

Abstract No. 6.2

Thursday 7th September 2017 at 14:15-15:00

Title: Adult children of parents living with Usher syndrome: Experiences across the life span

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Main focus: Both research and practice/Acquired deafblindness

Abstract: In this presentation I will share the experiences, challenges and reflections of children being raised by parents living with Usher syndrome and dual sensory loss, across the life span. Participants will share stories from different stages of their lives: childhood, adolescence and adulthood. Through this research we hope to identify particular themes and issues that are commonly faced by children of parents with dual sensory loss, with a view of comparing and sharing experiences and helping to raise awareness about the challenges and the triumphs experienced on this unique journey. Along with aiding organisations to provide superior, inclusive support long term to families and advocacy for more relevant support services for the Deafblind community. This study builds on the presenter's previous research on parenting and Usher syndrome.

Being the child of a parent or parents living with Usher syndrome presents some unique challenges and opportunities. Some studies have indicated that children of parents with a disability can develop positive skills and qualities that are absent in other children. However, research also clearly indicates that when inadequately supported, carers' physical, mental health and wellbeing can be jeopardized. Young carers can worry about the health of the person they care for, their own health and who will look after them in the future. Many teenager carers express a sense of isolation and alienation from their peers because the caring role varies considerably from more typical adolescent experience. Caring responsibilities can interrupt education and make the transition from home to independent living difficult. High numbers of adult carers reported on the negative effects on physical, mental and emotional health; and many said that caring work had taken a toll on personal relationships and limited their life choices including restrictions in their ability to take part in paid work, education or other career opportunities. The hearing children of Deaf parents have a unique experience as bicultural and bilingual members of the Deaf community, they are the critical link (interpreters and cultural mediators) to the hearing world, regardless of their age. They are a source of information, a spokesperson for the family and consequently some can grow up feeling that they have been deprived of a childhood.

This study uses qualitative analysis of 13 semi-structured interviews and has been approved by the Edith Cowan University Human Research Ethics Committee. Through this research we are interested to learn the participants' perspective of taking on the carer role, in whatever context that appears within individual families, and how this experience impacts on aspects of their lives, their relationships, and their mental, emotional and physical wellbeing across the lifespan. Drawing on this new research, specific to the Deafblind community, we will also examine what are the implications for practice and future research in this area.