the research articles were in the correct categories. One article was moved from the category on equipping parents to the category on empowerment, since it fit in better with the latter theme. However, it could be potentially be moved back into the equipping category, because it did elaborate a few aspects related to this area as well. Two articles were found not to fit into any of the main categories being researched. However, these two articles were similar to each other and were incorporated into their own separate section on siblings, since the information was valuable.

Some limitations were discovered in the articles studied. Most of the research articles analysed relied on volunteer participants in their research studies; only three articles relied on random sampling engaged through the educational system (Gottfried & McGene, 2013; Moriwaka, 2012; Ollison-Ford & Vernon-Dotson, 2009). When educational professionals or parents were engaged in these research processes, most of the participants were middle-class females. Only two studies had a reasonable mixture of men and woman from various class backgrounds (Moriwaka, 2012; Ollison-Ford & Vernon-Dotson, 2009). The impact of stress and the access to tools that can equip families from lower classes should be analysed more in depth. More research needs to be done on the effects of stress on men, since males may handle stress differently than females, in order to discover whether there are better ways to empower and equip males in dealing with special needs children. Another area that needs more research is the impact that special needs children have on non-special needs siblings. This attention can give educators insight on the factors that create stress for non-special needs siblings. It was difficult to find research studies that occurred in Canada or that were based on the Canadian educational system (Janus et al., 2007; Orfus & Howe, 2008). Most studies that were used for this paper were conducted in the United States. Therefore, the results may not be as transferable as a review wherein more of the research studies had been done in Canada.

Even though the research articles studied did not address the above-mentioned issues, they contained vital information to aid educators in their understanding of the impact of stress on the special needs family unit. This research review analyses three important aspects of stress addressed in these articles. The first concept covered is that the schooling process itself creates high stress levels for special needs families. After an analysis of the stress caused by the educational process, this review examines the various ways that schools can empower special needs families as they navigate the educational system. The research articles are then analysed to discover practical ways that educators can help to reduce the stress of special needs families. Lastly, a separate section addresses the effects that special needs children have on their siblings.

### **How the Schooling Process Creates Stress for Special Needs Families**

With reference to the research articles that matched the theme of how the schooling process creates stress for special needs families, all were qualitative studies that relied on volunteer participants. The three studies accessed used interviews and observation techniques to collect data on their research subjects. Most of the special needs students in these studies were younger children, pre-school to early elementary grades, with only one study using some students in grade 11 in its results (Edelman, Giangreco, Luiselli & MacFarland, 1997). Janus et al. (2007) elaborated the solitary study to interview only parents and not educational professionals as well. The three studies researched different aspects of stress for special needs families that can occur in the educational system.

As noted in two of the studies, parents often do not see their special needs child as the source of their stress, but rather the school system, the lack of support within the educational setting, and educational professionals' biased perceptions of special needs families (Broomhead, 2013; Hanvey, 2002). Children with special needs are often less likely to do well in the educational system compared to non-disabled students and, in one Canadian study, only 19% of special needs students reported having their needs met in the educational system (Hanvey, 2002, p 18). The special needs child's success in education is most affected by the classroom teacher and his/her willingness to support the requirements of the special needs student (Giangreco et al., 1997; VanWalleghem & Lutfiyya, 2013). However, some classroom teachers may view themselves as having little responsibility for the special needs student's education and leave it in the hands of others, such as educational assistants and resource teachers (Giangreco et al., 1997). Teachers can also have negative opinions of special education families, which can affect home-school relationships (Broomhead, 2013). Parents have likewise stated that poor communication or no communication between the school and home can be very frustrating and causes their stress levels to increase (Janus et al., 2007). Positive steps taken by schools will help to relieve stress by empowering special needs families.

### **How Schools Can Empower Special Needs Families**

Three reviewed qualitative studies highlighted ways that schools, and specifically special educators, can help to empower families of special needs children. All three studies used parents of children from various age groups and had input from special needs teachers. None of the studies commented on interviewing or receiving input from classroom teachers. The data collected in these sections had to do with intangible aspects of human relationships that can be hard to measure, such as empathy, compassion, and mutual respect. Van Haren and Fiedler (2008) reported on a study that not only looked at the unquantifiable resources needed to support families with special needs children, but also suggested practical methods for special educators to help special needs families; therefore, this article straddles the last two categories of this research review.

All three articles dealt with the importance of giving empathy to families with a special needs child (Moriwaka, 2012; Turnbull & Turnbull, 2015; Van Haren & Fiedler, 2008). Educators who display empathy to a special needs family help to empower the family members. Educators may accomplish this goal when they focus on cooperative and healthy communication between home and school (Moriwaka, 2012; Turnbull & Turnbull, 2015; Van Haren & Fiedler, 2008). When educators recognize and acknowledge that every family's situation is unique, and that the family is the expert in knowing and understanding its special needs child, they are practising empathy and compassion (Turnbull & Turnbull, 2015; Van Haren & Fiedler, 2008). When empathy and compassion are used as the bedrock for home-school relationships, educators can move on to find practical methods to empower parents and help reduce stress levels involved in special needs children's school experiences. In fact, establishing relationships based on empathy, compassion, and mutual respect is the first step in alleviating stress for special needs families.

### **Practical Tools To Aid Special Needs Families with Stress**

The research studies done in this next category looked at various practical ways that schools can help families deal with the stress of raising a special needs child. The main theme in these studies was parent education, or giving parents the skills and knowledge that they need to promote and aid in the development of their special needs child (Reio Jr. & Fornes, 2011). This can be done by training parents with specific teaching methods to support their special needs child's education, or by setting up support groups and mentors to assist parents in knowledge and awareness of what steps they need to implement for lowering family stress

levels (Daire, Dominguez, Carlson, & Case-Pease, 2014; Hastings & Beck, 2004; Reio Jr. & Fornes, 2011). All studies were qualitative, except for the study reported by Daire et al. (2014), which used a quantitative approach. All studies had a large number of participants, but the study reported by Ollison-Ford and Vernon-Dotson (2009) had the most ethnically diverse group of participants in the investigation. Special needs children in these inquiries were stated to be young, with the oldest age group participating being children in grade 5 (Hancock & Kaiser, 2003; Ollison-Ford & Vernon-Dotson, 2009). All studies reported high levels of positive feedback from both parents and teachers. One study went beyond looking at parent feedback and examined the level of learning that children experienced from having parents teach them. This learning was immediately assessed and then reassessed six months later to find out whether parent teaching is a viable method for special needs children to learn new skills and information (Hancock & Kaiser, 2003).

The results of these studies show that when practical tools are used to aid families in the education of their special needs child, there are many positive consequences. Parents who were given tools to identify stressors, knowledge and support systems, and helpful educational skills felt empowered and had more positive views of their special needs child's educational journey (Daire et al., 2014; Hastings & Beck, 2004; Kaiser & Hancock, 2003). Parents reported being extremely satisfied with the tools given to them (Hastings & Beck, 2004; Ollison-Ford & Vernon-Dotson, 2009; Reio Jr. & Fornes, 2011). As schools and families implemented these practical tools, more open and positive channels of communication began between schools and homes (Ollison-Ford & Vernon-Dotson, 2009; Reio Jr. & Fornes, 2011). Schools reported that parent involvement in school activities increased as parents felt championed and encouraged by the practical tools implemented to aid them (Ollison-Ford & Vernon-Dotson, 2009; Reio & Fornes, 2011).

When educators provide opportunities for parents to learn practical skills for dealing with stress, they empower the family unit. Subsequently, when parents are given useful tools to teach their special needs children, it helps to decrease their stress levels. Likewise, it is important to examine the effects of special needs children on their non-special needs siblings. They, like their parents, need to be given the skills and tools to be empowered, because this will further strengthen the family unit.

### **Extra Research Studies Examined: The Effects of Special Needs Children on Siblings**

Two research papers were examined that focused on the effects of a special needs child on non-special needs siblings in the family. These studies might fit somewhat into the other categories, yet because of the focus on the impact on siblings, they require their own section to address them.

In the first research paper, Gottfried and McGene (2013) reported on a quantitative study that examined the academic and non-academic effects that special needs siblings may have on their non-special needs brothers and sisters. The researchers conducted a six-year study and used a sampling of students in elementary schools. The criterion for students studied was that they needed to have one sibling who lived in the same household as a diagnosed special need. Data were collected from various sources and analysed with three different methods in order to ensure that results were consistent. The researchers asked three questions in their study. First, the researchers inquired into what were the achievement and non-achievement consequences for children who had a sibling with a special need, and whether these outcomes were positive or negative or both. They discovered that in achievement-based areas, siblings of special needs children were academically stronger than students with no special needs siblings, thus showing a positive result. Second, the researchers studied the effects of special needs children on non-achievement areas by examining truancy, tardiness, and behaviour of non-special needs

siblings. They discovered that the presence of special needs siblings had almost no effect in these three areas for their non-special needs siblings. Third, the researchers questioned whether there were any effects of special needs children on their non-special needs siblings, and whether those effects were uniform overall or only domain specific. They discovered that across the board academically, students with a special needs sibling had higher academic achievement than children with no special needs siblings. There was little to no effect in non-achievement areas between both groups of students.

In the other research paper, Orfus and Howe (2008) reported on a qualitative study that examined coping skills that siblings of special needs students use to adapt to a special needs sibling. This qualitative study used interviews and two sets of questionnaires to assess sibling coping skills, with attention to various potential hassles and uplifts derived from living with a special needs sibling. The researchers' requirement for the participants in the study was that they have at least one sibling with special needs. The children who participated were upper elementary students whose special needs siblings averaged 10 years old. The study had only a small sampling of families, with only 12 participating; therefore, more research needs to be done to establish the validity of this study's findings. This report found that non-special needs siblings primarily employed two different skills, wishful thinking and problem solving, to cope with the daily hassles and uplifts that their special needs sibling created. Wishful thinking was used to control the emotional aspects of the stress, and problem solving was used to deal practically with difficulties that may come up from coping with a special needs sibling. Parents' positive attitudes and matter-of-factness about the potential stress of a special needs child helped non-special needs children to cope with stress in constructive ways.

The reader of research gains understanding of the impact of special needs children on their non-special needs siblings from the above articles. Educators must acknowledge the ways that special needs children impact the social abilities, academic careers, and coping mechanisms of non-special needs siblings. The ways that non-special needs children learn in order to cope with their special needs sibling have a ripple effect in their own academic lives. Educators must have empathy and compassion that extends to the non-special needs siblings and awareness that they can support these siblings in practical ways, as well.

The research articles studied provide educators with essential information to aid them in helping special needs families in the educational system. The articles help educators to identify the ways that the schooling process creates high levels of stress for special needs families. This understanding can be used as a springboard for focusing on empowering special needs families. Through learning from these articles, educators can gain practical tools to reduce stress for special needs families, thus creating a positive educational experience for the whole family unit.

### **Summary and Discussion**

This review of research articles has demonstrated that considerable amounts of stress can occur for families during a special needs child's school years. Often, these stressors are caused by various problems in the educational system, such as misuse of resources or poor communication between school and home. There are, however, many practical initiatives that educators can implement to help decrease family stress. The research articles reviewed also demonstrate that there are specific strategies, such as strong communication between home and school, that educators can use to empower parents and families to reduce family stress levels. These methods of empowering and equipping can create positive effects in special needs families, which then are refracted back into the school community and home-school relationships.

Researchers need to continue studying possible causes of stress for special needs families in the educational system, and various ways that educators can empower and equip parents to address the effects of stress. A disturbing trend in the origins of stress for special needs families

involves teacher attitudes and views toward special needs students. Further study can be done to discover the sources of these negative views and attitudes acquired by teachers, and to address them. Research is also needed to find approaches and instructional methods to change teachers' views of special needs families and to train educators in compassion and empathy for all. Also, schools may not be using current resources to the best of their ability to benefit special needs families. Research needs to be done to learn how schools can improve their use of human and material resources in order to benefit special needs families in the most positive way.

As already stated earlier in this paper, there are three important categories where more research is needed for understanding the impact of special needs children in their lives and stress levels. More research needs to go into how the stress of a special needs child affects male caregivers, and what ways males can be empowered and equipped to handle this stress. Similarly, more research needs to be done on the impact of special needs siblings on non-special needs siblings. Investigators should examine what empowering and equipping supports can be put in place to aid non-special needs siblings in their growth. Finally, the effects of a special needs child on non-middle class families' stress levels and daily lives need to be scrutinized at a deeper level.

In summary, it is important to acknowledge the role that the educational system plays in creating stress for families with a special needs child. Teachers need to be taught in their preservice training to identify potential stress factors for special needs families and to be given skills to reduce or eliminate these triggers in their classroom. For teachers already in the educational field, time and energy must be provided to foster understanding of special needs families' stresses, to develop empathy and compassion for these families, and to employ practical tools with these families and within their classrooms. As teachers begin to adjust and adapt for families with special needs children, their initiatives will create change at the micro level of the classroom. Administration and specialty teachers, such as resource teachers, as well as school division and provincial personnel, need to focus on creating change at a macro level. This focus would involve implementing change in the school system itself. The school system as a whole, with insightful policies and practices, must be willing to do what it can to help special needs families. The stronger and more empowered the family unit is, the more it will aid the special needs child in his/her development.

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