

Grandparents Raising Children with Disabilities

Author: Landeia Phillips

Faculty Mentor: Joyce Rademacher, Department of Education and Technology, College of Education, Texas Women's University

Department: Department of Communications, College of Arts and Sciences & Honors College

Bio:

Landeia Phillips majored in communications and minored in Spanish at UNT, graduating with a Bachelor of Arts as an Honors Scholar. She completed a study-abroad program at the Universidad Internacional in Cuernavaca Morelos, Mexico, while serving as an education intern for El Corazon Del Padre Orphanage. She was president of the National Residence Hall Honorary Association, receiving the Outstanding Service and Professionalism Award. She was a member of Lambda Pi Eta Communications Honors Society and North Texas Forty Student Foundation. In 2006, she served as the USA Public Relations spokesperson for the Universidad Internacional Communications Department and as a Guardianship Services Summer Intern for the ARC of Dallas Special Education Advocacy Organization. After a summer internship with Southern Methodist University's Project Transformation, Phillips will enter Brite Divinity School at Texas Christian University in the fall of 2007 with a full scholarship from the Elmer D. Henson Awards Program. She presented her research at University Scholars Day in 2005 and 2006, and at Great Plains Honors Council, Lubbock, Texas, April 7–9, 2006.

Abstract:

This study provides factual evidence and testimonials on personal, family, and school issues that grandparents experience as primary caregivers for grandchildren. The research study focused on six components: (1) school efforts to collaborate with grandparents, (2) quality of services, (3) comprehension of grandchild's disability, (4) impact of special education services on family life, (5) availability of support agencies and caregiver training programs, and (6) physical/mental health tendencies of grandparents. Knowledge of the problems grandparents experience is important because special education advocates may gain useful knowledge to expand the success of the partnership with grandparents raising children with disabilities. The ultimate goal of the project is to explore means to contribute knowledge and to increase visibility of the need for research on how educators and other professionals can better assist grandparents with their unique needs in parenting and educating children with disabilities.

Introduction

McCallion, Janicki, Grant-Griffin, and Kolmer (2000) found that 2.5 million children were living with their grandparents in 1980. In 1994, this number is estimated to have increased to 3.7 to 3.9 million. This number represents a 40% increase in only 14 years. Grandparents are a growing group of adults providing primary care for their grandchildren, many of whom have special needs. The average age of a grandparent serving as primary caregiver is 60 years old. Researchers found that 40% of these grandparents have additional responsibilities to care for other family members. Robinson and Brosh (1980) found that student-teacher and family relationships of children with severe mental and/or physical challenges are understudied.

A great need for outreach by educators and support groups exists in the minority community, where the highest percentages of primary caregivers are grandparents who have problems knowing how to care for their grandchildren with disabilities (McCallion, et al., 2000; Kuykendall, 2005). In some cases, the grandparents have a difficult time finding appropriate support for their unique circumstances. In other cases, grandparents feel it is their sole obligation to care for the child with no outside assistance. For example, some grandparents may believe that if they are unable to adequately care for the child, they are not doing their job as caregivers. This independence causes physical and mental stress.

Mental and physical strength is mandatory for grandparents raising a grandchild with a special need. Mental and physical strength, however, is often lacking without appropriate awareness and access to support of educators, counselors, and special community organizations. It appears that America's grandparents are taking care of a large number of children with little or no guidance from support networks.

Rationale

I chose to do this study for three reasons. First, I have a sister who has a physical and mental disability, thus I have always had an interest in special education advocacy. I am especially interested in under-researched areas of problems of grandparents raising children with disabilities. I planned to collect factual information through a survey of personal and educational satisfaction grandparents experience as the primary caregivers of a child with disabilities.

I intend to increase interest and focus on the research gap within education and the social sciences on the efficiency of educational services for an increasing population of grandparent caregivers. The majority of current research involves the following: student-teacher interaction in regular or advanced educational settings; communication within traditional parent-child relationships; and traditional parent advocacy for children with disabilities. Minimal research has evaluated the satisfaction or concern of grandparents serving as primary caregivers. Therefore, the need for research is supported by the lack of scholarly research on grandparent caregivers of children with disabilities.

Research Questions

With my research, I intend to find answers to the following questions:

1. What are grandparents' level of satisfaction regarding various special education services and communication from administrators about these services?
2. What resources do grandparents who are primary caregivers identify as readily available from educational institutions and social support agencies?
3. Of these resources, which do these grandparents identify as most helpful?

Review of Literature

Grandparents are a unique community of individuals who need personal case-by-case assistance. Thus, the absence of convenient, inexpensive reliable resources may impede the

developmental skills of the child. Without the proper assistance, grandparents may suffer from unbalanced emotions, depression, and/or physical illness.

Research is needed on how grandparents can receive sufficient training, networking resources, and education on their rights while being primary caregivers. This research is needed in order to develop models of support for assisting grandparents with pertinent family and school issues associated with their role of raising a child with disabilities.

Family Characteristics of Grandparents as Caregivers

These grandparents experience both the joy of personal fulfillment and the exhaustion of physical work when filling the role of grandparents of exceptional children. Most caregivers are minority and are female heads of households. Some live in middle-class neighborhoods, but most live in low-income neighborhoods. These grandparents struggle with a lack of knowledge on how to adapt their child-rearing behaviors to the needs of a special needs child. For example, a grandparent may lack the knowledge of why an exceptional child with autism does not respond to some requests.

McCallion, et al. (2000) found that the educational background of grandparents varies. Some attended high school, some are high school graduates, and very few have a college-level degree. A lack of educational opportunity may result in a lack of awareness of terminology and symptoms associated with the disability of their grandchild. Vadasy (1987) cites examples of common concerns that may go unanswered:

- What are the special daily requirements for a young child with a disorder like cerebral palsy or spina bifida?
- How can a child with Down syndrome be helped to sit or crawl?
- What appropriate discipline techniques should be used with my grandchild?

Full-time caregivers can feel stressed and emotionally drained by their parental duties. They may also feel frustrated due to little or no training on how to cope with their responsibilities. Currently, there is a lack of service providers to accommodate grandparent caregivers. This may be due to resources focusing on the needs of traditional families.

Studies have shown that grandparents remain primary caregivers for as little as a few months or as long as 30 years. Through questionnaires and/or interviews, these grandparents stated that their experience of raising a grandchild with disabilities helps them grow into a more positive individual, in addition to gaining a close relationship with their grandchild. On the other hand, focus group studies have concluded that grandparents display numerous signs of depression, stress, and exhaustion. McCallion, et al. (2000, p. 59) stated, "Most grandparents neglect and overlook their personal feelings for the safety of the child." These grandparents may fear that support agencies or educators may believe that they cannot manage the responsibility of caring for an exceptional child. Grandparents do not want to see their grandchild taken by state authorities and placed into the foster care system.

The family dynamics of special children have been influenced by their parents who were shown to be unfit due to drug/alcohol abuse or were not present enough to be a responsible guardian. Additionally, Pemberton and Rademacher (2004) explained that many of these children experience mental and physical abuse, along with neglect, under their parents' care. Grandparents are placed in an uncomfortable situation at times because they want to allow their own child to be present in the grandchild's life, but often the grandparents observe that the parents are irresponsible. One positive aspect of this unique grandparenting role is that grandparents have a second chance to be a nurturing caregiver while increasing their knowledge of disabilities.

School Issues of Grandparents as Caregivers

In regard to school issues, grandparents may lack knowledge of important terminology regarding their grandchild's disability. Vadasy (1987) explained the need for the availability of communication resources to educate grandparents on the terminology and symptoms associated with the particular disability of their grandchild. Kuykendall (2005) reported the need for grandparents to understand the purpose and details of the Individualized Educational Plan (IEP). The IEP is an important written documentation of the child's curricular goals and objective for each academic year.

Another unfamiliar term is *Intelligence Quotient*. The IQ is derived from standardized tests to determine a mental age. Additionally, some grandparents are not familiar with the meaning of *Least Restrictive Environment*. The LRE is the legal mandate that children in special education must be educated to the greatest extent possible in the general education curriculum with normally achieving students. *Mental Retardation* (MR) is another term that is frequently used. MR is a diagnosis given to a person with an IQ score of 69 or less.

Pemberton and Rademacher (2004) reported that in addition to a lack of understanding regarding special education terminology, grandparents are often concerned about confidentiality issues. They often do not want information concerning the negative aspects of why their grandchild is being cared for outside of the traditional family unit to become public knowledge. Grandparents fear that a breach of confidentiality would create a stigma toward the child by peers and teachers.

There are some encouraging aspects of the grandparents' relationships with the education system. Kuykendall (2005) found that grandparents must be informed of any assessments or changes in the child's curriculum. School systems must also inform grandparents of their rights.

Grandparents are invited to help create an *Individual Education Plan* (IEP) for their grandchild, and the child's particular special education department is responsible for informing the primary caregiver of the child's progress. Moreover, if a grandparent ever disagrees with the decisions or point of view of a school district on a particular issue, they are entitled to go into mediation or to have a mediated conference to settle differences. These services are typically available free of charge.

School Support for Grandparents

Schools can serve as a great resource to help grandparents cope and overcome personal issues that may arise during the caregiving process. For instance, Parent Advocacy Coalition (2005) explained that training sessions for this unique group of parents have proven to make a significant difference in their everyday life. Given the education status and low-income level of the majority of caregivers, easy access to inexpensive resources is important to help grandparents be effective caretakers. McCallion, et al. (2000) have concluded that the grandparents who need the most help often receive the least. This conclusion may be due to the lack of funding for support organizations in underserved communities where children with disabilities are most prominent.

The Parent Advocacy Coalition for Educational Rights (2005) described a typical workshop. A keynote speaker from the community such as a teacher, child advocacy attorney, counselor, or social worker begins the event, offering advice and encouragement for grandparent caregivers. Next, roundtable discussions provide a forum for identifying the issues families face in raising children with special needs. The workshops may conclude with volunteer testimonials of success stories and a closing presentation. One grandparent from the Parent Advocacy Coalition for Educational Rights (2005, p. 1) stated, "I was overjoyed to walk into a room of

people who understood how I felt without explanation. No one knows as well as someone who's been there.”

The physical burden experienced by aging grandparents is caused by their duty to care for their grandchild seven days a week. In a focus group discussion, one grandparent reported that while she would like to be included with the younger parents and their children in after-school events, she was sometimes just too tired. In addition, she reported that it is sometimes difficult to communicate with the younger parents, thus causing more exclusion (Pemberton & Rademacher, 2004).

Educators can assist by developing after-school programs specifically for the special needs student population, which will alleviate stress and give some free time to the grandparents who desperately need it. The workshops would give families the opportunity to ask questions and voice their concerns with others who may be experiencing similar issues, providing a network of support for grandparents, by grandparents. Schools can take on the responsibility to create a module to identify deficient areas of support for this unique demographic group. The limited availability of institutions and funding for the support, education, and guidance of grandparents is an opportunity for service outreach to grandparent caregivers by educators and educational systems across America.

Educational systems have a great opportunity to utilize the expertise of their educators and counselors. These systems may also aid in providing financial assistance through government funding. The locations for holding meetings could be provided by local schools if necessary. As a result, grandparents will be more knowledgeable of the educational measures needed for their grandchild to be happy and well taken care of both in and out of the classroom setting.

Hypotheses

1. Informative research is needed within the fields of communication studies, education, and the social sciences to sufficiently equip educators and other professionals on how to better assist grandparents raising children with disabilities. Educators need creative education modules to help guide families and professionals who are responsible for educating and caring for children with disabilities.
2. The happiness, social skills, and motivation to learn of a child with disabilities may be dependent on a grandparent caregiver's knowledge of his or her child's impairments. Thus, a grandparent caregiver's ability to cope with their grandchild's special needs is dependent on their parenting skills and knowledge of special education advocacy.

Methodology

A survey of 50 questions was composed. The survey's structure was adapted from the National Center for Special Education Monitoring. A revision of the survey divided it into six sections: (1) school efforts to partner with grandparents; (2) quality of services; (3) comprehension of school services and technology; (4) impact of special education services on family life; (5) availability of support agencies and caregiver training programs; and (6) physical/mental health of grandparents. This research concludes with implications for practice that may inform school systems and support agencies on how to best support grandparents.

Limitations and Challenges

One limitation of this study was the lack of a local pool of subjects. Also, school confidentiality policies would not permit the release of student guardian information, despite the

presentation of official university research approval, drafted from the UNT IRB. A University of North Texas professor, however, was able to provide the names of five grandparents who were willing to be interviewed. Because this was a small convenience sample, this study should be treated as exploratory. The results presented are suggestive, and the study should be replicated with a larger, random sample in order to make generalizations to the population of grandparents raising grandchildren with disabilities.

Results

Ratings of Equal Partnership

The grandparents were asked to rate the school's efforts to partner with them in educating their grandchildren (refer to Figure 1). There were no problems indicated by the grandparents regarding discussion of their grandchildren's accommodations during IEP meetings (100%), documentation of concerns and recommendations (100%), written justification for not placing the child in a regular classroom (100%), teachers being available to speak with grandparents (100%), and teachers treating grandparents as team members (100%). Only one grandparent indicated that the schools did not treat him or her as an equal partner (80%). There was concern from two grandparents that the school was not sensitive enough to the students and their families (60%). Additionally, more than half of the grandparents felt that they were not receiving information in an understandable way from the school (40%), nor were they being sought out for their input in their grandchildren's education (40%). There was great concern regarding the receipt of information about grandparent support organizations (20%), as only one grandparent felt they were given adequate information. The grandparents, with the exception of one, were also concerned that their opinion was not desired by the school regarding their grandchildren's

education (20%). Finally, none of the grandparents perceived their needs being met in terms of receiving special assistance to permit them to attend IEP meetings (0%).

Ratings of Teacher and Administrative Support

The grandparents were asked to rate the support from the teaching and administrative staff (refer to Figure 2). All of the grandparents indicated that the schools had someone on staff that they could speak to with any questions they may have (100%) and they were all given choices by the schools as to the services that address their grandchildren's needs (100%). Two grandparents felt that the schools did not communicate regularly regarding the grandchildren's progress toward their IEP goals (60%). Less than half felt that the schools gave them the help they needed to play an active role in their grandchildren's education (40%). The area of most concern was that only one grandparent felt they had been offered adequate training from the schools about special education issues (20%).

Ratings of Quality of Services

The grandparents were also asked to rate the school on their quality of services (refer to Figure 3). All of the grandparents agreed that the schools provided services in a timely manner (100%). There was some concern, from two of the grandparents, that their grandchildren were not receiving all of the services that were documented on their IEPs (60%). Two grandparents were concerned that after-school and extracurricular activities were not accessible to students with disabilities (60%), and that the teachers did not understand their grandchildren's needs (60%). Only one grandparent felt that the schools were providing teachers and staff with training to improve their communication with parents and grandparents (20%) and only one grandparent agreed that the schools provided opportunities for the students and their families to learn about students with disabilities (20%).

Ratings of Grandparent Participation in Child's Life

The grandparents were asked to rate their own involvement in their grandchildren's life and they all perceived themselves as heavily and effectively involved (refer to Figure 4). All of the grandparents indicated that they engage in learning activities with their grandchildren at home (100%) and ask their grandchildren to talk about what they are learning in school (100%) and about their homework assignments (100%). Additionally, all of the grandparents agreed that they communicate the importance of doing well in school to their grandchildren (100%) and meet with their grandchildren's teacher(s) to discuss needs and progress (100%).

Ratings of Knowledge of Disability

The grandparents were asked to rate their own knowledge of disability (refer to Figure 5). All of the grandparents indicated that they know their grandchildren's disability (100%) and the characteristics of that disability (100%). Two grandparents indicated that they were not confident in their ability to communicate or explain their grandchildren's disability (60%). Only one grandparent indicated that they participate in an organization for grandparents with disabled grandchildren (20%). There was great concern by most of the grandparents that they did not receive information from their grandchildren's schools about services available (20%) and that they were not aware of resources available for following changes in state and federal laws that affect special education (20%).

Ratings of Physical and Mental Health of Grandparents

Finally, the grandparents were asked to rate themselves in terms of their physical and mental health (refer to Figure 6). All of the grandparents felt confident in both ability to discipline (100%) and ability to care for their grandchildren (100%). Three out of the five grandparents indicated that they were physically able to participate in recreational activities with

their grandchildren (60%) and the same number agreed that they were stressed about their grandchildren's well-being (60%). Two grandparents said that they were tired when their grandchildren come home from school each day (40%) and that they were physically and/or mentally exhausted at the end of the school week (40%).

Conclusion

Summary

A review of the results indicates that there are some important factors working in favor of these grandparents as they raise grandchildren with disabilities. Four out of five of the grandparents think that they have an equal partnership with the schools in planning their grandchildren's educational goals. The majority also agree that they receive satisfactory discussion of the grandchildren's accommodations and modifications during IEP meetings. Grandparents also indicated that teacher availability was not a problem for most of them and all of them believe that the teachers treat them as team members in working on their grandchildren's education. All of the grandparents were given a choice of services for their grandchildren's education and felt that those services were provided in a timely manner by the schools. Finally, as far as their own abilities, all of the grandparents indicated that they are participating effectively in their grandchildren's lives and are confident in their ability to care for them.

There are also some areas of concern, where improvements seem to be needed to help these grandparents in educating and raising their disabled grandchildren. None of the grandparents indicate receipt of assistance in getting to IEP meetings and only one grandparent felt that his or her opinion was even wanted from the schools regarding his or her grandchildren's educational planning. Only one grandparent agreed that information was made available regarding support groups and services and special education training for families. Only

one grandparent was aware of resources to track changes in state and federal laws regarding special education. There also seems to be a deficit in sensitivity at some schools to these disabled students and their families, as two grandparents experienced this lack of sensitivity and two grandparents did not feel that the teachers understood the needs of their grandchildren. Aside from school, some of these grandparents indicated some personal concerns that affect their grandchildren. Three of the five grandparents indicated that they were stressed about their grandchildren's well-being and two out the five reported that they were tired by the time their grandchildren get home and experience mental and/or physical exhaustion weekly.

Implications

An increase in special education services and resources, available through a child's school, may decrease a grandparent's stress level as it relates to the child's well-being. Additionally, the development of unique, special education after-school programs may decrease grandparents' physical health burden of feeling tired when grandchildren come home from school each day, as well as physical or mental exhaustion they may feel by the end of the school week.

References

- McCallion, P., Janicki, M.P., Grant-Griffin, L., & Kolomer, S.R. (2000). Grandparent caregivers II: Characteristics of the grandparents and the children with disabilities for whom they care. *Journal of Gerontological Social Work, 33*, 57–83.
- Kuykendall, E. (2005). *What you need to know about special education*. Retrieved October 30, 2005, from <http://www.gibell.com/bg/specialeducation.html>.
- Parent Advocacy Coalition for Educational Rights. *Grandparent to grandparent*. Retrieved October 28, 2005, from <http://www.pacer.org/parent/grand.htm>.
- Pemberton, J. B., & Rademacher, J. A. (2004, October). *Research on grandparents raising grandchildren with disabilities*. 26th International Council on Learning Disabilities.
- Robinson, E. H., & Brosh, M. C. (1980). Communication skills training for resource teachers. *Journal of Learning Disabilities, 13*, 162–165.
- Vadasy, F. P. (1987). Grandparents of children with special needs: Supports especially for grandparents. *Children's Health Care, 16*, 21–23.

Figure 1. Grandparents' Ratings of Partnership with School

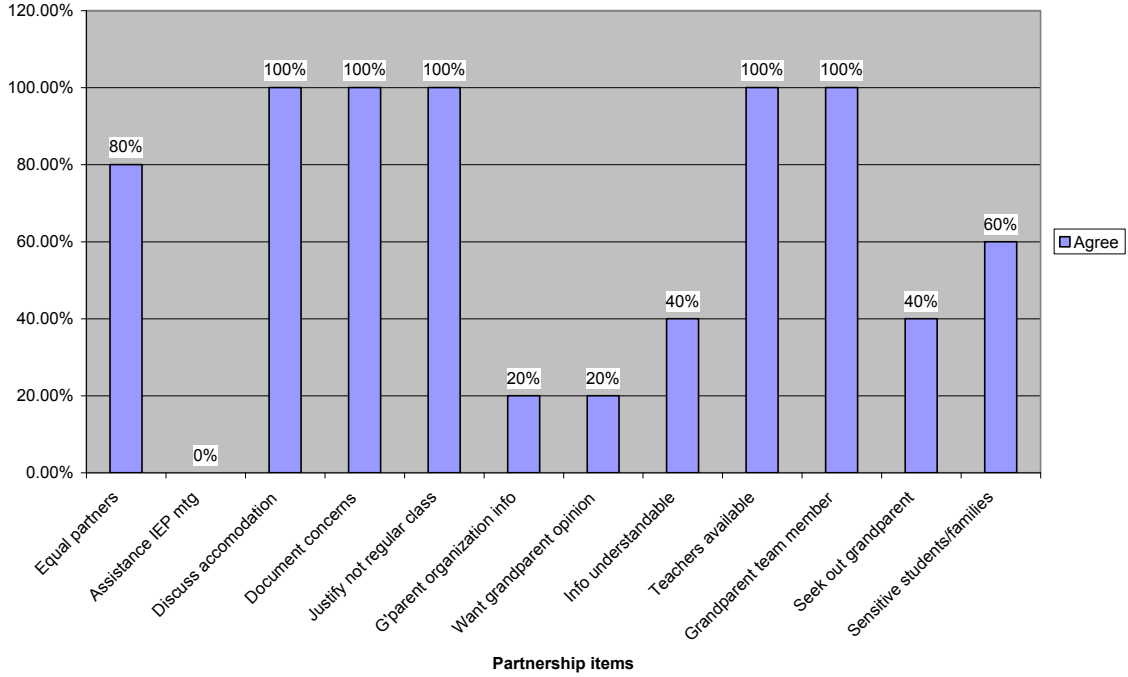


Figure 2. Grandparents' Ratings of Teacher and Administrative Support

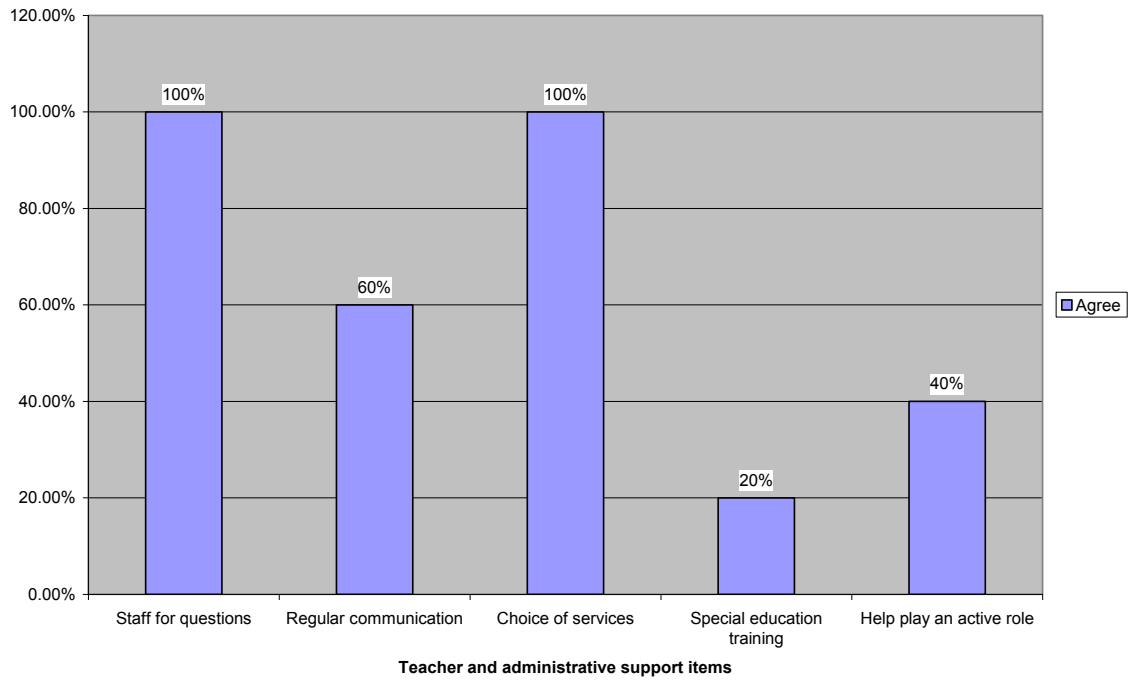


Figure 3. Quality of Services

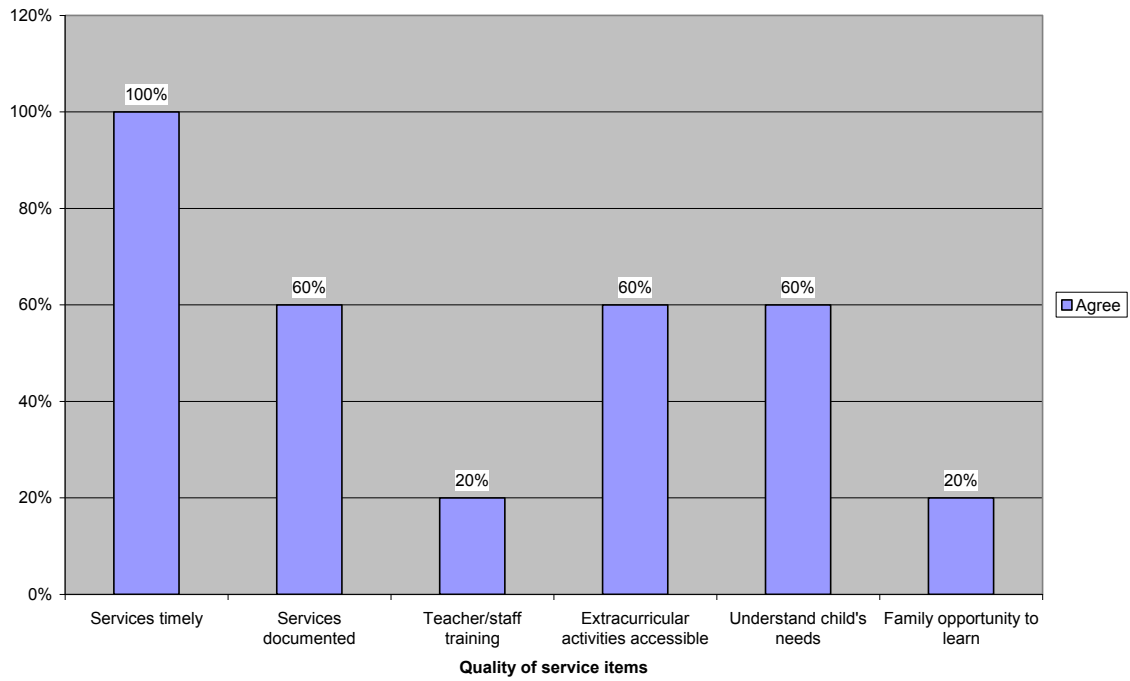


Figure 4. Grandparents' Ratings of Participation in Child's Life

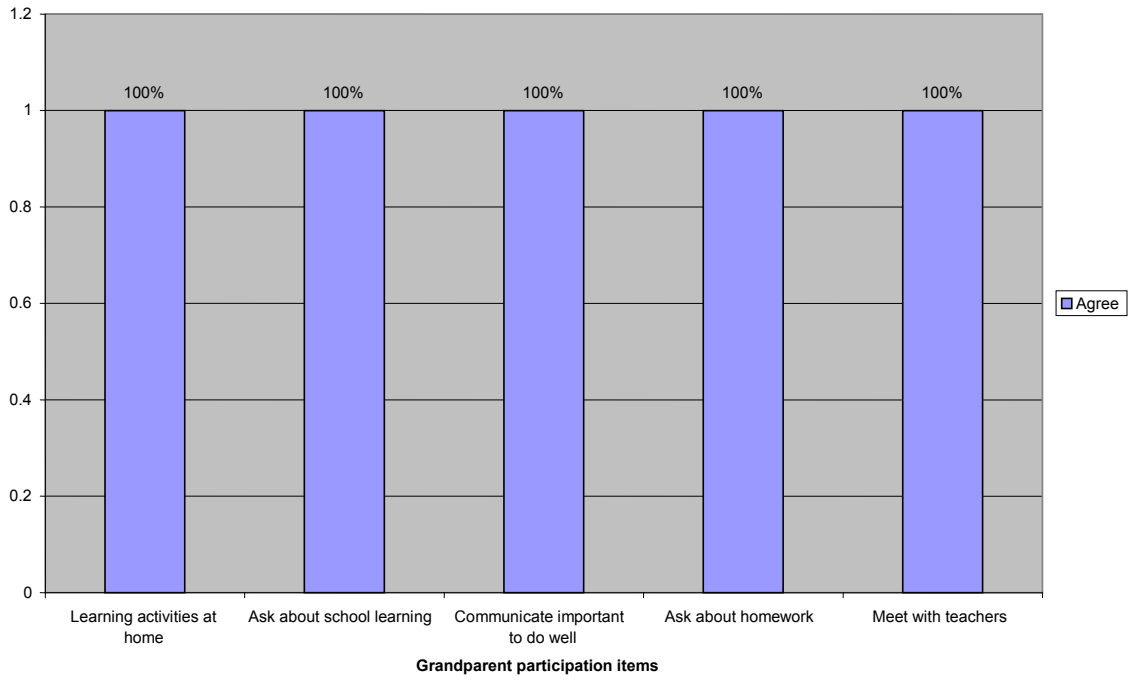


Figure 5. Grandparents' Ratings of Knowledge of Disability

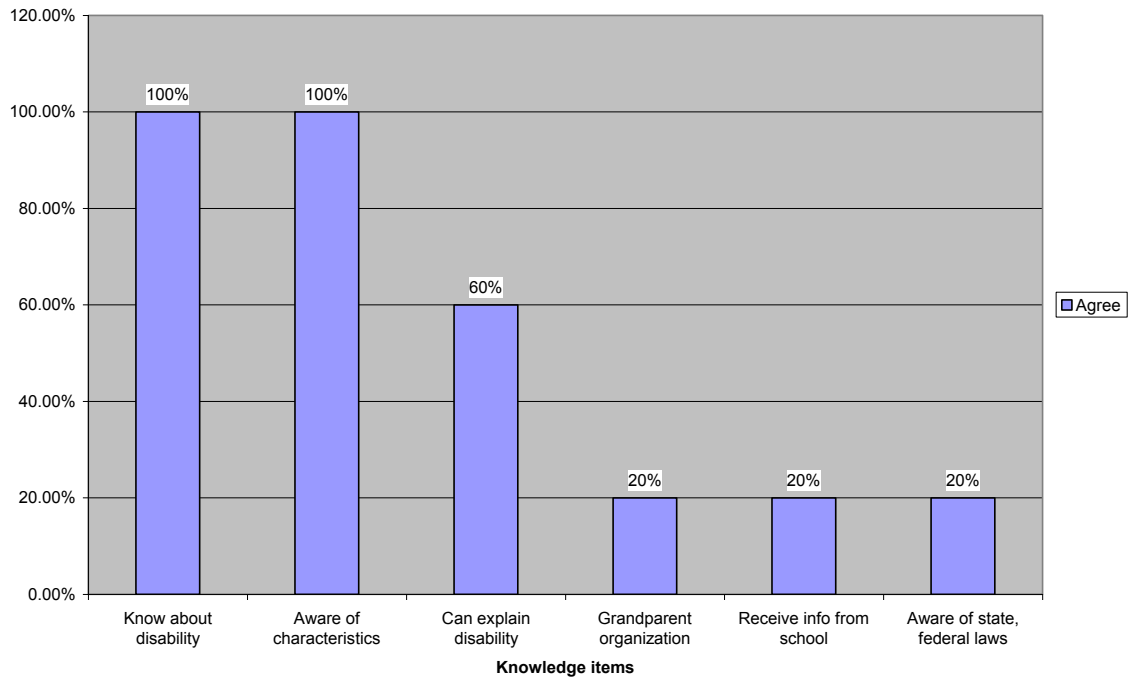


Figure 6. Effect of Care for Child on Grandparent

