

Families' Perspectives of the Effectiveness of a Video Social Story as an Introduction to the Fragile X Program at Boston Children's Hospital

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Fragile X Syndrome (FXS) is the most common inherited form of intellectual disability. Individuals with FXS also may have behavioral difficulties. Two common behavioral challenges include social anxiety and autism, with the social anxiety being related to poor adaptation to transitions. Research has shown that social stories, depictions of situations, skills, or concepts using pertinent social cues, can help individuals with autism feel more comfortable and have a better understanding of an event or set of circumstances. The Fragile X Program at Boston Children's Hospital created a video social story with the aim of helping patients decrease their levels of anxiety and improve their ability to handle transitions during the clinic visit. Families who visited the Fragile X Program between January 2009 and March 2013 were recruited to participate in an online survey to assess their perceptions of the effectiveness of the video and to gather any recommendations for improvements to the video. An online survey was distributed to approximately 66 families. Nine (13.6%) responded, and all thought the video would be at least somewhat helpful in preparing for their next visit to clinic. All participants believed it would be at least somewhat helpful to have a printed social story in addition to the video social story. Beyond a printed social story, suggestions to help families prepare for clinic included better describing the length of the visit and bringing a form of entertainment for the child. The results of this project will hopefully lead to the adaptation or creation of additional resources to help prepare families for their visits to the Fragile X Program at Boston Children's Hospital, as well as to other comprehensive Fragile X clinics throughout the country.