

Out of the Chrysalis of Silence, Into a World of Possibilities: Family Experiences of Having a Child Who Uses a Speech Generating Device

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Out of the Chrysalis of Silence, Into a World of Possibilities: Family Experiences of Having a Child Who Uses a Speech Generating Device

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Abstract:

There are children in this world who are silenced by disability. The struggles of these children as they attempt to find a voice are difficult and often considered insurmountable. With advances in computer technology, devices are available to assist the child to have a voice. This voice is not found easily or acquired without difficulty. Even after finding and acquiring the necessary device, the child requires education and support to learn to use the device effectively. Challenges may be specific to the child's disability, the support systems involved with the child, or even the technology itself. It is the adults

in the child' s life, and the child' s family in particular, who provide needed support and assistance in helping him/her find an effective way of expressing his/her ideas. Families are an essential component in assisting their children to learn to use the device. My pilot study examined parents' likes and dislikes of their child' s communication device. The preliminary data from that study illuminated several factors that increased the struggles of these children and their families as they work together to learn the device. These factors include financial, emotional, and developmental costs; as well as the lack of appropriately trained professionals; and excessive time lapses from evaluation to receipt of the device. The purpose of this study was to give a voice to the experiences of families around a child' s use of one type of augmentative and alternative (AAC), a speech generating device (SGD), by analyzing family' s experiences of the child' s use of a SGD as seen through the lens of the child' s primary caregiver. Interpretive phenomenologic methods for data collection and interpretation were used to elucidate the experience of families who have a child who is currently using or who has previously used a SGD as a method of communication. One cannot learn about the lived experience of the family without first listening to their story and allowing the family to share how their child' s use of a SGD affected the life of their family.

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