UNIVERSITY OF BRISTOL

University of Bristol - Explore Bristol Research
General rights

Taylor & Francis
Taylor & Francis Group

An ethnography exploring the limits of dedifferentiation in the lives of adults with intellectual disabilities

C. A. Banks , R. Gooberman-Hill & D. Wainwright

Published online: 06 Oct 2020.

Submit your article to this journal ⏎

Article views: 424

View related articles ⏎

View Crossmark data ⏎

Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

🔓 OPEN ACCESS   Check for updates

An ethnography exploring the limits of dedifferentiation in the lives of adults with intellectual disabilities

C. A. Banks 🅐 [a]*, R. Gooberman-Hill 🅐 [b] and D. Wainwright 🅐 [a]

aDepartment for Health, University of Bath, Bath, UK; bTranslational Health Sciences, Bristol Medical School, University of Bristol, Bristol, UK

ABSTRACT

Background: Dedifferentiation refers to the trend of positioning people with intellectual disabilities together with other disabled individuals for political purposes, to act as a counter to differentiated approaches. This article explores the influence of dedifferentiation in professional support settings through the lived experiences of people with intellectual disabilities and their staff.
Methods: Ethnographic research, including participant observation and interviews, conducted with an intellectual disability social care provider and an independent community café, both based in an area of England.
Results: Tensions exist between dedifferentiation aims and the lived experiences of people with intellectual disabilities, who often struggled to achieve in areas including independent community inclusion and paid employment.
Conclusion: Dedifferentiation has disadvantages for people with intellectual disabilities. It can underestimate and mask needs that people experience in relation to their disabilities. Policy and professional support might be improved by (1) recognising these limits and (2) incorporating people's real-world needs into support provision.

The positioning and influence of dedifferentiation in intellectual disability policy and practice

During the twentieth century, policies and services for people with intellectual disabilities in liberal democracies experienced periods of significant change (Thomson, 1998; Toms, 2017). Rather than segregating people with intellectual disabilities from what could be termed as mainstream society – through, e.g., accommodation, education and health care – the central aim of policy was transformed to focus on including people with intellectual disabilities into mainstream life.

From the 1990s, this shift was further consolidated by dedifferentiation (Sandvin & Soder, 1996); a term that emerged out of the social model of disability movement, itself arguing that it is social relations and institutions that disable people rather than their impairment(s) (Oliver, 1983).

Dedifferentiation describes the move away from categorising people with disabilities by their pathology and towards thinking about and seeing all people with all disabilities as a whole group who should be afforded the same rights and opportunities as non-disabled groups. This stance is evident in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), which largely does not differentiate between intellectual and physical disabilities. The implications of this for people with intellectual disabilities are that the design of policies and services are based on assumptions around positioning them on equal footing with people without intellectual disabilities. These approaches continue to shape intellectual disability policy and practice in the UK (NHS England, 2019) as well as in other developed countries (United Nations, 2010) where equal forms of independence and access to community life are central policies aims.

There is evidence to show that some people with intellectual disabilities have benefited from such policies. For example, more people have since moved into community settings (Burton, 2004), have relationships with others, including sexual relationships (Rogers, 2009), and paid employment continues to be a main policy goal (Department for Work and Pensions & Department of Health, 2017). Yet, research findings on the benefits of these changes are equivocal. To take employment as a case in point, the tendency to group people with intellectual disabilities with people with other (non-intellectual)

---

disabilities is problematic. For example, in their 2017 manifesto, the Conservative Party stated that they would achieve employment for 1 million more disabled people by 2027, but they did not specify initiatives aimed solely for people with intellectual disabilities (Department for Work & Pensions & Department of Health, 2017).

The continued focus on paid work is concerning given that rates of employment for people with intellectual disabilities remain extremely low. In 2019, Public Health England (PHE) reported that of all the adults with intellectual disabilities known to services, 6% were reported as being in paid employment, and over two-thirds (68.3%) of these jobs comprised fewer than 16 working hours per week. This is compared with 52% of people with disabilities that do not affect cognition and 82% of people without a disability. Further, PHE states that these rates "do not seem to be" increasing over time (2019), suggesting that grouping people with intellectual disabilities with people with other disabilities may be masking the reality of employment figures for people with intellectual disabilities.

Elsewhere, despite community inclusion remaining an enduring policy aim, studies have found that the type of inclusion aspired to within these policies – where people with intellectual disabilities access services and resources without professional support – continues to elude many people with intellectual disabilities (Simpson & Price, 2009; Power & Bartlett, 2018). Permeating many of these studies are the ways in which there is a struggle to find a balance between respecting the autonomy of people with intellectual disabilities with the need to protect them from harm. Such tensions are elucidated by Hawkins et al. (2011) whose ethnographic study explores support for people with the genetic condition Prader-Willi syndrome and how, because of behaviours associated with this condition, these tensions are acutely felt.

The evidence on dedifferentiation is at best confusing, and there is a need to better understand how policies and care models influenced by this trend are experienced in people's everyday lives. This article reports findings from an ethnographic study with organisations supporting people with intellectual disabilities based in an area of England, consisting of one large and one small city. The study explored how government policies, that are influenced by dedifferentiation trends, were experienced and played out in the lives of people with intellectual disabilities and the staff supporting them.

Research setting

This research was funded by the Economic and Social Research Council (ESRC). In June 2014, the study received approval from the Social Care Research Ethics Committee (protocol number: 14/IEC08/0019) and from a departmental research ethics committee at the University of Bath.

The findings in this article are a subset of a wider ethnographic study conducted from July 2014 to April 2015 (see Banks, 2018). Presented here are findings from fieldwork conducted with an intellectual disability social care provider organisation called Singertree Trust, and Station Park Café, an independent community café offering volunteering opportunities for people with intellectual disabilities (for anonymity purposes all names and places have been assigned pseudonyms). Singertree Trust was at the time of conducting the research a national registered charity providing housing and day service support for adults and children with intellectual disabilities and/or autism. Housing services included supported living, residential and nursing care. Day support services included employment training, therapeutic services and day centre services. Station Park Café was at the time of conducting the research an independent community café run in conjunction with the adjacent church, and provided volunteering opportunities to people wanting to become part of their community. Volunteers were mostly made up of older people and people with intellectual disabilities. Both organisations were situated in the local area and some people receiving support through Singertree Trust also volunteered at Station Park Café.

Methods

After identifying a local organisation, Singertree Trust, the research team arranged a meeting with the senior manager who agreed that the organisation would participate in the research. Together with a colleague, the senior manager identified people with intellectual disabilities who could be approached and asked to participate in the study. Selection criteria included identifying a range of individuals to reflect different housing and support circumstances, as well as individuals who the manager believed would not become distressed by taking part in the research. Arrangements were made to visit these individuals in their homes and invite them to take part in the research.

The other organisation presented here – Station Park Café – was identified through a snowballing approach (Vogt, 1999). Station Park Café employed people with intellectual disabilities on a voluntary basis and was managed by Steve Connors, who was interviewed to understand the role people with intellectual disabilities played in the café, as well as the ethos and intentions behind involving them in work-related pursuits.

We outlined the research to potential participants in a Participant Information Sheet (PIS), and explained how consent would be obtained and recorded prior to participation. People with intellectual disabilities were offered easy read versions of their document. All individuals asked agreed to take part.

As the research involved people with intellectual disabilities who might require support from others when deciding whether to participate, potential participants were given an extended period of up to 2 weeks to decide. Both support staff and people with intellectual disabilities were asked to provide formal consent through a written signature. Where necessary, people with intellectual disabilities were given the option of providing verbal consent, validated in writing by a family member or member of staff who was familiar with the person, and could confirm whether consent had been given. The authors acknowledge the benefits and disadvantages of proxy consent (Wrigley, 2006) but took the decision for this study that the benefits outweighed the disadvantages.

Three to five days per week were spent in the field, with days generally lasting between 6 and 8 hours. Fieldwork consisted of participant observation with people with intellectual disabilities and the people supporting them in a range of settings at Singertree Trust, including supported living and residential care homes, day centres and employment training services; as well as within the front and back of house of the independent community organisation, Station Park Café. Observations, interpretations and informal conversations were recorded in field notes after each visit. In-depth interviews were conducted with support staff and managers, all of which were audio-recorded, and were used by the researchers to discuss observations and interpretations that had been made in the field. The majority of people with intellectual disabilities said that they found formal interviews difficult. To respect this, less formal conversations took place during participant observation, and were recorded in field notes.

Analysing the ethnographic material

Prior to commencing fieldwork, a documentary analysis (Coffey, 2014) was conducted of academic and grey literature on intellectual disability government policy, including existing critiques of this policy, and empirical research conducted in this area. Once fieldwork material started being captured through field notes, and latterly interviews, these were annotated and then coded using a combination of inductive and deductive coding approaches. These approaches were used iteratively to explore the material in an open-ended way, as well as to structure the material after early themes had begun to emerge. Such a combined approach acknowledges the interplay between context, structure and agency (Layder, 1998). From here, codes and early themes were developed (while the researchers remained open to other possible interpretations) to structure the material and to draw together early inferences about what was going on in the field. Although what people frequently said and did, and the commonalities between these, were considered to be significant, the researchers were also interested in what was not said/left unsaid as well as the dissonances between accounts and actions. Themes relating to the findings in this article include the tensions and contradictions around employment training services and paid employment and state-led community participation.

As field notes were recorded, aspects that were considered to be significant were highlighted/marked for concern. At the end of each week of fieldwork, entries were re-read and areas that had previously been identified as significant were reconsidered. Word documents, and where appropriate diagrams, were produced with headings, short summaries and phrases describing codes and early themes. As fieldwork progressed, these codes and early themes were reviewed for significance and accuracy. Into the latter stages of fieldwork and analysis (when interviews took place), field notes and interviews were considered side-by-side, so that thick description could be achieved (Geertz, 1973), and context retained throughout analysis and interpretation (Auerbach & Silverstein, 2003).

Findings

The ethnographic material presented here are a carefully selected subset drawn from participants and settings involved in a wider ethnographic study (see Banks, 2018) comprising a number of organisations supporting people with intellectual disabilities. The subset presented here are ethnographic vignettes or portraits selected because they elucidate the issues around dedifferentiation. Rather than being sampled on characteristics such as sex, gender, age or level of disability, individuals' experiences were selected on the basis that their stories best illustrated the themes under discussion.

We present ethnographic material collected at Singertree Trust with three men with intellectual disabilities and a range of their supporting staff. Of the three men with intellectual disabilities, one man, Ray, was in his 70s and living in a residential care home called Chatsview Road. We present ethnographic material collected with Ray and his supporting staff at Chatsview Road, as well as at a service called Goatsgruff farm that Ray attended daily.

The other two men, Mark and Joey, were in their mid-20s and living together in a supported living home called Sanderstead View. We also present ethnographic material collected with some of Mark and Joey's support workers, David and Emily, who worked at Mark and Joey's supported living home; and Jane and Samantha, who provided support at Mark and Joey's employment training service, Pigtree Farm. Extracts are also presented from a public talk given by Singertree Trust's CEO when speaking on a national media outlet. Finally, we present interview extracts from Steve Connors, the manager based at Station Park Café, an organisation offering volunteering opportunities to people with intellectual disabilities.

The problem with independent community inclusion

Sanderstead View, one of the supported living houses within Singertree Trust where Mark and Joey lived, was known as a "transitions" house. This is because it had been established with the aim of supporting young adults in making the transition from children's to adults' services, a process acknowledged as difficult to get right (Care Act, 2014; Patton & Viner, 2007). The eventual aim for the transitions house was to enable the people living there to become less reliant on their support staff. The organisational view was that this would lead to as much independence and involvement within their local communities as possible.

A key aspect of attempting to achieve independence in community life involves how local authorities calculate people's support hours on the principle that they should not be supported when they do not need to be, as this creates unnecessary dependence on staff. This principle was reflected in Mark and Joey's support hours as each man was funded fewer than 20 h of support a week and these hours were often used to assist them in completing day-to-day domestic tasks and responsibilities – such as shopping and housework – for which they required support. Mark and Joey's support workers, David and Emily, described how the fixed number of support hours Mark and Joey were allocated were not enough to enable them to do everything they wanted, which usually entailed social activities both inside and outside the home. Consequently, the men tended not to have enough support hours to enable them to engage in all the social activities they wished.

Another example of how Singertree Trust was attempting to achieve independence and inclusion for people with intellectual disabilities can be seen when Mark and Joey would go into the community with their support workers. During one food shopping trip, where Mark and Joey were accompanied by their support worker, Emily, Mark asked Emily if they could go for coffee and lunch. Emily said that this would not be possible, adding that it wouldn't be fun for her to sit in a café and watch them eat and drink. When Emily later reflected on this encounter, she explained how she used to do this with people she supported but that Singertree Trust had recently changed its rules in relation to staff expenses. In order to deter staff from remaining the default option for people with intellectual disabilities to access the community with, staff were now required to pay for their own food and drink if going out with people they supported: Emily said that this was not something that she was able to afford.

This issue of attempting to include people with intellectual disabilities within their wider communities and on their own terms was the selected topic of discussion by Singertree Trust's CEO when they were invited to speak on a national media outlet. The CEO posed the question of whether provider services are, in some ways, "part of the problem", in that although the professional support they provide to people with intellectual disabilities may be good, it may also serve to separate people from life "just as you or I understand it". This refers to the issue of professional support unintentionally encouraging people in receipt of support to become dependent on these services rather than forging their own relationships outside of their professional support circles. The crux of this discussion was summed up by Singertree Trust's CEO when they described how:

> Some aspects of this very carefully thought out support is all too quickly becoming an end to itself, and can even become a barrier between the individual and the world into which they are trying to get. If this carefully managed support doesn't actually act as a catalyst, connecting people to other non-paid people in the community, are we not creating another form of dependence? … These challenges are leading me to completely rethink the priorities I have. I am convinced that we need to respond to the deep cries within people for personal relationships. We have to find ways to enable people to genuinely connect to others in their community.

The views of the CEO at Singertree Trust on how such genuine connections with non-paid people can be achieved are echoed in the local authority policy to keep support hours to a minimum. Such views are also reflected in organisational policy at Singertree Trust around staff expenses. If left unchecked, both support hours and staff expenses were viewed organisationally at Singertree Trust as "another form of dependence" inhibiting people with intellectual disabilities from forming non-paid friendships in the community.

Paid employment: an unattainable goal

As part of working to enable people with intellectual disabilities to live more independent lives, Singertree Trust supported people to develop employment-based skills through training placements. The services themselves were designed to replicate real-life working environments, for instance, by concentrating on aspects of work ethos such as punctuality and productivity. The aim of employment training services had originally been to provide people with safe environments in which to develop workplace skills from which they could move into paid employment in the community. A manager at Singertree Trust explained that unintentionally these services often became permanent support settings for people. There were concerns among managers that these services were limiting people's ability to access their communities in independent ways. Recognising this, Singertree Trust was developing strategies to encourage people to move on from employment training services. This was reflected in the small department of job coaches that had been established to support people into paid employment outside of their support service.

Despite the problems voiced by Singertree Trust managers about employment training services, they were still widely used by the organisation, and included activities such as farming/gardening and arts and crafts. Within the farm work, there were a small number of paid employment opportunities in landscaping work, which involved the regular use of large lawn mowers. This work was carried out by the most physically able people with intellectual disabilities, who were usually young men.

Mark and Joey, the two young men living at the supported living property, Sanderstead View, attended Pigtree Farm employment training service several days a week where they both worked at the farm's nursery. Joey regularly kept himself busy and often appeared keen, asking support workers if he could take on jobs, which usually involved asking to use electric equipment and heavy manual tools. His attitude and approach towards his work was noted by Jane, one of his support workers, who remarked that because of his abilities Joey would soon be moved out of the nursery and into other areas of the farm. Work on the nursery was viewed as more straightforward than other areas of the farm, such as the paid landscaping work. Soon after he started working in the nursery, Joey asked Jane and his other support worker, Samantha, to move him on to landscaping work.

Whereas Joey appeared to be thriving under the farm's conditions, the researchers observed how Mark often struggled to get on in this environment. Quite often Mark would tell the fieldwork researcher or his support workers, Jane and Samantha, that he had pains in his stomach and needed to go home. Jane and Samantha would sometimes describe Mark as "lazy", saying that this was his way of trying to get out of doing work. Mark's perceived lack of motivation to engage had previously resulted in him being sent home by staff who felt that he was not doing his job properly. Despite this, however, we observed how Mark could become engaged when he was involved in activities he appeared to find fulfilling. Occasions when he chopped up wood or branches from trees appeared to ignite energy within him and he would become excited, taking on a managerial role and instructing everyone else what to do. However, Mark's support workers were often not comfortable allowing him to chop wood or take branches from trees, as they were concerned that he would injure himself, others or damage the trees.

Another participant was Ray Winder, an older man in his 70s, who lived at a residential care home, Chatsview Road. Ray's house manager described how the local authority considered Ray to be too old to benefit from pursuits such as paid employment or formal education. Instead, Ray had been allocated a gardening placement at Goatsgruff Farm. Along with a small group of other people with intellectual disabilities, Ray attended Goatsgruff Farm for around three and a half hours every morning. All work was carried out with assistance from support workers and included tending a nearby allotment, potting plants in the greenhouse, and doing arts and crafts.

Rather than being viewed as a step towards paid employment, and so greater independence, Ray's work at Goatsgruff Farm was framed in terms of therapeutic support, to provide him with a daily purpose. Support workers at Chatsview Road explained how Ray could be very "bossy" towards people in his house, which could be viewed by others as aggressive. They found that attending Goatsgruff farm was a tonic for Ray in enabling him to retain a balanced mood. Aware of the importance of farm work to Ray, staff decided to help him to start his own vegetable patch in the garden at Chatsview Road, in the hope that this would help further with what they perceived as his aggressive behaviour. Unfortunately, during the fieldwork period the vegetable patch became unusable because it had been built on a wall that began to subside. Although staff had alerted the relevant department at Singertree Trust about this, during the fieldwork period the wall remained unfixed. Both the researchers and staff at Chatsview Road observed how Ray was distressed by the loss of his vegetable patch.

During the fieldwork, time was also spent outside of Singertree Trust in a community-based organisation called Station Park Café, which provided voluntary opportunities for different groups of people, including people with intellectual disabilities. During an interview with Steve Connors, the manager who ran the café, he described how for a few years the café had done its best to make sure it included adults with intellectual disabilities in meaningful ways. He outlined the challenges of making this happen:

> Originally, that sometimes took the form of purely providing space, and sometimes we had so many adults with learning disabilities that they weren't really meaningfully occupied, and it felt like they were just being parked here to keep them safe during the day. About five years ago, we changed the format of the café slightly, and at the same time we made a decision that we would do all we could to ensure we would include adults with learning disabilities, but that they were here for a meaningful purpose. And as a result, we have at least one, usually two adults at any one time, helping us with clearing tables, taking out orders and other front of house duties … They get, I believe, in return, they get value and pride that they are giving a service, and they also get a rhythm of life.

In relation to the problem of meaningfully including people with intellectual disabilities in employment, Steve pointed out that the ethos at his café was very different to a conventional paid employment setting. At the café, value was not just about production, nor was it about moving on to what might be termed "real" work. Rather, it was about ensuring that people were supported and felt valued in the setting:

> It works here because our aim is to be a supportive, welcoming environment … when employment is competitive and is about producing things, it can be very hard for someone with learning difficulties to compete with that.

Steve gave an example of a man working at the café who was deafblind and a wheelchair user, explaining how ensuring that this man made a valuable contribution involved understanding what he could contribute in the context of the café. Steve described that this was about the importance of finding ways to ensure "we are giving people value", which was about having a set up with a range of things that people could do, and in ways that allowed them to see how what they did contributed to making things succeed. Importantly, he said, people with intellectual disabilities needed extra support to work out their role, what they were good at and how they could contribute.

Steve's descriptions draw out the contrast between the kinds of sheltered therapeutic work that was taking place in his café and "real" work as paid employment. This indicates the differences between work that measures value through economic productivity and work that measures value through people's individual contributions and ability to participate in society as a whole. For Steve, when working with people with intellectual disabilities, it was the latter type of work that was of focus, because this allowed people to feel that, however small their contribution, they were genuinely part of something.

Discussion

We have presented ethnographic material from intellectual disability support settings, showing how people in receipt of support and their staff experienced policies and services that have been influenced by the dedifferentiation approach to position people with intellectual disabilities on equal footing with other citizens who do not have intellectual disabilities. Dedifferentiation stems from important movements of the twentieth century calling for more equal terms for marginalised groups. Aspirations to achieve empowering and inclusive experiences for people with intellectual disabilities – individuals who tend to be able to exercise little power and choice over their lives – is understandable. However, our findings illustrate how there can be disadvantages for people with intellectual disabilities when policies and services position them on equal terms with people without intellectual disabilities. Framing intellectual disability in these ways can be problematic because it potentially means that the support required to meet the needs associated with people's specific disabilities are at risk of being masked, underestimated or missed altogether. This is evident in our findings above showing how independent community inclusion and paid employment outside of provider support networks were largely not attainable for the individuals with intellectual disabilities we spent time with.

The flaws underpinning notions of community inclusion

Notions of community inclusion that are influenced by dedifferentiation depict a largely romanticised view of people with intellectual disabilities as individuals able to take a central and commanding role in accessing their communities. Despite other scholars critiquing this (see, e.g., Burton & Kagan, 2006), such a view has remained a prominent feature of intellectual disability policy. This is indicated in the following excerpt from *Valuing People Now*:

> For all of us, rights come with responsibilities. Citizenship is also about contributing to society, in whichever

way we can. People with learning disabilities have traditionally been viewed as recipients of care and of services. But they, too, have a role to play as contributors. Wherever possible, people with learning disabilities should be supported to work, pay taxes, vote, do jury duty, have children, and participate in community activities or faith groups. Many people with learning disabilities in using direct payments or personal budgets will contribute to the economy by becoming employers. All these things benefit the wider society. (Department of Health, 2009, p. 32, para.16)

Elsewhere, the social model of disability (Oliver, 1983) – a precursor to dedifferentiation – also presents problems when considered in relation to the ability of people with intellectual disabilities to engage in community life. Arguably the social model of disability has had greatest success in achieving better access to community resources for people with physical disabilities than it has for people with intellectual disabilities. Its rallying cry has tended to be defined by exposing limitations caused to people by the physical environment, for example, inaccessible workplaces and transport systems. Although people with intellectual disabilities may experience challenges with physical environments, their exclusion also relates to cognitive and social aspects such as difficulties in learning new skills and in developing relationships with others. Crucially, there is a huge difference between altering physical environments to that of accommodating for the effects of cognitive impairments on people's ability to perform tasks and relate to others. This exposes deficits in the social model's attempt to emancipate intellectually impaired people in the same way as physically impaired people (Shakespeare, 2013).

Returning to the ethnographic material presented in this article, an idealised notion of community life where people with intellectual disabilities can fully exercise their individuality is apparent in the comments by Singertree Trust's CEO, who described how people with intellectual disabilities need to be able to experience life "just as you or I would understand it". We can see the expression of this through the organisational policy of eradicating staff expenses, the intention being that this would remove any existing barriers to inclusion that people with intellectual disabilities experience. This was a genuine attempt by Singertree Trust to disentangle itself from the paradox of State support – the contradiction that the provision of support can inadvertently create greater dependency on the State. However, when this policy was exercised in real life, we saw how, rather than encourage Mark to access the community on his own terms, it actually led to fewer opportunities for inclusion because Mark was unable to leave the house without the support of staff. He did not have – and was unable to

independently create – a social network outside of his support workers or family, factors that were further exacerbated by the fixed hours of support that Mark received. Taking away staff expenses removed what limited autonomy and choice Mark could exercise and showed how inherently dependent he was on staff to access community resources. Such an example illustrates how the lives of people requiring support to manage their lives can be intrinsically shaped by their dependence on others.

The CEO's view that people with intellectual disabilities have a deep desire for personal relationships is compelling. Indeed, Mark often expressed a desire to form relationships with others and once during a conversation said, "I might get a girlfriend next year. I want to go and find one". However, the hopes for these meaningful relationships being achieved by limiting time spent in his professional support context does not acknowledge the extent to which – as a person with an intellectual disability – Mark required these networks to engage in public life. The regular times that support workers were authorised to go out with Mark, such as during food shopping trips, then seemed to become occasions for him to transform into leisure activities with support workers. It could be argued that food shopping trips had provided Mark with an opportunity to spend time with his staff in places that were safe and familiar to him. However, after the organisational rule changes regarding staff expenses this was no longer something his support worker Emily felt able to do. Paradoxically, Mark's ability to engage with others and to fill his need for personal relations was made less possible as those individuals best placed to provide some form of this – his support workers – were prevented by the organisation's policy from doing so on the grounds that community inclusion should take place outside of the boundaries of their professional support networks.

These tensions that we observed playing out between Mark and his professional support echo those in Schelly's (2008) reflexive ethnographic account of supporting a person with intellectual disabilities and autism, for whom Schelly was expected to offer choice but in doing so caused the person being supported to become distressed. Such accounts show how, although independence and choice are benevolent and understandable aims, they can fall apart in practice when the experiences of people with intellectual disabilities are framed as synonymous with those of people without the same disabilities. This illustrates the importance of considering the individual needs of a person rather than adhering to a set of overarching abstract values that may not be relevant to a subjective, and indeed different, lived experience.

Employment: human value versus economic value

A similar kind of disconnect, to that seen in dedifferentiation-shaped approaches to community inclusion, also exists in the approach taken to employment. Organisationally, Singertree Trust placed less value on employment training services, viewing these services as inhibiting access to the same work opportunities that are available to people without intellectual disabilities. This was evident when job coaches were tasked with determining ways of moving people on from employment training and into paid work in the community. These objectives are described in Singertree Trust's own documents:

> Having a paid job should therefore be seen as the default outcome for young people with a learning disability, just as it is for their non-disabled peers. It isn't just about financial independence, but also social independence, learning new skills, meeting and interacting with people of different ages and backgrounds, being part of a local community, having a valued social role, improved mental well-being, increased physical activity, increased confidence, independent travel skills, gaining a sense of responsibility, being accountable to someone other than your parents, feeling pride in one's work, stepping towards the future, and not being bored – the list goes on.

The value placed on and time given towards promoting paid employment for people with intellectual disabilities stems from benevolent desires to improve people's lives; beliefs that are rooted in the emancipatory potential that comes with earning one's own money and being able to decide how to spend it. This notion of work as contributing to a sense of self is arguably a valid one through which governments attempt to find ways to include marginalised people in society and to improve their lives. Evidence suggests that some people with intellectual disabilities would like to work and view this as a means by which they are able to express themselves and feel ownership over their lives (Hall, 2005).

Yet, the rhetoric of paid employment as a real possibility for the majority of people with intellectual disabilities is not supported by other studies, which suggest that many people with intellectual disabilities are unable to enter into the workplace as productive employees on the same terms as people without intellectual disabilities (Verdonschot et al., 2009). This is solidified by reading employment figures for people with intellectual disabilities, which remain extremely low, with only a minority of people with intellectual disabilities able to secure jobs that are more than 16 working hours per week (Public Health England, 2019). Despite this, employment for people with intellectual disabilities is still heavily pursued by government (Department for Work & Pensions & Department of Health, 2017) and there continues to be confused views about the attainability of paid employment for people with intellectual disabilities. One reason for this may be because employment rates for people with intellectual disabilities are often grouped together with those for disabled people without intellectual disabilities.

In addition to misrepresentations of employment rates, evidence also shows that organisational diversity strategies – aimed at improving access to employment for disabled people – can become barriers for people with intellectual disabilities. A 2017 study by Moore, McDonald and Bartlett looked at disability-inclusive recruitment practices within a large Australian retail organisation, and found that despite organisational efforts to include disabled people into their workplace, grouping together all disability types under their organisational diversity strategy actually made it more likely that people with intellectual disabilities would be overlooked in favour of people without intellectual disabilities. This is because diversity strategies are:

> often understood in terms of efficiency and value adding to the demands of the operating environment. Hence, there is greater opportunity for managers to legitimise *not* employing people with ID compared to other diversity groups, as they may be perceived to be less efficient. (Moore et al., 2017, p. 9)

The ethnographic material presented in this article on paid employment initiatives at Singertree Trust reveal similar contradictions as despite the resources and time that were put into employment initiatives, for many people with intellectual disabilities paid work was not an achievable reality. Further, as was evident in Mark's experiences of work in the employment training service at Pigtree Farm, presenting paid work as a social aspiration that is attainable for the majority of people with intellectual disabilities can have insidious effects on people for whom this kind of work is not likely to be an option. As Redley equally states, employment policies cannot be "rooted in economic reality" (2009, p. 497) when this is not an inclusion solution that is going to work for the majority of people with intellectual disabilities.

For Steve Connors at Station Park Café, work for people with intellectual disabilities was valued in terms of social engagement and self-worth, rather than being motivated by economic status. The voluntary work that Steve was promoting at Station Park Café could be seen as similar to Ray's experience at Goatsgruff Farm, as both were about acknowledging the intrinsic human value of each person by finding what they were able to

do to contribute in the work context. Indeed, this value was recognised by staff at Ray's home who, in observing how farm work was helpful in balancing his moods, sought to bring this into his living environment by setting up a vegetable patch in the garden of his home. Yet, there is indication that the wider organisation missed or underestimated the value Ray placed on these pursuits when after the vegetable patch became unusable it was not fixed.

On the face of it, there are strong similarities between Singertree Trust's articulation of its employment aims with the kind of value-making that Steve described he was trying to achieve at his café. Problematically, however, when these ideas about value were translated into practice at Singertree Trust, rather than the focus being about the act of contributing in and of itself, huge importance was given to whether people were seen to be replicating "normal" employment behaviours, *i.e.,* working in autonomous, self-sufficient and productive ways. Rather than recognising some of the positive experiences that Pigtree Farm could offer to people like Joey, the view was taken by the senior job coaches at Singertree Trust that this type of service limited people's ability to take on "real" work in the community. The reality was, however, that Joey was most probably thriving under the conditions at Pigtree Farm because he was sheltered from the demands and expectations of a "real" working environment.

Focusing on "real" work was perhaps most damaging for someone like Mark who experienced difficulty in functioning under any kind of working conditions, even the more sheltered employment settings. Mark's situation was particularly frustrating for him as he wanted to do what were seen as tasks for able people – like chop down trees and use the lawnmowers – but he was usually not given permission to do these things and so often appeared to feel disenfranchised from the work at the farm. Mark's support workers were also enmeshed in this bind as they were torn between following guidance to respect his self-determination with a sense of their duty of care to ensure that he did not injure himself and/or others.

While policy initiatives are benevolently attempting to improve the lives of people with intellectual disabilities, they are often based on abstract assumptions about capability, capacity and political power, rather than on a grounded understanding of the limits that people experience in their everyday lives as a result of their impairment(s). The extent to which these limitations are an inescapable consequence of physiological impairment, or result from social and environmental circumstances that could be changed, is a moot point, but the lived reality is that these limitations do exist, and will not simply disappear on removal of the care and support that people with intellectual disabilities require to make their way in the world.

Masking the limits that an intellectual disability can impose on people's ability to live their lives in certain ways can mean that other crucial aspects of support such as "care" "security" and "wellbeing" are often ignored (Redley & Weinberg, 2007, p. 767). Indeed, this study found that emotionally related connections were found to be lacking in the lives of many people with intellectual disabilities. Although some people with intellectual disabilities talked about wanting independence, by for example getting a job, this was often perceived as a stepping stone towards the goal of achieving a more meaningful place in other people's lives. Despite the huge pendulum swing in intellectual disability policy over the last five decades, within State-led support these kinds of meaningful experiences remain elusive to many people with intellectual disabilities.

The narratives of the people with intellectual disabilities and support staff presented here exemplify both the latent and explicit tensions that exist between intellectual disability policy and lived experience. The desire to empower people with intellectual disabilities, to enable them to enjoy the same freedoms and opportunities that many other members of the population have access to, rubs up against the reality that in myriad ways these individuals remained highly vulnerable and deeply reliant on others around them. The challenge is to develop effective forms of support, from both professionals and the third sector, that recognises people's intellectual, physical and emotional needs, while allowing for a meaningful connection with civil society to develop.

Conclusion

In this article, we explored how people with intellectual disabilities and their staff experienced policy objectives in the context of support that has been influenced by a dedifferentiation perspective. We have shown how the support provided to people with intellectual disabilities reflects current policy objectives of encouraging them to become a part of their communities, often on equal terms with people without intellectual disabilities. Individuals were often unable to achieve the levels of autonomy and independent community inclusion that were expected of them, and required support from others to engage in activities, such as days out in the community and certain types of employment. These issues brought to the fore the disadvantages of dedifferentiating services for people with intellectual disabilities, who because of their cognitive impairments

are often unable to achieve aspirations in the same way as other citizens without intellectual disabilities. By focusing heavily on equalising aspects and not the real needs that people with intellectual disabilities experience as a result of their disabilities, policy fails to make provisions for the difficulties that exist in their day-to-day lives. This raises the question of whether, rather than being expected to live in ways similar to people without intellectual disabilities, people with intellectual disabilities might be better supported through approaches that recognise the real-world needs associated with their disabilities. This may include fostering employment activities and social relationships within the protected boundaries of professional support rather than aspiring for people with intellectual disabilities to achieve these on equal terms with other people without the same kind of disabilities.

ORCID

C. A. Banks http://orcid.org/0000-0002-5212-6217
R. Gooberman-Hill http://orcid.org/0000-0003-3353-2882
D. Wainwright http://orcid.org/0000-0002-5818-4952

References

Auerbach, C., & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York University Press.

Banks, C.A. (2018). Are people with learning disabilities really being empowered? An ethnography exploring experiences of empowerment policies in UK social care support [Doctoral dissertation. University of Bath]. University of Bath. https://doi.org/10.1080/09687599.2020.1804231

Burton, M. (2004). Viva Nacho! Liberation Psychology in Latin America. *The Psychologist*, 17(10), 584–587.

Burton, M., & Kagan, C. (2006). Decoding valuing people. *Disability & Society*, 21(4), 299. https://doi.org/10.1080/09687590600679899

Care Act (c. 23). (2014). The Stationery Office. https://www.legislation.gov.uk/ukpga/2014/23/contents

Coffey, A. (2014). Analysing documents. In U. Flick (Ed.), *The SAGE handbook of qualitative data analysis* (Chap. 25., pp. 367–379). Sage Publishing.

Department of Health. (2009). *Valuing people now: A new three-year strategy for people with learning disabilities*. The Stationery Office. Cm. 10531. https://lx.iriss.org.uk/sites/default/files/resources/Valuing%20people%20now.pdf

Department for Work and Pensions & Department of Health. (2017). *Improving lives. The future of work, Health and disability*. The Stationery Office. Cm. 9526. https://www.gov.uk/government/publications/improving-lives-the-future-of-work-health-and-disability

Geertz, C. (1973). Thick description: Toward an interpretive theory of culture. In *The interpretation of cultures: Selected essays* (Chap. 1, pp. 3–33). Basic Books Publishers.

Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health and Place*, 11(2), 107–115. https://doi.org/10.1016/j.healthplace.2004.10.007

Hawkins, R., Redley, M., & Holland, T. (2011). Duty of care and autonomy: How support workers managed the tension between protecting service users from risk and promoting their independence in a specialist group home. *Journal of Intellectual Disability Research*, 55(9), 873–884. https://doi.org/10.1111/j.1365-2788.2011.01445.x

Layder, R. (1998). *Sociological practice: Linking theory and social research*. Sage Publication.

Moore, K., McDonald, P., & Bartlett, J. (2018). Emerging trends affecting future employment opportunities for people with intellectual disability: The case of a large retail organisation. *Journal of Intellectual & Developmental Disability*, 43(3), 328–338. https://doi.org/10.3109/13668250.2017.1379250

NHS England. (2019). The NHS long term plan. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

Oliver, M. (1983). *Social work with disabled people*. Macmillan.

Patton, G. C., & Viner, R. (2007). Pubertal transitions in health. *The Lancet*, 369(9567), 1130–1139. https://doi.org/10.1016/S0140-6736(07)60366-3

Power, A., & Bartlett, R. (2018). 'I shouldn't be living there because I am a sponger': Negotiating everyday geographies by people with learning disabilities. *Disability & Society*, 33(4), 562–578. https://doi.org/10.1080/09687599.2018.1436039

Public Health England. (2019). People with learning disabilities in England 2019: Chapter 2: paid employment, 28 October. GW-649. https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england

Redley, M. (2009). Understanding the social exclusion and stalled welfare of citizens with learning disabilities. *Disability & Society*, 24(4), 489–501. https://doi.org/10.1080/09687590902879122

Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: Interactional impediments to political empowerment. *Sociology of Health & Illness*, 29(5), 767–786. https://doi.org/10.1111/j.1467-9566.2007.01015.x

Rogers, C. (2009). (S)excerpts from a life told: Sex, gender and learning disability. *Sexualities*, 12(3), 270–288. https://doi.org/10.1177/1363460709103891

Sandvin, J., & Soder, M. (1996). Intellectual disabilities in the Nordic welfare states. In J. Tossebro, A. Gustavsson, & G. Dyrendhal (Eds.), *Policies and everyday life* (pp. 237). Høyskole Forlaget.

Schelly, D. (2008). Problems associated with choice and quality of life for an individual with intellectual disability: A personal assistant's reflexive ethnography. *Disability and Society*, *23* (7), 719–732. https://doi.org/10.1080/09687590802469206

Shakespeare, T. (2013). *Disability rights and wrongs revisited* (2nd ed.). *Routledge*.

Simpson, G., & Price, V. (2009). From inclusion to exclusion: Some unintended consequences of valuing people. *British Journal of Learning Disabilities*, *38*(3), 180–186. https://doi.org/10.1111/j.1468-3156.2009.00572.x

Thomson, M. (1998). *The problem of mental deficiency: Eugenics, democracy, and social policy in Britain c.1870-1959. Oxford historical monographs*. Oxford University Press.

Toms, J. (2017). Citizenship and learning disabled people: The mental Health charity MIND's 1970s campaign in historical context. *Medical History*, *61*(4), 481–499. https://doi.org/10.1017/mdh.2017.55

United Nations Convention on the Rights of Persons with Disabilities, (UNCRPD). (2006). Convention #A/RES/61/106. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

United Nations Monitoring the Convention on the Rights of Persons with Disabilities. (2010). Guidance for human rights monitors. Professional training series No. 17. HR/P/PT/17. https://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf

Verdonschot, M. M. L., de Vitte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, *53*(4), 303–318. https://doi.org/10.1111/j.1365-2788.2008.01144.x

Vogt, W. P. (1999). *Dictionary of statistics & methodology: A nontechnical guide for the social sciences*. SAGE Publications Ltd.

Wrigley, A. (2006). Proxy consent: Moral authority misconceived. *Journal of Medical Ethics*, *33*(9), 527–531. https://doi.org/10.1136/jme.2006.019711