

Interview with Extended Families

PART 3

In this third instalment of my interview with Julie Langdon, the CEO of Extended Families, we talk about shame and stigma associated with disability in CALD communities and how this affects access to services.

Julie felt that the issue was a significant one in most communities, however, she also indicated that it manifests differently in different CALD communities. For example, in the Chinese community, education is highly valued and if a young person is not managing academically, some parents feel it reflects badly on the entire family. In cases where a child has a disability, “families want programs that will help their child be ‘normal’ or to ‘appear normal’.” There is a level of denial and difficulties acknowledging the issue. According to Julie, families are concerned with “what other people think...they seek social skills training and tutoring believing this will help their child ‘fit in’”.

In the Vietnamese community, having a disability can contribute to social isolation as individuals worry how they will be perceived by the community. Julie felt that individuals had a tendency to “blame themselves”, especially men. A Vietnamese man once told her that, in Vietnamese culture, the man is viewed as somehow more responsible if a child is born with a disability: the child is seen as a product of the male, whereas the mother is the ‘vessel’, which carries the foetus. Therefore, a greater degree of ‘blame’ is apportioned to the man and he ‘loses face’ in the community. In these cases, Julie said that men can become disengaged from their families or may not even acknowledge their child’s disability. Often the women in these relationships feel unsupported by their husbands and need to take on the caring role on their own.

The Vietnamese Families with Special Needs Group in particular, has been instrumental in addressing some of the isolation and lack of support experienced by these families. The group was initially set up by a man whose son has cerebral palsy. He was aware of other people in the community who were experiencing isolation due to disability and weren’t coping. The group’s main focus is on improving mental health and wellbeing and overcoming isolation. Members recently expressed at a group session what the group meant to them. Statements such as, “I came to this group because I thought I might get information about services and funding but I found a family and a community...someone made me come because I was depressed and I was isolated and now I have friends and I am happy” echoed the sentiments of the group. The group reinforces that families are not alone and that having a disability is not something people should be blamed for. These are powerful messages that help families feel supported and connected.

In addition to culturally influenced perceptions of disability, the refugee experience can have a significant impact on families. Julie knows of a family from a refugee background who had experienced war and extreme trauma. The parents have post-traumatic stress disorder and four out of the five children have significant developmental delays. “We know that the parents aren’t fully present for their children through their own trauma,” questioning to what degree do the parents’ limited capacity to provide adequate developmental opportunities and stimulation affected the outcomes for these children?

