

### **Grappling with uncertainty: Parental strategies for supporting decision making**

Christine BIGBY<sup>1</sup>, Jacinta DOUGLAS<sup>1</sup>, Elizabeth SMITH<sup>1</sup>, Terry CARNEY<sup>2</sup>, Shih-Ning THEN<sup>3</sup>, Ilan WIESEL<sup>4</sup>

<sup>1</sup>La Trobe University, Living with Disability Research Centre, Bundoora, AUSTRALIA; <sup>2</sup>Sydney University, Sydney, AUSTRALIA; <sup>3</sup>Queensland University of Technology, Brisbane, AUSTRALIA; <sup>4</sup>University of Melbourne, Melbourne, AUSTRALIA

*Background* Supported decision making is a key mechanism to support the rights of people with intellectual disabilities to participate in decision making about their own lives. This study aimed to understand the issues that parents found difficult in supporting exploration of their adult child's preferences and assisting them to understand decision constraints or consequences. It also explored parental strategies for grappling with these. *Method* A social constructionist perspective was used, and data collected through in-depth and repeated interviews with parents of adults with intellectual disabilities. Twenty-three parents participated in three or more interviews. Data were analysed using grounded theory methods. *Results* Results fell into two categories. *Making the right decision* captured parental uncertainties about the "right decision" and concern about issues such as their adult's limited awareness of possibilities or impact of preferences on longer term goals. Parental visions for their adult's future

informed their support strategies which centred around *Grappling with uncertainty*, and were about controlling, influencing or attempting to expand horizons of the adult. *Conclusions* This in-depth account of difficulties faced by parents and their strategies adds knowledge of the lived experiences of parents, important for developing capacity building resources and accountability mechanisms for supported decision-making schemes.