POSTER ABSTRACT

Developing citizen advocacy for adults with intellectual disability

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In 2010, the Report of Disability Policy Review Keogh 2010 was prepared on behalf of the Expert Reference Group on Disability Policy and its findings contributed to the subsequent Value for Money and Policy Review of Disability Service in Ireland Report DoH 2012, which evaluated the efficiency and effectiveness of Health Service Executive HSE funded statutory and non-statutory disability services in Ireland. The Keogh 2010 report emphasised the importance of advocacy in developing person centred care services. This impetus became more important as various media scandals highlighted some incidents of poor care to people with intellectual disability. In 2016, Sage Advocacy & Support for Older People were given funding to develop a citizen advocacy project for adults with intellectual disability in Ireland. This study presents the findings from engagement with adults with intellectual disability, their families and formal caregivers.

This project sought to gain understanding and depth into the perspectives of people with intellectual disability on their life world and to generate other stakeholders’ perspectives regarding caring for this population. Consequently, the study used a qualitative approach, which enables deep and rich insights to people’s lives and experiences and is valuable in examining the interpersonal aspects of care important to patients. Specifically narrative inquiry has the potential to produce themes from the accounts of the study participants. Ethics approval was gained from University College Dublin. Participants were recruited from contacting the facilities who provided care to adults with intellectual disability. Nine focus groups 5 with service users and 4 with service providers were held as well as 4 semi structured interviews 4 with family members of the person and 2 with key stakeholders with intellectual disability and a survey with the Irish Association of Social Workers. Data were analysed using Braun & Clarke’s thematic analysis approach with the assistance fo NVIVO 10. Five themes were developed: Personhood, Service Challenges, Family experiences, Society’s approach to people with intellectual disability, The need for my voice to be heard. These themes enabled multiple perspectives to be considered, particularly emphasising the need to prioritise the will, preference, values and beliefs of people with intellectual disability and the need for service users and families to empower rather than be paternalistic. Limitations of the study will also be presented.
Keywords: intellectual disability; advocacy; adults