

## CONFERENCE ABSTRACT

### At the interface between formal and informal care: Supporting families caring for a person with Intellectual Disability in Ireland

17<sup>th</sup> International Conference on Integrated Care, Dublin, 08-10 May 2017

Bianca van Bavel<sup>1</sup>, Attracta Lafferty<sup>1</sup>, Diarmaid O'Sullivan<sup>2</sup>, Paul O'Mahoney<sup>2</sup>

1: University College Dublin, Ireland;

2: Family Carers Ireland, Irenald

---

**Introduction:** Amidst changes to traditional family caregiving in Ireland, with families becoming smaller, people waiting longer before having children, and increasing life expectancy, the question of how to ensure the health and wellbeing of persons with intellectual disability and their families challenges the interface of formal and informal care provision. This study examines professional and family supports in place for families caring for a person with intellectual disability, and the relationship with carer resilience.

**Methods:** A cross-sectional survey of family carers for a person with intellectual disability was conducted. All carers surveyed were in receipt of a social welfare payment for the care they provided. The questionnaire comprised of a number of psychometric instruments. The Family Support Scale was used to assess the availability and perceived helpfulness of family, friends, informal, and formal supports to carers and their families during the past three to six months. [1] Information was collected about the range of multidisciplinary support services required by carers during the preceding six months. [2] Carer resilience, the process that enables carers and their families to adapt, manage, and negotiate in the face of adversities [3], was also measured. The quantitative survey data was descriptively and inferentially analysed using SPSS 20 statistical software.

**Results:** A total of 247 carers participated in the survey. The findings revealed that the main sources of support available to carers were their family General Practitioner (81.4%), their other children (74.6%), their friends (72.7%), and relatives (72.5%). From those supports availed of by carers, their partner (88.7%), school/college/day-centre (79.9%), and their other children (73.1%) were rated as the most helpful by carers. Levels of perceived family support, other informal supports, and formal supports were positively correlated with carer resilience.

**Discussion and Conclusion:** Findings from this study provide a better understanding of the supports availed of and those perceived as helpful by families caring for a person with intellectual disability. Findings also highlight the importance of perceived family and professional support on carer resilience. With the changing nature of family caregiving, families with a person with intellectual disability need to be valued and sustained with support from both formal and informal supports, services, and resources. Therefore carers should be

included and consulted as part of service evaluations, so that resources can be appropriately tailored, allocated, and best utilised by families. Caregiving situations should be assessed individually, and service providers and policies need to acknowledge and take into account this diversity in caregiving circumstances and integrate with families in order to provide care for people with intellectual disability living in the community.

**Limitations:** This study comprised a cross-sectional survey of family carers of a person with intellectual disability, who were in receipt of a social welfare payment for the care they provided. This is only a subset of carers and further research is needed to examine the experiences of other cohorts of carers.

**References:**

- 1- Dunst CJ, Jenkins V, Trivette CM. Family support scale: Reliability and validity. *Journal of Individual, Family, and Community Wellness*. 1984;1(4):45-52.
- 2- Beecham, J. Collecting and Estimating Costs. In M.R.J. Knapp (ed.) *The Economic Evaluation of Mental Health Care*. 1995; 157-174.
- 3- McCubbin HI, McCubbin MA. Typologies of resilient families: Emerging roles of social class and ethnicity. *Family relations*. 1988; 1:247-54.

---

**Keywords:** family carers; intellectual disability; formal and informal supports; resilience

---