

Chapter 11

Disability

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ABSTRACT

The number of children living with a disability is substantial and expanding. Children with disabilities and their families are disproportionately exposed to adverse experiences, increased stress and stigmatization, face more barriers, and are more likely to be diagnosed with mental health disorders. Unfortunately, adequate and specifically tailored professionals, programs, and interventions aimed to enhance resilience, support families, and decrease stigma have not increased proportionately. Certified Child Life Specialists (CCLS) promote coping, validate emotions, and use play-based techniques to build relationships and increase understanding of difficult experiences. By increasing the availability of Certified Child Life Specialists in community settings, children with disabilities and their families will gain additional advocacy, insight, and opportunities to lead fuller, more supported lives.

INTRODUCTION

With advances in science, technology, medicine, and life-saving interventions, children with disabilities, complex medical needs, and comorbid conditions are living longer lives with more specialized interventions. The number of children defined as having a disability has steadily increased throughout the last decade (World Health Organization, 2021). With over two hundred and forty million children and young adults globally categorized as having disabilities (Unicef, 2021) and disability strongly correlating with poverty and inequity (Kuper et al., 2014), Child Life Specialists must expand services beyond the hospital to decrease the risk of trauma and increase access to quality care.

Universally, children with disabilities experience more adverse experiences such as abuse, neglect, and maltreatment (Ammerman, 1997), have challenges with maladaptive behaviors, difficulty communicating their needs, experience more healthcare exposure with less access to quality care (World Health Organization, 2021) and have undermanaged pain experiences (Breau & Burkitt, 2009). Interpersonal relationships can also be challenging due to stigma, isolation, bullying, attachment challenges, and communication barriers. These factors often lead to undesirable and unsafe behaviors, negatively impact mental health, and contribute to lifelong health disparities.

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Disability

Disability-related stressors also affect family members. Caregivers with increasing responsibilities have less time to manage myriad emotions that accompany having a child with a disability. Caregivers must manage additional care, services, behaviors, and educational opportunities and are responsible for ensuring the quality of life for their child. These stressors have been noted in families globally (Olawale et al., 2013; Cheshire et al., 2010; Basaran et al., 2013; Wu, et al., 2017). In order to ensure adequate adjustment for the future, professionals must address the individual and unique needs of siblings. Siblings function better long term when they receive specific interventions to process their experiences.

Advocacy and providing quality care that focuses on strengths and individual needs are essential to optimize functional outcomes, yet barriers remain. Despite the need for interventions, adequate and equitable services have not increased proportionally, and access to quality services is not universally available. These gaps should be considered an opportunity for growth and improvement and can be mitigated with the professional skills of a Certified Child Life Specialist (CCLS).

Child Life Specialists focus on normalizing experiences, supporting and validating emotions, and processing potentially adverse and traumatic experiences while considering the perspective of the individual, family, and culture with a resilience-focused, family-centered lens. Their expertise in play-based interventions and emphasis on the value of building and maintaining relationships allow for unique expression and processing of experiences. This combination of professional scope and individually-tailored interventions is particularly impactful for children with disabilities but is limited to pediatric hospitals and emergency departments where Child Life Specialists primarily practice.

To positively impact the lives of children with disabilities, Child Life Specialists need to focus on meeting the needs of children with disabilities while becoming a standard of care in community settings. Settings include but are not limited to schools, daycares, respite care, outpatient clinics, rehabilitation centers, day programs, and relevant community nonprofits. Additionally, the case for employing Child Life Specialists in young-adult and geriatric facilities is warranted to ensure adults with disabilities continue to receive resilience-enhancing services, particularly regarding potentially traumatic medical procedures, transitions, and other triggers.

This chapter connects the specific needs of those with disabilities and the unique professional scope of Child Life Specialists constructed through theory, evidence-based practice, and case studies.

Specific chapter objectives:

- Discuss the history and evolution of language and models of disability, community, and culture and how this influences care.
- Consider disability-related stressors and disparities for children with disabilities and their families.
- Understand the correlation between stressors and behavior.
- Consider the experiences of children with disabilities and their families through a Diversity, Equity, and Inclusion (D.E.I.) lens.
- Conceptualize the current practices of Child Life Specialists with children who have disabilities.
- Apply successful child life evidence-based practice in hospitals to a variety of broader community settings.
- Contemplate future directions for continued advocacy of the child life profession as a standard of care for children with disabilities in all settings.

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