'Never think doing a job is easy': The lived experience of work for people who have an intellectual or developmental disability.

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Abstract:	Introduction The proportion of people with an intellectual or developmental disability (IDD) in paid employment is low internationally despite policy efforts. Evidence suggests multiple and varied explanations for this, including organisational, social and personal barriers. That evidence has not focused on first-person experiences which may provide a depth of understanding and explanation of the work-related experiences of people with IDD. Method A hermeneutic phenomenological approach and an exploratory research method of a 'creative collaborative partnership' was adopted to illuminate the work-related experiences of six people with a mild IDD. Findings Six work stories composed of narratives and visual images were collaboratively created revealing a complex range of positive and negative experiences and perspectives of paid work. Five collective narrative frames emerged: the quest 'to do', navigating bureaucratic seas, finding a good fit, forging of identity and finding both friend and foe. Conclusion The collaborators' stories highlighted that individuals supporting people with IDD towards or in work, including occupational therapists, need to adopt a nuanced systemic perspective of the context surrounding the person. This includes identifying allies and allowing people with IDD to decide how (if at all) they describe their IDD status to others as they establish their worker identity.

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A day in my working life

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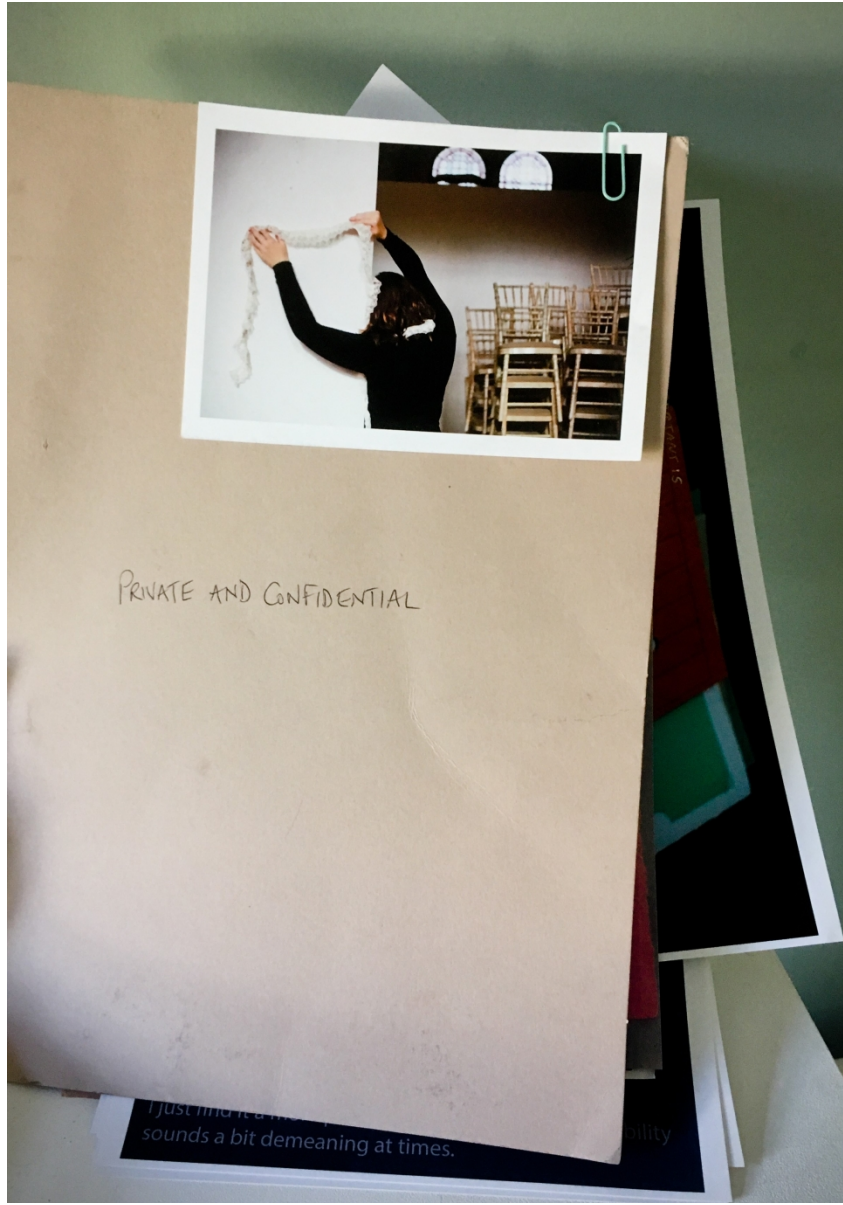
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Never think doing a job is easy

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Introduction

Enabling the participation of people with IDD in paid employment has long been an ambition of government policy in the United Kingdom (UK) (DWP and DH, 2017); moreover, it is something that people with IDD want (Iriarte et al., 2014). However, employment rates of people with IDD remains low with less than a fifth in paid work, the lowest proportion for all groups of people with disabilities in the UK (Powell, 2020). In this article, the terms IDD is predominantly used and is inclusive of the terms intellectual and learning disability.

Barriers to employment for people with IDD are considered to be many and varied and are experienced worldwide (WHO, 2011). Yet, the lived experience of people with IDD in paid work who have attempted to overcome these many barriers is either absent or appears only fleetingly within the literature.

Research rationale

The exploration of employment options for people with IDD is an opportunity for occupational therapists to expand and apply their core skills and challenge the occupational injustices faced by this population (Ineson, 2015). It is therefore important to have a deeper understanding of the complex barriers directly experienced by people with IDD both in seeking employment and when in paid work. This improved insight could support effective and targeted interventions to reduce barriers when consultation is sought from occupational therapists.

Literature Review

National and international policies hold to the premise that inclusion in the labour market through paid work enables people with IDD to experience a better life (Johnson et al., 2010). Addressing the issue of employment for people with a disability more broadly, The World Health Organization's World report on disability (2011) placed work and employment as one of its six key priorities and outlined the vulnerability of people with a disability to poverty and poor health outcomes. However, policy efforts to increase the proportion of people with IDD in paid employment appear to have failed in the UK with rates barely changing in over a decade (PHE, 2020).

Proposals to address this failing include: shifting cultural perspectives, so that there is a recognition of the positive influence people with IDD can bring to a workplace (Melling, 2015); developing internationally agreed models, metrics and terminology to support policy implementation (Lysaght et al., 2015); creating improved and agreed outcome measures, particularly regarding inclusion for people with IDD (Lysaght et al., 2012; Humber, 2014); and to

make changes to employment support systems (Nord, 2016). To further these proposals the cited literature calls for systemic changes to societal barriers to increase employment rates of people with IDD. Reviewing his social model of disability 30 years since its inception Mike Oliver concluded that it had' barely made a dent in the employment system 'internationally (Oliver, 2013, p.1025) it appears that conclusion remains pertinent today at least for people with IDD.

Historically, through institutionalisation, work has functioned both as a form of punishment for people with IDD as well as therapy, while now paid work is proposed to symbolise societal and political 'equality or citizenship that invites participation in society '(Johnson et al., 2010, p.99). The goal of inclusive labour market participation was a key feature of the seminal green paper *Valuing employment now* (DH, 2009b), which still is the only UK policy document to have focused solely on work for people with IDD (Humber, 2014). Therefore, the static growth figures in employment of people with IDD suggests a lack of equality which can be critiqued with occupational therapy and science concepts of occupational injustice (Hocking, 2017) and occupational deprivation (Whiteford, 2000). Wilcock & Hocking (2015) defined occupational justice as the provision of equitable resources and opportunities 'to do, be, belong and become what people have the potential to be and the absence of avoidable harm' (p. 414). Hocking (2017) went on to frame occupational justice within social justice and the treatment of people with respect alongside equity of societal resource distribution. Similarly, Whiteford defined occupational deprivation as a state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual (Whiteford, 2000) and Wilcock and Hocking (2015) explicitly identified lack of access to work as an example of occupational deprivation.

The principal focus of the empirical research literature on work for people with IDD is the exploration of predictive factors associated with successful employment and the evaluation of outcomes. The predictive factors identified predominantly focus on the personal, educational and social situation of the individual with an IDD and the relationship of these factors to the likelihood of gaining employment. The personal factors contributing to or associated with gaining employment included, in part, the role of self-determination (Southward and Kyzar, 2017) milder levels of IDD (Nord, 2016) and family support (Gilson et al., 2018). Meanwhile, the experience of people with IDD in paid employment, the employment environment, the role of workers who support people with IDD into employment and the social and cultural barriers have received far less attention.

Definitions of what makes 'successful' employment for people with IDD appear to largely derive from policy drivers such as inclusion and improved quality of life and broadly indicate that being in employment leads to improvements in quality of life (Akkerman, 2016). However, the measures

and definitions of quality of life outcomes applied in the studies are varied and few studies involved people with IDD collaboratively in the research questioning the validity of some of the findings. Where greater collaboration did occur, rich data was gathered highlighting both positive and negative experiences taking place in the working environment and a desire to have increased opportunities in the workplace and to promote work skills (Akkerman et al., 2014). In Timmons et al's (2011) collaborative study the personal factor that was most important to people with IDD at work was gaining earnings (Timmons et al., 2011).

Within the small number of studies located conducted by Occupational Therapists it was suggested that both OT specific assessments (Coakley and Bryze, 2018) and OT specific work programs (Smith et al., 2010) could benefit individuals moving towards or in employment. However, only Ineson's (2015) single UK-based case study research explored supporting a person with a severe IDD into employment. When reflecting on the lack of success of this endeavour, Ineson (2015) highlighted the level of complexity she experienced including the lack of responsiveness from three employment agencies and the limited aspirations and condescension evident from the person's keyworker and home manager. In this regard Ineson (2015) demonstrated the complex barriers that surround people with IDD who are trying to access employment and consequently highlighted the importance of learning from and listening to people with IDD who have been successful in gaining paid employment.

Research Aims

- To illuminate the lived experience of people with intellectual and developmental disabilities who engage in paid work.

- To gain new knowledge that will inform employment support practices for people with intellectual or developmental disabilities.

Method

This research adopted hermeneutic phenomenology as its method. Finlay (2011) describes this interpretive approach as seeking 'to do justice to everyday experience, to evoke what it is to be human' (Finlay, 2011, p.3). It applied four characteristics of this approach; the use of interpretation; extending beyond science towards the humanities; researcher reflexivity; and attention being paid to expressive writing, with the potential use of myth or metaphor (Finlay, 2011). To enhance the written work stories crafted from the individual interviews in conjunction with the research collaborators, images were produced with support from an artist (photographer) who brought a combination of creative and interpretive expertise to the collaboration.

Consequently, the research applied inclusive research principles outlined by Walmsley and Johnson (2003) to address the power imbalances between researcher and research collaborators. Central to these four principles is the commitment to taking people's stories and words seriously and affording them credibility (Walmsley and Johnson, 2003). The phenomenological methods were underpinned by critical realist assumptions that a reality exists independently of consciousness, but that knowledge of that reality is always mediated through our consciousness (Finlay 2009). Thus, the interpretations of the participants' experiences and perspectives offered a mediated insight into a broader reality with potential relevance to other people and other contexts. The critical realist stance thus justified the inclusion of the more explanatory second aim to inform employment support practices and, as Shakespeare (2014) points out, aligns with the need to understand the complexity of disability in the social world.

Research Ethics

This research gained ethics approval via [Blinded for review purposes] January 2017.

Research process

The research process will be outlined in four phases that involved the creative collaborative partnership, the role of a photographer and subsequent image-making in enriching and supporting the communication of the research collaborators' experiences.

Phase 1- Research development

Consultation took place between the first author as lead researcher and a self-advocacy group of people with IDD who confirmed the value and importance of the proposed research and who reviewed and guided key ethical processes related to recruitment, data collection and analysis. Additionally, they piloted the semi-structured interviews which were constructed using domains outlined in the Model of Human Occupation (Taylor, 2017a) and the narrative framework of 'before work', 'the job' and 'future employment hopes'. For example, questions structured under the MOHO area of the Social environment included: 'Tell me about the people you work with? What do your family / carers think about your job?'

Phase 2 - Recruitment and data collection

Six research collaborators were recruited to the research with the support of work consultants from the region's employment support provider for people with a learning disability. All research collaborators provided written informed consent, following provision of accessible easy read research information. *Table 1 - Research Collaborator Demographics and Data Collection*, provides a summary of the research collaborators' demographics and the approach to data

collection and analysis. All collaborators names apart from the co-author have been changed for confidentiality purposes and collaborators have agreed to their information be shared.

Each research collaborator took part in two initial semi-structured interviews with the lead researcher. Crowther et al's (2017) approach to constructing hermeneutic phenomenological narratives was used to craft these transcripts into the narratives of each person's experience of seeking work, doing their job and hopes for the future. This process included: retaining sentences that held meaning; removing extraneous data, (i.e., discussion about pets or social activity since the last meeting); keeping content that held the story; supporting the story's flow by adding in words to link sentences; moving sentences to allow the organisation of the narrative; and reading it out loud to listen to how the narrative sounded. The narratives once constructed were then shared with the research collaborators and editing carried out with their guidance.

A minimum of three further meetings then took place with each research collaborator, the lead researcher and artist. In the initial meeting the research collaborator shared their narrative story and shaped and developed visual ideas with the photographer to agree the visual medium and subject of the visual component to their story. The collaboration with the photographer led to a highly individualised image creation outlined below in Table 1. Finally, the research collaborators revisited, reviewed and agreed both the narrative and visual aspects which made up their work story.

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Table 1 - Research Collaborator Demographic and Data Collection
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Collaborator **	Job	Age and Situation	Meetings	Visual description and titles
1. Jo (male)	Cleaner and café worker (P/T)	Age 29 Living with his sibling	1 meeting with work consultant and researcher 2 meetings for interviews with the researcher 4 meetings with photographer and the researcher, 3 at his workplace including one with a family member present	Title – 'A day in my working life' Jo took images of his working environment and tools around the site and the photographer constructed a photo montage with black spaces representing the breaks during his working hours (Illustration 1)
2. Rebecca (female)	Administrative assistant, (P/T)	Age 27 Living with her family	1 meeting with work consultant and researcher 2 meetings for interviews with the researcher 4 meetings with photographer and the researcher	Title – 'Work plan confidential' Rebecca's workplace was the only one that wasn't accessed during the study due to the sensitive data files she handled. Rebecca chose pictures that formed part of what looked like a clinical file (a tool in her workplace). The pictures in the file were about the fullness of who she is and not just her diagnosis. (Illustration 2)
3. Mark (male)	Assistant caretaker, grounds man, volunteer (P/T)	Age 31 Living alone	1 meeting with work consultant and researcher with subsequent interview with the researcher 1 further interview with the researcher 4 meetings with photographer and researcher including 1 in each work setting	Title – 'Working man' Mark was clear from the outset that he wanted portraits taken in each work setting, including engagement with objects that he was working with. 6 portraits were taken in all, two

				in each setting (Blinded for review purposes).
4.Tabitha (female)	School catering assistant (P/T)	Age 31 Living with her family	1 meeting with work consultant and researcher 2 meetings for interviews with the researcher 2 meetings with photographer and researcher	Title for film – 'Never think doing a job is easy' A short film focusing on Tabitha's doing the task aspects of her job including filling milk and water jugs, taking out the rubbish etc. A still from the film forms Illustration 3.
5. Jennifer* (female)	Volunteer (P/T)	Age 44 Living with her husband	1 meeting with the work consultant and researcher 2 meetings for interviews with the researcher 2 meetings with the photographer and the researcher	Title – 'Waiting to bloom' Jennifer's image was a split image of her working in a florist (the job she desired) and her voluntary cleaning job. (Blinded for review purposes)
6.Kenneth (male)	Cleaner (P/T)	Age 40 Living alone	1 meeting with work consultant and the researcher 2 meetings for interviews with the researcher 2 meetings with photographer and the researcher	Title – 'Working with an analytical eye' Kenneth's image is a picture of the stairs that he cleans with descriptions on the image of how he sees and can fixate on the environment. (Blinded for review purposes)
*Jennifer had shown interest in the research at the time of being in employment, but lost her job prior to sharing her story. ** All names apart from the co-author have been changed for confidentiality purposes.				

Phase 3 - Data analysis

The six work stories (the written words and the images) were then analysed by the lead researcher individually and as a collection of six narratives. This analysis involved applying a hermeneutic reduction through dwelling with the stories and seeking emergent essences and meanings within them (Finlay, 2011). This produced a synthesis of insights that applied to the collection of stories. This involved close attention to language and metaphor to identify five emergent narrative frames. A group meeting with all the research collaborators then took place where the narrative frames were shared and a public exhibition of the photographs and written stories planned and curated collectively ().

Phase 4 - Dissemination

The public exhibition took place in a city library to share the work stories and visual / video images () with all research collaborators taking part. Additionally, a commitment was made to collaboratively presenting findings either through virtual content or pre-recording at national and international events.

Trustworthiness and verification

Trustworthiness was assured by the adoption of inclusive research principles jointly applied with the research collaborators. Intersubjectivity, namely the recognition of an intertwined understanding between the researcher and research collaborators, was adopted in the research (Finlay., 2011) and openness and rigour within the research process was supported through use of a reflexive diary by the lead researcher and by doctoral supervision. Verification, or the act of confirming the stories, was jointly owned with the research collaborators who reviewed, agreed and edited their work in collaboration with the researcher and photographer. Similarly, the narrative frames were shared with the research collaborators for resonance rather than validity, as reality of the first-person experience was not in question.

Findings

The findings of this research were firstly the six research collaborators' combined narrative and visual work stories, a full record of which can be located in the public exhibition catalogue () and secondly the five narrative frames drawn from the joint consideration of these 6 stories.

As neither the entire work stories' narratives nor all the images can be shared in this article, one of the authors, who collaborated in this research, has supported the selection of example images. A

summary of the development of the narrative frames has been collated in *Table 2 - Analysis Overview.*

Table 2 – Analysis overview

Collective narrative frame	Research collaborator narrative
The quest 'to do' The quest narrative emerging of the enduring pursuit 'to do' to work over many years.	'At the job centre 3-4 years: 'my nan went with me so if there were any awkward questions, they could ask her' (Jo) 'It took an awful long time to get where I wanted to be' (Rebecca) 'It was frustrating when I had applied for a job and they didn't reply or told me they couldn't offer me the job. So, I just kept on looking. At times I did feel a little bit fed up. But well, I just kept on looking' (Mark) '...lots and lots of different types of jobs' (Tabitha) 'I'm proud like you know I've done something… in the community' (Jennifer) 'Existing in this 'no man's land' what am I to do?' (Kenneth)
Forging of identity Descriptions around self-identification relating to IDD and the experience the impact of this alongside labels imposed by others and a search for the role of worker.	'Having an LD made it hard for me to find work, travel and reading and writing.' (Jo) 'Disability sounds demeaning at times" (Rebecca) 'I don't mind the term learning disability' - 'I do find it hard to talk to people at times' (Mark) '…when I'm spot on, I'm spot on, when I'm not I'm terrible' (Tabitha) 'I was like very slow and apparently you have to be quite quick' (Jennifer) 'can be hyper-focused consumed with detail' (Kenneth)
Navigating bureaucratic seas Descriptions in each story of protracted journeys seeking work and ineffective or insufficient support.	'I didn't ask why they didn't find me work' (Jo) '…a lot of false promises' (Rebecca) 'I kept on applying for jobs in that time. I know I've applied for a large number of jobs. I was always looking for paid work'. (Mark) 'There was the time I was at the job centre for two years and that's bad enough. What they do is after two years they give you two options. You go into college again…' (Tabitha) 'I've been looking for so many jobs and because something which we found I had my hopes up and then it just didn't happen' (Jennifer)

	'The feelings I have are always one of disappointment, disillusionment of things not quite working out, me ending up feeling like I've not fully pulled my weight, and me feeling like the people, the job coaches, support workers… haven't pulled their weight' (Kenneth)
Finding a 'good fit' An evident sense of connectedness with his work setting and job competence indicating belonging – Also the opposite of not having a good fit is communicated.	'I'm most proud of all of it all really' - 'When it looks clean and sparkles' (Jo) '… you're going to get there eventually and it's going to be great' (Rebecca) 'I feel proud I'm helping to keep the warehouse clean and sometimes do people a favour…helping everyone' (Mark) 'I hope in the future to have a part time paid job for 10, 14 hours a week. I don't know what kind of job because I've been looking for so many… '(Jennifer) 'After this, what work I don't want is easier to say than what I do want because what I do want is kind of impossible, it's not realistic (Tabitha) 'I don't enjoy coming here for one moment. I don't like this place… I feel trapped being here because if I weren't here what else would I do?' (Kenneth)
Finding both friend and foe Narratives described both positive examples of crucial support both at home, in services and the workplace and also negative experiences that hindered and challenged.	'…they're nice people at work'. (Jo) 'The learning impairment doesn't affect my job, not really, if anything it helps. Makes it a bit of a pain to find work, because people don't understand it correctly'. (Rebecca) 'The work consultant used to be a member of staff at the Centre and he referred me to them. It was both our idea to look for paid work' (Mark) '…love my team if I didn't have my team, wow' (Tabitha) 'I suppose I started looking for paid work because, like, I had ESA (employment and support allowance) for a year and then they stopped it… Luckily my family has been helping me financially. Even with a job I don't know I might still need their help. (Jennifer) You know, my family were very hostile to the idea of me becoming unemployed due to my mental health…' (Kenneth)

The quest to do

Within the lived experience of the six collaborators' work stories, was an often relentless pursuit of work-related activity, replete with challenges, towards the ultimate goal, which was to 'do 'a specific job, or, for most collaborators, any paid job.

'It's quite hard really to say what job I would want to do. It's difficult, cause like, I did a floristry course at college for two years and I did work experience in a florist and that's what I wanted to do. I didn't get it. So, anything, anything really.' (Jennifer)

'Doing' was also a key feature of the visual component of the creative collaborative partnerships. Four of the research collaborators represented their work in the act of doing it. This was most significantly demonstrated by Tabitha in her video filmed in her work place (Still image – Illustration 3), but was also exemplified in the collective still images taken by Jo 'A day in my working life' of his work routine and tools (Illustration 1).

Illustration 1 – A day in my working life

Forging of identity

The narrative frame 'forging of identity' was drawn from the stories, referencing the experience of having an IDD and pursuit of the worker role identity. The research collaborators were asked what the label of IDD or learning and intellectual disability meant to them, as well as being asked about the impact of their IDD on their experience of work.

'I tried nursery at one point, I thought I could get into nursery, that's when it hit me, I had a disability actually. What happened was I was told I had to be more aware... Aware of my surroundings I forget things that are so normal, ah.... it's hard, sorry. It's really complicated.' (Tabitha)

Similarly, the narratives contained references to what appeared to be imposed labels about having a disability as identified in the quotation below from Rebecca who, working with clinical files, choose to use the file in her image to challenge the labels and expectations she felt people had of her in her image 'work plan confidential' (Illustration 2).

'I don't want to go round carrying cards saying: 'I have this that and this please be careful', you can look a bit of an idiot. I think that if it's really going to affect you in life, to be honest. 'She's a moron', 'Don't speak to her she's weird'. Mainly it's what I think people think but some people just give me stares sometimes. I think sometimes I look threatening. I don't like to say 'I'm special, treat me different', I don't want to do that. I want to be treated like everybody else'. (Rebecca)

Illustration 2 – Work plan confidential

Navigating bureaucratic seas

The next narrative frame that emerged from the collective stories related to 'navigating bureaucratic seas', highlighting challenges of negotiating extended bureaucracy and systems within the social, cultural, structural and physical environment. This included a sense of being unsupported and processed within bureaucratic systems.

'I did used to see people from the job centre for a few years, but they were not really helpful in finding paid work' (Mark)

For Kenneth this system was all the harder to bear due to the strong sense of negative social judgement:

'There's no understanding of how people like me struggle with the world of work. It's like if you don't work or you're doing a very menial level type of work for a very short length of time like I do that somehow you know, it's one step up from being a complete lay about or scrounger'. (Kenneth)

Finding a good fit

The focus of the quest illuminated in the work stories was to gain a job that is 'a good fit', specifically a job that the collaborator was happy and content in. Of the six collaborators, there appeared to be an equal split between those who had a sense of having found 'a good fit' in their work (Jo, Rebecca and Mark) and those who were still searching (Tabitha, Jennifer and Kenneth).

Finding 'a good fit' was characterised by a narrative including a sense of arrival, belonging, contentment and competence in work. It was particularly represented in the visual images of Mark's where he chose to have self-portraits taken in each (three) of his paid and voluntary work settings.

'I get two 15 min breaks and half an hour for lunch. I normally sit in the canteen and relax.' (Mark)

Alternatively, the collaborators who had not achieved a good fit in their work, or (as in Jennifer's case) did not have paid work at the time of the study, included descriptions of a sense of disquiet, discontent, unsettledness and ongoing pursuit of something more.

'I'd like two jobs I could do without stress. Stress is the most annoying thing. I mean, to be always striving.' (Tabitha,)

Finding both friend and foe

The environment also formed the basis for the final narrative frame. This related to the role of people in supporting or restricting access to and engagement in work: 'finding both friend and foe'. The presence or absence of support contributed strongly to the sense of success or failure in pursuing the work goal.

Personalised and skilled employment help was highly valued.

'The most helpful support to finding work was probably the (Access to work) funding getting there, the taxi money. The most helpful people were the employment support provider as they helped me find this job.' (Jo)

Support and camaraderie from co-workers was similarly greatly appreciated particularly when the role was challenging, as described in Tabitha's video title 'Never think doing a job is easy'.

'The best bit of my job is working with those girls. They are really good, when I first got to the school it was really weird, I got a big 'hello'. I've got the group who are really nice. I've got the gatekeeper who is really nice. It's my team and that's what I'm going to say, it's my team.' (Tabitha)

Negative features of social or working environment were also found in many collaborators' work stories. These included difficult experiences with work colleagues and unwelcome expectations from family members.

I know my husband wants me to have a paid job and my mother in law. She desperately wants me to get a paid job... She was over in April and she said, 'have you found one' and 'how are you getting on' and I said 'no I'm still looking' and one time she came with me to a meeting and I wish she wasn't there, and she was like interfering and it felt uncomfortable. (Jennifer)

Illustration 3 – Never think doing a job is easy

Discussion and implications

The six work stories and five narratives frames illuminate the challenges that people with IDD encounter either at work or in their attempts to find work that is meaningful to them. They also reveal some positive experiences of work and point to explanations for these. Increased understanding of these challenges and positive experiences may inform future work-related support for people with IDD. These are collated in *Table 3 – Findings summary*. Although the only known comprehensive first-person study of people with IDD's experience in paid work, the findings corroborate previous research findings and resonate with related theory.

In the narrative frame '*The quest to do*' the collaborators collectively articulate a drive 'to do' 'any' kind of paid work. This focus was also observed by Lindstrom et al. (2014) who highlighted the primary attribute of work when they used a quotation from a carer in their study for the title of their paper: 'Just having a job'. This quest also echoes with the universal need 'to do' as outlined by Wilcock and Hocking, (2015). However, as Wilcock and Hocking (2015) state, doing does not exist in isolation but is situated in a broader world. Therefore, it is possible that societal pressure 'to do' work, experienced as a demand or requirement for people with IDD and inherent within policy drivers may also contribute to this drive 'to do' (Johnson et al., 2010; DWP and DH, 2017). Being in employment in the UK has been aligned with citizenship (Johnson et al, 2010) a feature evident in this research. All research collaborators communicated that they were 'work-able' as identified their choice of exhibition title. In this they stressed the importance of being viewed as occupationally able and owning the role of worker as opposed to being viewed as disabled. These experiences reinforce the importance of consideration being given to employment for this occupationally deprived population. At the same time they draw attention to the fact that people with IDD may be particularly vulnerable to the risk, identified by Sage (2019) in his analysis of the large scale European Values Study, that privileging work identities above all others may undermine well-being and sense of selfhood for people out of work or in work which they consider is not valued by wider society.

Alongside variable identification with the worker role, the narrative frame *'forging of identity'* demonstrated a range of experiences and feelings towards terms that they or others used to describe them as a person with IDD. Many collaborators experienced or feared derogatory and abusive terms. But even for more neutral terms, such as 'learning disability' or 'impairment', the extent to which people with IDD chose the terminology themselves appeared central to whether they experienced it as helpful or unhelpful. This coheres with disability scholar Tom Shakespeare's (2014) argument that in consideration of disability identity it may be useful to consider 'labels and badges' (p.95) in which being given a label is likely to be experienced as negative and stigmatising whereas choosing a name or a badge is more likely to feel positive and empowering. As well as challenging overtly stigmatising and insulting language those supporting people with IDD should acknowledge the value of allowing people with IDD to decide how (if at all) they describe their IDD status to others at work

Experiences of being labelled was one aspect of the broader range of challenges and barriers that people faced *'navigating bureaucratic seas*' to find and maintain work. Without exception all collaborators engaged with protracted public sector bureaucratic processes in seeking work. These findings were also apparent in Ineson (2015) when she identified environmental, societal

and prejudicial barriers and noted the 'chasm' between policy aspiration and the experience of her participant who had a severe learning disability.   The presence of these barriers support Oliver's (2013) perception that the social model of disability had left employment systems unaltered despite the 30 years since its creation. Similarly, it reinforces the continued need for occupational therapists to address occupational deprivation and occupational injustice at broader societal and cultural levels (Whiteford 2000, Hocking 2017).

'Finding a good fit' in a paid work settings was experienced by three of the six research collaborators. Features of this included feelings of competence, contentment and belonging in their work environment where the quest for work had been achieved. This accords with Wilcock and Hocking's (2015) definition of the features of occupational interaction as 'doing, being, belonging and becoming' (p.134) and Lysaght et al. (2012) associating 'belonging, reciprocity and need fulfilment '(p.1339) with inclusion. Similarly, as Johnson et al. (2010), state the findings resonate with the assertion that work can provide 'companionship, relationships, intrinsic interest, and a sense of belonging and contribution that brings benefits '(p.109). However, Johnson et al (2010) challenge the suggestion in policy that work equally brings financial autonomy or betterment for people with IDD. The collaborators' experience of part time employment in receipt of a low wage would support this assertion. While only a group of six people, all research collaborators continued to require support from their family and/or the UK benefit system indicating a challenge to achieving financial independence. This is in keeping with other findings which explored work-based outcomes for people with IDD (Lindstrom et al., 2014). Replacing such means tested benefits with a 'Universal Basic Income' (Standing, 2017) could be one solution to this.

For some research collaborators '*Finding a good fit* at work was associated with good health and well-being, whereas for others being unable to find work (one collaborator's experience) or having a poor fit in work had a detrimental impact. In these three collaborators stories there was a continued quest and a sense of it being 'impossible' or 'not realistic' for their job hopes to be realised. These findings echo Iriate et al's (2014) findings that some people with IDD felt they had no choice but to stay in a job they did not enjoy. Unfortunately, as a recent British government report found, these experiences are not exclusive to the collaborators in this research but are experienced by many people working in contemporary Britain (Taylor, 2017b).

The importance of the social environment in predicting the success or failure of accessing and sustaining work was identified by all research collaborators and was contained in the frame '*finding both friend and foe*'. The term 'friend' or positive support included direct support from family members, work colleagues, managers and individual employment support workers. The

positive impact of these social factors has been noted in other research findings. The importance of family advocates were identified by Gilson et al., 2018, while the contribution of positive employer relationships in the work setting was noted by Lindstrom et al., 2014 and the value of trained employment support found by Nord, 2016. Similarly the presence of ineffective or unsupportive people in work or support services and negative family or social pressure were linked to collaborators' experiences of a poor fit in work.

Negative experiences of the social environment or lack of inclusion in the workplace have been identified in other studies which have included self-report from people with IDD (Akkerman et al., 2014). The potential negative influence of familial expectations on work related outcomes remains unexplored in literature at this time. Nevertheless, the extended impact and duration of, at times, repeated negative interactions with the social environment are a unique insight of this research. The implications are that the social environment must be a key consideration for occupational therapists and others assisting people with IDD to secure or maintain employment.

Table 3 – Findings summary

Positive experiences	Key challenges	Practice Implications
All collaborators communicated a desire to be viewed as work-able, namely having an identity as an occupational being.	Privileging work identity above all others may undermine well-being and a sense of selfhood for people with IDD	It is recommended that work is considered and supported for this occupationally deprived population.
All collaborators when given the opportunity choose specific descriptors of their disability clearly self-identifying.	Collaborators described experiences of labels being applied that were negative and stigmatising.	It is recommended that in addition to challenging discriminatory labels for people with IDD, people are given an opportunity to self-identify in relation to their impairment.
3 collaborators had a positive fit in their work describing feelings of competence, contentment and belonging in keeping with definitions of inclusion.	3 collaborators who either were not in work (1) or experiencing a poor fit in work (2) described work as having a detrimental impact on their health and well-being.	While not exclusively experienced by people with IDD, consideration should be given to people whose work is having a detrimental impact on their health and well-being.
All collaborators recognised the importance of achieving paid work following often many years of voluntary work.	All 5 collaborators in paid work at the time of the study, did not secure financial autonomy from their work which was low paid and P/T.	It is recommended that attention is paid to the shortfall between policy aspiration and the experience of people with IDD related to the financial renumeration of employment.
Experiencing a supportive social environment at work and home was a key feature of a positive working environment and good fit in a job.	Working in an unsupportive or negative social environment at work had a detrimental impact on the person's health and well-being.	It is recommended that consideration of the support of the social environment is crucial for anyone assisting people with IDD to secure or maintain employment

Limitations

Although highly rich phenomenological occupational written and visual narratives were created describing the lived experience of seeking and being in paid work with an IDD this only included six individuals from southern England. Furthermore, the research collaborators who participated in the research did not include anyone with a moderate to severe IDD. This indicates a need for further research to establish if the experience of these research collaborators resonates more widely in the IDD population of people with differing needs. Further research examining the breadth and effectiveness of OT's support in and around employment is indicated.

The application of the creative collaborative partnership was found to support inclusive research principles. However, the study was not fully inclusive in every research phase i.e.: due to challenges of geography and time, the research collaborators were not involved in co-creating the narrative frames.

Conclusion

This paper promotes the importance of the first-person occupational narrative in illuminating the experience of the small number of people with IDD in paid employment. It highlights the pressures and successes experienced by people with IDD in work and demonstrates the importance of taking seriously the desire to work whilst equally not privileging work identity above all else.

The implications for occupational therapists include the suggestion to widen practice considerations when supporting a person in relation to work including allowing people with IDD to decide how (if at all) they describe their IDD status to others at work. A further implication is to support people to identify allies in their social environment that may help them to secure and retain work and to challenge unhelpful or negative behaviours encountered from others. The findings point to the needs to adopt a nuanced systemic understanding that goes beyond a focus on the individual to consider the complex social context of work and working in contemporary society. The occupational therapy profession should draw on this understanding to actively participate in influencing social policy relating to the meaningful participation in work of people with IDD. The 'creative collaborative partnership' is a positive method for supporting inclusive research with people with IDD and other groups of people who may be deemed vulnerable.

Key findings

• People with IDD faced major challenges finding paid work.

• Work experiences were mixed and complex with aspirations often unmet.

• Participants appreciated allies who understand their systemic and individual challenges.

What has the study added

People with IDD aspire to meaningful work and appreciate support to secure and sustain it. This entails a nuanced and critical understanding of the individual and social challenges they face.

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