Chapter 8

Parent Involvement in the Education of Children with Chronic Diseases: Working and Sharing for Children

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ABSTRACT

Through parent involvement, children with chronic diseases have a lot of gains with respect to their achievement, cognitive skills, behavior, and motivation. However, although involving parents is not a new issue in the education of children, there are potential challenges while implementing parent involvement in the education of children with chronic diseases. Teachers and parents need clues and directions to figure out how to work together in order to achieve a common goal. Therefore, this chapter aims to provide information about (1) the background and benefits of parent involvement focusing on the education of children with chronic diseases, (2) the challenges encountered by parents and practitioners through this process, and (3) the solutions for those potential challenges. Lastly, recommendations for successful strategies for successful parental involvement are discussed.

INTRODUCTION

Parents are the primary educators of their children in early years of life. There has been a consensus among the researchers that parents play a vital role in their children’s education. Therefore, it is critical to understand the parents’ role in any aspect of children’s education across different programs since the parent involvement may take different forms to adapt the different requirements and needs of children and families in different contexts. Particularly in the last couple of decades, there have been growing number of research studies in the field of parent involvement. Most of these studies (e.g., Tekin, 2011a) built a great deal of literature evidence for the benefits of parent involvement in any phase of children’s education. The benefits of parent involvement are not limited only to the children but also for the par-
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ents, teachers, as well. The benefits of parent involvement can be seen in different domains of children’s development including, behavioral development (Pong & Ju, 2000), social and emotional development (Prior & Gerard, 2007), cognitive-intellectual development (Grolnick & Slowiaczek, 1994), and academic development (Tekin, 2011b). Thus, parent involvement in the education of children has become an inevitable dimension in any education program.

Parents began to become involved in nursery schools at the beginning of 20th century in the in Europe and the United States. Most of these nurseries were located in college or suburban towns and welcomed primarily stay-at-home mothers who served as paraprofessionals in the classrooms, assisting a teacher and taking physical care of the facility. The major view of parent involvement was that parents know what they want for their children and thereby should be involved in the school (Tekin, 2008). However, these parent involvement efforts were limited mainly to middle-class families and children without any disadvantages, thus excluding the children with special needs and health problems such as chronic diseases.

Following the World War II, an extensive parent involvement initiative was introduced by Head Start in the 1960s and 1970s and Head Start was designed for particularly disadvantaged families. Later, Head Start was required by the government to ensure the utmost level of family involvement. This implication made the parent involvement as one of the main characteristics of Head Start (Tekin, 2008). In Head Start programs, parents began to decide on a level of involvement well-suited to their lives and commitments. According to the rationale, if children are to achieve their fullest potential; there must be an opportunity for Head Start parents to influence the character of programs that affect the development of their children (Henrich & Blackman-Jones, 2006).

Chapter I of the Title I initiative, called Even Start, was eventually brought in as a family-centered education program that funded local efforts to improve educational opportunities for children, and mandated involvement of parents through an initial agreement between the program and parents. In this agreement, parents agreed to attend orientation sessions for parents, participate in parent/child/staff events during the year, read with the child, and attend at least five hours of family-school partnership workshops offered by the school (Gestwicki, 2007).

Parent involvement was also mandated by the Education of All Handicapped Children Act of 1975, later reauthorized as the Individuals with Disabilities Act in 1990 Amendments of 1997, and Individuals with Disabilities Educational Improvement Act of 2004 (Tekin, 2008). Parents of children with special needs were required by these programs to monitor whether the individualized education program (IEP) for their children was in line with state standards for achievement. Families were also required to be involved in all aspects of the planning process for their children’s education (Gestwicki, 2007). This application was designed to encourage to benefit from parents during the decision making processes.

Moreover, Goals 2000 was introduced which also required every state to develop policies that help local schools and agencies to increase parent-school partnerships (Patte, 2002). Goals 2000 also aimed to have every school actively engage parents and families in a partnership that sustains the academic work of children at home and shared educational decision-making at school, including parents of children who were disadvantaged (Epstein et al., 2002). This was another critical step towards the improvement of parent involvement programs in the education of children with chronic diseases.

Lastly, No Child Left Behind (NCLB) legislation was signed into law in 2002. One of the major characteristics of the NCLB was that the parents were given more rights by law. For example, schools were required to provide parents with more information about their child’s progress in school and the performance of the school. In addition, the NCLB requires parent involvement programs in schools and obliges them to develop a written parent involvement policy that includes parents in creating and