Key findings

- People with IDD have important stories to tell in relation to their experience of seeking and carrying out paid employment (Ramsey, 2018).

- Five narrative frames emerged from participants work stories. These included, the quest ‘to do’, finding a good fit in a job, navigating bureaucratic seas, finding of both friend and foe and forging of identity.

- In line with the general population, there was a beneficial impact of working on participants with IDD when they found a ‘good fit’.

- Participants with IDD experienced a high number of challenges and barriers to finding a job over extended periods of time. They also highlighted highly variable degrees of effectiveness in the support they received from employment support providers.

- This research provides a renewed focus on the importance of occupation for this occupationally deprived population and of gaining the right individualised support to facilitate participation in the workplace.

- A ‘creative collaborative partnership’ appears to be a valuable approach in supporting participant involvement and inclusive research principles.

Project aims

- To illuminate the lived experience of having IDD and engaging in paid work.

- To explicate new knowledge that will inform the practice of occupational therapists and other people supporting people with IDD in relation to employment.

- To apply an exploratory research design, ‘creative collaborative partnership’, to maximise participant engagement and support inclusive research principles.

Background

This research explores the lived experience of people with IDD in paid employment. In recent years there has been a sustained focus on employment in the policy and social environment of the UK. However, paid employment rates of people with IDD are low at 6.5% (Department of Health, 2012).

The barriers facing people with an IDD on entering employment are numerous and complex (College of Occupational Therapy, 2007). Studies exploring work with people with IDD largely have focused on identifying factors that support individuals to gain employment (Southward & Kyzar, 2017) and outcomes from being in employment (Akkerman et al, 2016). However, the ‘voice’ of the person with IDD in relation to their experience of paid work is often limited or absent from academic papers. This research sought, through an exploratory research design, to address this limitation in the research base.
Methodology

This research is a qualitative study of the lived experience of six participants with IDD who are or were in paid employment. The research aimed to maximise the involvement and ‘voice’ of the participants throughout the research process. This hermeneutic phenomenological study employed an exploratory collaboration between the participant, researcher and a photographer called a ‘creative collaborative partnership’. In this context the data gathered are the participants’ work stories, which include co-crafted written narratives (Crowther et al, 2017) and visual images. Within the research two stages of data analysis occurred. The first stage was the co-construction of a work story in narrative and visual form which was followed by the application of a hermeneutic phenomenological reduction by the researcher, described as immersion in the lived experience paying particular attention to the artistic dimensions and to emergent essences and meanings (Finlay, 2011). The five narrative frames identified in the key findings were identified from the work stories.

Recommendations

- People with IDD’s voices and experiences should be central to policy, service and metric development related to improving engagement of people with IDD in paid work.
- Active consideration of the person’s perspective related to their experience of their IDD alongside the five narrative frames may benefit those supporting people with IDD in employment.
- Occupational therapists working with people with IDD are recommended to discuss the goal of employment with the people they support, embracing the consultancy role in order to enable access to work and a reduction of health inequalities for people with some of the most complex IDD.

Publications


This study, conducted in 2017-2018, received funding via a Research Career Development Grant from the UK Occupational Therapy Research Foundation

Grant holder: Diana Ramsey

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Acknowledgements

Thank you primarily to the six participants for sharing their stories and their families and employers for supporting the research. Thank you also to the Sussex based employment support provider, Sharon Boothroyd (Photographer), Brighton Speak Out, The University of Brighton (Dr Josh Cameron and Dr Bill McGowan) and Kent Community Health Foundation Trust for their support of this project.

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