Rethinking Ambiguous Loss for Families of Children with Disabilities: The Intersection of Motherhood, Disability, Education and Culture

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Abstract

The parenting experience is often portrayed as a journey. When a child is born with significant disabilities, the journey takes a very different form. Some parents are able to cope with these unexpected situations, but others experience more challenges, feeling lost in the middle of nowhere, or immobilized and unable to move on with their lives. Thus, this talk explores the differences in how mothers of children with disabilities make meaning out of adversity. My argument is grounded in disability studies and theory of ambiguous loss in family studies. Although these two theoretical frameworks are distinctively established in different fields, it will be of interest to all scholars and students of disability studies, child and family studies, education and sociology more broadly.

Disability studies challenges traditional medical models of disability and embraces a social model for understanding disability. This social model views disability not as a deficit but a complex social characteristic influenced by culture, society, and individual identity. Drawing on research and personal narratives from families in both the United States and South Korea, this talk provides a framework for understanding the lived experiences of caregiving, adaptation, and agency.

A central concept for understanding these family dynamics is **ambiguous loss**. This theory, developed by Pauline Boss, reframes the emotional experience of parents, particularly mothers, who often grapple with a loss that remains unclear and unresolved. Unlike traditional grief models, ambiguous loss acknowledges the continuous and cyclical nature of coping with a child's disability. It highlights the complex and often contradictory emotions faced by caregivers as they navigate a journey that challenges societal expectations of a "normal" family, requiring them to find new meaning and a new way of learning to live with ambiguity.

The presentation also challenges the conventional view of caregiving as a one-way process. It introduces the concept of **bidirectionality**, redefining the individual with a disability not as a passive recipient of care but as a meaningful, contributing member of their family and community. By recognizing this mutual influence, we can better appreciate the multifaceted nature of adaptation and the growth that occurs within the entire family unit over time.

Finally, the talk delves into the specific cultural context of motherhood and disability in Korea, where deeply ingrained societal beliefs about being a "good" mother and a "normal" child create unique challenges. This section of the presentation illustrates how Korean mothers, despite facing self-blame and a reluctance to seek formal support, are active navigators of their children’s lives. Their stories reveal a proactive engagement in redefining their caregiving role and building meaningful social support networks. By examining these diverse experiences, the presentation offers a deeper understanding of the complex intersection of motherhood, disability, society, and culture.