

Chapter 12

Learning, Growing, and Connecting in Sickness and in Health: Exploring Technology, Parenting, and Young Children with Serious Medical Illnesses and Chronic Disabilities

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ABSTRACT

Even though parenting may have originated out of evolutionary necessity, parenting today has taken on many different meanings related to the larger social and cultural contexts in which it is situated. One of the dominant forces impacting parenting across the most recent decades is technology, which has allowed the easy access and transmission of information via the internet, enabled long-distance communications, and provided an additional medium for education and entertainment for even very young children. Although technology maintains a seemingly universal presence in the lives of parents and their children, it is used in different ways according to the individual circumstances that each family faces on a day-to-day basis. This chapter will explore the various ways in which typically developing children, children with disabilities, and children with chronic illnesses and their parents utilize technology to access information, acquire social support, and achieve parental and developmental goals. Technology offers a valuable resource for meeting the needs of parents and young children of all abilities.

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INTRODUCTION: CONTEMPORARY PARENTING AND TECHNOLOGY

The emphasis of this chapter is on parents' use of innovative and contemporary technologies across abilities and conditions; therefore the premise begins from a norming perspective, which is parenting without exceptional circumstances and how that changes when families are faced with adversity in their children's health and well-being. Children with serious medical illnesses and chronic disabilities endure many obstacles as they persist through cognitive, social, and emotional developmental milestones. The one common thread for children with serious illnesses or chronic disabilities is that the future is unknown and therefore questions arise regarding their full potential. Initially questions about the ill or disabled child flood the minds of their parents; what will they be able to do, how will this affect their life, what about their friends, and what about school, how will this impact their education? Health is one of the primary qualities that parents desire for their children, so when a child becomes seriously ill or is disabled, it is shocking and even devastating. However, even at the end of the day, and even when a healthy child seems off in the distance somewhere, parents still want their children to be happy, have fun, and experience life in all of the best possible ways. As unreal as it seems and as difficult as it is to accept, eventually reality moves in; and parents begin to wonder about what their role in their child's illness or disability needs to be now. Perhaps everything they thought about parenting now seems to be null and void, yet children still require structure, rules, limitations, and experiences. Life has changed it has not ended, the child's needs have somewhat but not completely changed; likewise, the parenting role has somewhat but not completely changed. The purpose of this chapter is to investigate what parents can do for their child and themselves throughout the challenges of illness to achieve cognitive, social, and emotional development for their child as they

all adjust to the child with an illness or disability. Our goal is to demonstrate how the challenges that seriously ill or disabled children and their parents encounter may be managed with less effort and stress given advances in information, media, and communication technologies. In other words this chapter aims to identify how parents can scaffold their child's learning and development through the use of technology; and how parents can develop an arsenal of knowledge and tools that can promote a childhood laden with happiness rather than stress and anxiety.

What is a parent, or even more frightening, what is parenting? Parenting has been formally defined as "the care and nurturing of offspring between conception and independence" (Bjorklund, Younger, & Pellegrini, 2002; p. 3). Sounds simple right? Most people who have observed the modern day process of parenting might disagree. Most would agree that parenting is probably the most difficult job on the face of the earth; and the most important job because our children are our future. You can look around and at least know that parenting is complex as there are parenting manuals, magazines, courses, resources, and for those who need them, there are parenting interventions. There are parent groups, parent-teacher conferences, parent advisory councils, and room parents; there are single parents, grandparents, stepparents, foster parents, teen parents, first time parents, and adoptive parents. Companies market their products to parents, professionals educate parents, specialists advocate for parents; thus it is no surprise that the ever-present "parent" is also heavily researched across academic fields as well. But with all of these forms and contexts, just what does it mean to parent? And more importantly, what does it mean to be a parent today?

Those who study parenting do not always agree on an exact classification of parenting, let alone the specifics of its nature and goals. In fact, what further complicates the study of parenting is that multiple perspectives exist regarding the origins, development, and importance of parent-

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