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Services for people with disabilities

2006 Twilia Ann Janssen Herr Disability Award

Please Ask Me: Teenagers Speak Out

I received the Twilia Herr Award from ALIA in August 2006, for my participation in the project, 'Please Ask Me: Teenagers Speak Out'. Conducted by The Spastic Centre of NSW, the project aims to capture the collective knowledge of young people with cerebral palsy to inform the provision of a range of information resources. This project has involved in-depth interviews of adolescents with cerebral palsy; discussing their experiences as a teenager with a disability, the knowledge they have gained and insights that may assist others.

Cerebral palsy is the most common physical disability in childhood. There is currently no Australian research which provides in-depth detail about what adolescents with cerebral palsy experience, particularly from their perspective. The outcomes will make a significant contribution to academic research and support service delivery in the disability sector. A direct outcome of this project will be the development of information resources for adolescents with cerebral palsy.

Up to the present time, seven interviews with young people in the 14-18 year age group have been conducted and digitally recorded by family therapists or youth workers. Volunteers working for The Spastic Centre have transcribed and de-identified the interviews, protecting the identity of the participants. A second round of interviews with 18-25 year olds is almost complete.

Themes have emerged from the interviews and these are being closely examined. One of the most common themes to emerge is education and how

teenagers gauge the level of support they have received from their schools, specifically their teachers.

The issue of family relationships is another strong theme which has been raised in all the interviews done to date. Many of the teenagers felt that their parents and siblings are "always going to be there no matter how different I am", tending to look beyond the disability and instead focusing on their abilities.

My participation in this project has benefited me in a number of ways. As a person with cerebral palsy, it has helped me to understand the needs of adolescents with the disability. As a graduate in Information Management, it has helped me to gain experience in undertaking a research project and the benefits of capturing and disseminating information in diverse ways. It has been a valuable experience for me to work in an interdisciplinary team comprising information professionals, researchers, social workers and psychologists.

To date my involvement has included:

Research & Ethics Application

As part of the project team, I contributed to the development of the Research and Ethics application and the development of the interview topics.

Literature Review

I read through literature on the experiences of teenagers with cerebral palsy or disabilities from Australia and overseas. I had also sought and read any new literature that had been published this year, reading on the practice of narrative analysis.

Data analysis

I am conducting narrative analysis with the de-identified interviews and working with the project team to extract and categorize the themes that have emerged from the interviews.

Cameron Tang
ectang@optusnet.com.au

