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The Capabilities of People with Intellectual and Developmental Disabilities under Personalisation: A qualitative analysis of work, learning and social inclusion

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by

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Abstract

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Doctor of Philosophy

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Statistics suggest that employment is inaccessible to people with intellectual and developmental disabilities. This creates a social, spatial and experiential divide that limits opportunities for social participation and learning. In the UK as elsewhere, social care is framed by ‘personalisation’ policy, which aspires to support personal autonomy yet is associated with a cost-cutting agenda and fragmented provision. The option to employ a Personal Assistant (PA) might support social participation.

The conceptual framework for this study is the capability approach, chosen for its focus on the practical opportunities available to people to achieve a life they have reason to value. Building on sociocultural learning theories, the study links work, learning, and social participation or ‘inclusion’. It explores how learning arising through social participation might enhance the capabilities of the people concerned.

Video-supported qualitative methods were used. Five young people with intellectual and developmental disabilities took part, each employing a PA and working in a context matching their preferences. For each, a parent, a co-worker or supervisor and the PA took part. Young people were filmed at work. This video supported recall and reflection in semi-structured discussion with participants. Video and discussion content was analysed by case, then thematically, in an iterative process.

PA support opened opportunities for social participation outside domestic and disability settings. The contribution of personalisation was ambivalent. People found work through bottom-up initiatives outside ‘social care’ parameters and in implicit challenge to them. Joint negotiation of preferences and opportunities resulted in unpaid work in not-for-profit contexts. Working this way enhanced the capabilities of young people to differing degrees. Collaborative relationships between young people, PAs and people in the workplace underpinned reciprocal learning processes, shown in themes of effort and recognition, mutual adaptation and affiliation. Findings for participatory learning were significant against a backdrop of substantial constraints on young people’s opportunities. This study challenges conceptions of autonomy as solo performance and social norms that delegitimise work outside employment both of which can impede access to participation and reciprocal learning in public settings.

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Research Thesis: Declaration of Authorship

Abigail Croydon

Title of thesis: The Capabilities of People with Intellectual and Developmental Disabilities Under Personalisation: A Qualitative Analysis of Work, Learning and Social Inclusion

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Date:26.04.23

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This thesis has been written on the basis of collaborative work with young people, and with their families and the people with whom they work. I have gained a huge amount of knowledge and understanding from the people who collaborated with me, which I cannot repay, and which sustained my interest like nothing else could. They made any amount of effort worthwhile.

Finally, thanks go to the Economic and Social Research Council for funding this research.

Chapter 1 Introduction: Research aims and parameters

1.1 Lives after education: Under-occupation and social exclusion

This study concerns the adult lives of young people with intellectual and developmental disabilities and their 'capabilities' (Sen, 1992) – what they are free to do and be, in practical terms, in the social and cultural contexts in which they find themselves. The key capabilities of concern are the capability to learn and to participate socially. The study takes as a starting point the segregation of young people with intellectual and developmental disabilities from the world of work, their absence from the public spaces of adult life and the lack of opportunities for social and cultural learning and participation (among other things) that result from these exclusions. This position is reflected in an employment rate that has remained below 8% (Nuffield Trust, 2022) throughout a decade of interventions, indicating the scale of under-occupation, undeveloped potential and social exclusion.

Historically, people with intellectual and developmental disabilities have been kept separate from the majority. It is now several decades since the beginning of 'de-institutionalisation' and more than a decade since the landmark international human rights treaty, the United Nations Convention on the Rights of People with Disabilities (UNCRPD: United Nations General Assembly, 2006). In addition to basic rights to life and to health, the convention protects the rights of disabled people to the 'full development of human potential and sense of dignity and self-worth' (Article 24), to work 'on an equal basis with others' (Article 27) and to 'full inclusion and participation in the community' (Article 19). In addition, inclusive employment and 'social inclusion' are part of the UN's sustainable development goals (United Nations, 2016). For people with intellectual and developmental disabilities these rights are especially far from being realised (Browne & Millar, 2016; Equality and Human Rights Commission, 2018; Louw, Kirkpatrick & Leader, 2019).

While at school, people with intellectual and developmental disabilities are likely to have had varied experiences of inclusion and exclusion: included in the social practice of schooling and excluded by an ethic of competitive individualism (Slee, 2019). The end of schooling marks a turning point – one immediate outcome is a lack of places to go, things to do and people to connect with. Adults with intellectual and developmental disabilities often know little about what it is to be employed, to experience a workplace culture, to have work relationships or work towards a shared goal. In an economic context in which employment is the dominant form of social cooperation, a lifelong lack of employment (or comparable alternative) imposes extensive restrictions on what people can do and be, raising challenging questions as to how they lead their lives and with whom.

Although there is no consensus on its precise meaning, social inclusion is a key concept in disability discourse. The UN (United Nations, 2016, p. 17) defines it as 'the process of improving the terms of participation in society… through enhancing opportunities, access to resources, voice and respect for rights'. Various factors and aspects may be highlighted in different accounts (see Simplican *et al.*, 2015), but the concept originated in opposition to social *exclusion*, which is usually linked to unemployment and poor quality of employment, to material poverty and to forms of discrimination. Being out of employment is considered to drive social exclusion, even for people who have experience of employment and have no disability (Pohlan, 2019). For the people who are the topic of this study, exclusion can take the literal form of social, spatial and experiential segregation from the working majority. They are likely to experience patchy and unreliable provision (Power *et al.*, 2020). They may have access to passive leisure activities in the home setting (Charnley *et al.*, 2019) and to structured activities in disability-dedicated settings (Gray *et al.*, 2014). Accordingly, many interact mainly with professionals and family members (Harrison *et al.*, 2021), and have limited experience in the public sphere of civil society.

The concept of two realms in which people operate on a daily basis – public and private spheres – has a complex history, but is useful here to conceptualise social exclusion and what is missing from the lives of many people with intellectual and developmental disabilities. The public sphere, governed by shared norms and values, is supposed to be the locus of political and social debate and is considered the cornerstone of democracy. In modern sociology it is also the realm of public institutions and paid employment, by contrast with the private, domestic sphere of women, children and unpaid reproductive and care work (see Anderson, 1995; Landes, 1998). People with intellectual and developmental disabilities have inhabited this sphere as 'cared for' people (e.g., Garland-Thomson, 2011), without full adult status. They have also been confined to it in literal ways, since employment is the key mode of social cooperation in high income societies.

In this study, I engage with feminist conceptions of relational agency which have developed from a critique of the gendering and exclusions of the public/private dichotomy. The reforms of personalisation can be interpreted as entrenching care as a matter for the domestic sphere – for families and private individuals – rather than a public concern. Research suggests that they have had a disproportionate impact on women in extending their responsibilities for care (Malli *et al.*, 2018; Forrester-Jones *et al.*, 2021). I argue that under current social arrangements people with intellectual and developmental disabilities have restricted access to the public sphere, and that this exclusion is impoverishing in multiple ways, amplifying the disadvantage of impairment. From a capabilities perspective, a group excluded from or segregated within civil society, or subject to discrimination ‘on the basis of ascribed social identities by institutions in civil society’ (Anderson, 2017, p. 317), does not have the capabilities necessary to function as equal citizens.

The major reforms of personalisation have been in place since the early 2000s. In the UK specifically, they were supposed to deliver ‘an integrated, community-based approach for everyone’ (Social Care Institute of Excellence, 2022). The personalisation vision of empowered social care recipients living in cohesive and inclusive communities, acting confidently as shoppers for services (Carey, Crammond and Malbon, 2019; Power *et al.*, 2021), is supposed to have replaced the paternalism of building-based day care. In other words, this state of segregation should not prevail. But it is part of the shift of responsibilities embodied in personalisation that the question of how and where people might achieve such agency and social participation is, paradoxically, a private matter.

The theory and practice of personalisation have been debated extensively in academic and professional literature. A critical omission from the thinking around personalisation and social care is how it leaves a particular group of people – who have been at least notionally inclusively educated, who are young and not ill – socially and occupationally disconnected. Here, I focus on those around the middle of the spectrum of intellectual and developmental disability, whom I argue are neglected in policy and research, as they fall between two stools. They have budgets adequate to employ PAs. They are not on the ‘blurred edges’ of intellectual disability (Williams, Swift & Mason, 2015), or among those squeezed out of both work and care (Hall & McGarrol, 2012). Yet they do not have the intensive care needs and distinct requirements for inclusion as people with profound and multiple disabilities (de Haas *et al.*, 2022). They may have skills, strengths and preferences, as recognised in personalisation policy, but without personal, psychological and communication support, they may struggle to meet the complex demands and restrictive norms of social participation in public spheres.

Decades of unchanging statistics suggest that employment is effectively inaccessible to people with intellectual and developmental disabilities in general, regardless of the theoretical right to work, anti-discrimination legislation and supported employment schemes. Yet employment is so far the dominant option, socially and in policy, that no viable, substantial or sustainable alternative is envisaged for their lives - for how and where they might spend their time, how they might build skills or structure their lives in meaningful ways or begin to achieve ‘social inclusion’. For the majority, employment provides structure and occupation, and membership of a community. For people with intellectual and developmental disabilities the scaffolding for social participation, learning and personal development ends when schooling ends. Day care, more or less modernised, may then take up some parts of some days, and third-sector organisations may provide some opportunities for learning and self-advocacy (Nind, Coverdale & Croydon, 2020). Yet for the most part these are disability-specific and part-time arrangements that cannot measure up to the scale of the task.

I approach this topic from the perspective of personal experience, as a parent involved in the dilemmas on a daily and yearly basis. I am familiar with how they affect my daughter and her cohort of friends and acquaintances. While personalisation can seem to offer young people an escape from a lifetime of unambitious day care, in doing so it also provides a substantial task for allies and supporters, which is enduring, practically and ethically demanding, and without societal support. As a feminist I note that the responsibilities handed over by personalisation disproportionately affect women and lock issues of care and interdependence more completely into the domestic sphere, where social inclusion cannot be achieved. The task of balancing care and agency is disproportionately allocated to women, including a predominantly female care staff whose work is given little social and financial value. I also approach the topic bearing in mind my research experience with young people and families from social and cultural backgrounds different from my own and those that I encounter as a mother. No matter how inclusive or otherwise their education may have been, their post-school choices are similarly limited. In research and in private life, I encounter energetic, enquiring and adventurous people whose options do not seem equal to their characteristics and potential.

1.2 A way forward?

The research task underpinning this thesis is to consider how, in the landscape that I have described, people might find a way forward. One dimension of personalisation has potential to offer an alternative to day care and life in the domestic sphere. The personal budget available to eligible people may give access to a PA, an ally chosen to suit the individual, in age and interests for example, who can offer support to navigate the complexities of participation in public spheres. Specifically, a PA may enable a person to take a working role that engages their interests and motivations as far as possible, and to build skills and connections through social participation. As I discuss in Chapter 3, this may be achievable outside the constraints of formal employment.

For young people in particular, participating in the social and cultural activities of work might offer substantial opportunities for learning, especially for learning in (adult) ways that are qualitatively different from the experiences of schooling. One-to-one relationships can enable support to be tailored to overcome the specific practical, social and learning challenges that arise for an individual young person, and to provide a bridge between their interests and those of the workplace and co-workers. This can be characterised as a form of relational agency, ‘helping the individual to negotiate the world around them and intervening in the social world to make it more accommodating of the individual’ (Davy, 2019, p. 109). Such a bridge might address the social exclusion often reported by the minority of people with intellectual and developmental disabilities who are in employment. This specific provision under personalisation provides an opportunity to examine social participation as a learning process involving young people and those they encounter through their work, and to obtain a close-up view of such participation through the accounts of those involved.

Working with PA support is currently pursued by few people, yet it is potentially relevant to a wider population. The practice draws on aspects of personalisation, notably the tailoring of support to an individual profile and the use of a personal budget to pursue personal ends. It does not have to represent the retreat to individualism that critics have charged personalisation policy with promoting. It might instead be a means for individuals to attain a life that is less separate from the social majority and to pursue goals other than the personal and financial ‘independence’ inscribed in policy. It could promote socially embedded learning by those involved and the capabilities of participants, that is, their practical freedom to pursue the kind of life they want through relational support.

In the disability literature PAs are often seen in instrumental terms, as people who perform personal care tasks and support basic living functions, such as shopping and personal administration, and who have welfare and safeguarding responsibilities (Ratzka, 2004). But their role has also been seen as emancipatory, as ‘a major condition for the possibility of disability equality’ (Mladenov, 2012, p. 4). Deployed to enable someone to take part in society, personal assistance can be conceived in ‘existential-ontological’ terms (Mladenov, 2012, p. 25) as a means to achieve autonomy. Looked at in this way, such support might provide a new perspective to debates on individualist versus collectivist approaches in social care.

Initially, this research idea emerged from a kind of opportunism, from the perspective of a parent seeking potential in available policy. The chance to develop the idea into a wider investigation came with a studentship linked to the Self Building Our Lives[1] project, focused on informal,

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[1] A research project examining how people with intellectual and developmental disabilities and their supporters were responding in practice to the new policy landscape, led by Andrew Power and Melanie Nind at the University of Southampton and Ed Hall at the University of Dundee.

lifelong and community learning. The studentship provided a framework, time and support to explore in depth issues that I regarded as under-recognised. I could use the insights of an informal case study - my daughter's - while engaging with the academic and research literature to inform and develop those insights. The fieldwork would enable me to research other cases of people and families finding ways to include themselves in work in public settings. I hoped to understand the arrangements and perspectives of these people and to modify and develop my intuitive and personal responses on this basis.

In disability research, parents' perspectives are often regarded with ethical suspicion. They are seen as having their own interests and perhaps their own needs for 'choice and control', and are unreliable proxies for the voice of their child (e.g., Cummins, 2002). Yet this characterisation overlooks the relationality on which selfhood depends, particularly in interdependent relationships between family and adult children with intellectual and developmental disabilities. Feminist literature on relational autonomy (Mackenzie, 2014; Davy, 2019; discussed in Chapter 2) has informed the thinking in this study about how the support of an ally, and the relationships enabled by that alliance, might be important in increasing the range of opportunities open to people with intellectual and developmental disabilities. Understandings of the self as relationally constituted also provide a rationale for incorporating the perspectives of PAs, parents and co-workers in the study, though the key focus remains on the capabilities of the young people themselves.

In planning the research, I drew on personal and research experience, thinking about how to approach engaging with a diversity of young people. I wanted to offer an experience of the research process that was meaningful to them and to use engaging and rewarding visual and attentional supports. I hoped that the process of making and sharing video of work in action might support collaborative relationships and viewing it encourage the kind of reflection that the research topic needed. I had previously found that photographic stimuli, personalised to the participant and topic, could be effective in establishing joint attention, sometimes eliciting spontaneous responses that could be explored. Using video rather than photographic stimuli, showing people engaging in the work they had chosen, seemed an obvious development. Video samples of people working might provide a way to share experience of it and to focus attention on what people could do, rather than on what they could say. It might provide cues for discussion and allow participants to respond and comment without needing to establish through language the reference points for their comments.

In developing the research design, the emic perspective was important, as I aimed to understand what individuals understood as their purposes in working and the significance of the roles and interactions involved. Equally, understanding how and why families and individuals had made arrangements and established relationships, and how these worked from the perspective of others – the PAs and co-workers particularly – seemed to be core questions. Recruiting these key stakeholders and sharing the video with them might fill out the account of work and allow us to explore interdependent relationships in work. I wanted the key (disabled) participants to engage in thinking about my topics, though learning in particular is a challenging, abstract concept. This required providing engaging material for them to consider – the video footage – which might also stimulate new ways of looking at what they were doing. The video could also serve to keep the discussion focused on the realities of work, rather than on assumptions or expectations about it. Sharing video, I hoped, would support dialogue and communication as the basis for understanding and explaining the social reality of their work (Puigvert, Christou & Holford, 2012). The research design evolved on this basis. A valuable feature of film or video that became increasingly evident as the project progressed was its function as a support or analogue for verbal commentary. In qualitative research writing, the words of participants often serve to convey key messages, but the words of these participants, disembodied and decontextualised in the form of writing, do not convey their character or competence, whereas film is able to give a visual account of who they are, and what they can do and be.

1.3 Linking work, learning and social participation

It is noticeable and confirmed by research that social contact between people with and without intellectual and developmental disability reduces stigma (e.g., Walker & Scior, 2013), and that what matters is the quality of the contact, not ‘mere exposure’ (Keith, Bennetto & Rogge, 2015). This points to the limitations of seeking to influence attitudes through disability awareness schemes (e.g., Department for Work & Pensions, 2018a). By contrast with these, the learning embedded in the everyday negotiation of relationships in work might have significant potential. The literature on participatory learning – learning rooted in social co-participation within authentic activity, context and culture (Lave & Wenger, 1991; Rogoff, 2016) – establishes strong links between taking part in shared endeavours, learning by doing so and achieving social cohesion as people adjust their roles in the light of the skills and priorities of others taking part.

Such links imply that learning is distributed among co-participants and that ongoing processes of adjustment influence social and cultural practices. Creating ssocial closeness by sharing experiences in common ground is thought to be a characteristic human social-cognitive process (Wolf & Tomasello, 2020). Hence this kind of reciprocal learning can be linked to more inclusive social participation. The fact that such learning is seen as ‘situated’ – as socially, culturally and context-specific – provides a strong basis for promoting participation in shared (public) activities, rather than extending participation in educational settings where a more individual and cognitive view of learning prevails.

Other aspects of participatory learning theory resonated with the topic of work undertaken by people with intellectual and developmental disabilities, such as the legitimacy of taking part, even when the role is relatively minor (‘legitimate peripheral participation’) and the ‘guiding’ of participation (Lave & Wenger, 1991; Rogoff, 2003), in which the role of a more experienced person, the PA perhaps, is key to extending skills and knowledge. Critical to participatory learning theory is the necessity for access: learning depends on increased access to participating roles in ‘expert performances’ (Lave & Wenger, 1991). This aspect of participatory learning gives grounds for a critique of policy and social arrangements, since people with intellectual and developmental disabilities have limited access to the kinds of social participation necessary for reciprocal learning to take place.

1.4 Capabilities, learning and participation

The theoretical framework for evaluating complex questions about work, learning and social participation in this research became the capabilities approach. In the first year of study I came across writings on disability by capabilities scholars (Burchardt, 2004; Terzi, 2005; Mitra, 2006). I turned to the writings of Martha Nussbaum and Amartya Sen, the founding scholars of the approach, and Ingrid Robeyns’ more recent account of the framework (Sen, 1999; Nussbaum, 2006; Robeyns, 2017). The approach has developed into an intellectual discipline (Robeyns, 2017) that takes ‘social justice’ or equality in the distribution of opportunities among people as a key concern - often between high- and low-income populations, but also between groups who are advantaged or disadvantaged within populations, including high-income ones. I found it to be a rich and flexible tool, with particular advantages in the context of this study. Robeyns (2016, p. 1) introduces it as a framework that entails two normative claims:

> first, … that the freedom to achieve well-being is of primary moral importance and, second, that well-being should be understood in terms of people’s capabilities and functionings. Capabilities are the doings and beings that people can achieve if they so choose — their opportunity to do or be such things as being well-nourished, getting married, being educated, and travelling…

In this framework, impairment and disability are conceived in terms of their impact on ‘capabilities’. Being able to take part in education, to work and to participate socially are key capabilities – those that are ‘fertile’ in generating further capabilities (Nussbaum, 2011, p. 98). The central measure of equality – capabilities – captures the concern that I had started with, that is, what, in practical terms, people are able to do and be in their lives. Capabilities are freedoms or ‘real opportunities’ to achieve functionings, which may be basic or complex, such as ‘being happy, having self-respect, taking part in the life of the community, and so on’ (Sen, 1992, p. 39). Hence choice, or having a range of options from which to choose, is intrinsically valuable, yet this capabilities conception of choice is significantly different from that found in personalisation (Burchardt, Evans & Holder, 2015).

Capabilities are key, as Sen (1999) understands development to be the ‘process of expanding real freedoms... and the removal of various types of unfreedoms’ (p. xii). Capabilities matter above income or material resources, since income and material resources are important only in what they enable people to do and to be; that is, in the capabilities that a person can generate from them (Robeyns, 2017). As people with distinct characteristics and in different circumstances may need more or less resource to achieve a given function, and may have varying abilities to make use of any resources available to them, it is equality of ‘capability’ that counts. Within the scope of this study, I interpret this as specifying, for example, that to achieve the capability to work, people with intellectual and developmental disabilities may legitimately require the resource of PA support, and that policy should support that capability as a matter of equality.

The capabilities approach has provided a solution to the question of which theory or account of disability to follow. A key consideration was the understanding that human heterogeneity is ‘an empirical fact’ (Sen, 1992, p. xi); that differences are pervasive, multidimensional and significant. Diversity is a central conceptual characteristic in the approach and provides a key motivation for its development. Other approaches in welfare economics are seen as catering explicitly to assumed norms – Rawls’ (1971) exclusion of people with intellectual disabilities from claims to citizenship is often cited. In a capabilities approach, an impairment is an aspect of diversity in personal characteristics, and counts as one of the personal, social and environmental factors necessary for an assessment of equality. Differences in values and aims provide a further significant source of diversity.

In the light of these sources of diversity, agency, or the freedom to pursue reasoned aims and values, is central to addressing ’people’s deprivations’ (Sen, 1999, p. xi). The histories of paternalism and normalisation in provision for people with intellectual and developmental disabilities make the priority for agency critical in assessing their lives and capabilities. The capabilities framework highlights, for example, the formation of adaptive preferences as a feature of entrenched inequality, whereby disadvantaged people modify their expectations in the light of what they perceive to be achievable for them.

The capabilities approach is explicitly concerned with ‘social arrangements’ – policy, institutions and social norms – and their impact on people’s lives. Social arrangements involve the key questions of educational provision, state benefits and social care for people with intellectual and developmental disabilities, while social norms have been at the centre of debate about intellectual and developmental disability since the 1960s (Foley, 2016). Sen (1999) highlights the connection - the ‘deep complementarity’ (p. xi) - between individual agency and social arrangements. People’s capabilities are ‘inescapably qualified and constrained by the social political and economic opportunities that are available’ (p. xii). The capabilities approach examines policy from the perspective of this complementarity, examining how far a given policy promotes people’s capabilities.

In these ways, ‘capabilities’ represent a correction to the focus in mainstream economics and in alternative theories of justice on income and resources in themselves, rather than what can be achieved with them. In Robeyns’ example (2017, p. 51) this means that ‘an effective capability-enhancing policy may not exist in increasing disposable income, but rather in fighting a homophobic, ethnophobic, racist or sexist social climate’. The approach requires a broad analysis of factors affecting people’s capabilities. Models of disability often construe disability (whether as a biological or social construction) as the defining factor In disabled people’s lives, yet a large body of research suggests that it is compounds of factors of various kinds that matter in the production of ‘corrosive’ disadvantage (for example, Wolff & De-Shalit, 2007; Robeyns, 2017). The concept of capabilities addresses the range of factors that influence what people with intellectual and developmental disabilities are able to do and be.

The capabilities approach therefore serves three central purposes here: to focus on the significance of diversity amongst people, including but not limited to their impairments; to argue for the significance of agency for people with intellectual and developmental disabilities; and as a tool to evaluate social arrangements (Sen, 1999). Though the overall picture of advantage and disadvantage of a particular individual may vary, by definition a person with intellectual and developmental disabilities will need more support than the average person. Questions of ‘care and support’ are fundamental in disability, and as feminists have argued, there is a need ‘to reconsider the basic distribution of responsibility… among societal institutions, specifically the family, the state and the market (Fineman, 2013, p. 13). In this sense, in my interpretation, a capabilities approach supports an analysis of the impact of personalisation policy.

Feminism has been a key source of work on the ethics and politics of disability, in which the voices of disabled women and family members of disabled people have been prominent (Morris, 2007; Kittay, 2011; Davy, 2015). The capabilities approach and feminism have in common an opposition to implicit norms applied to individuals, of being non-disabled, non-dependent and free of caregiving responsibilities. There are other shared factors. The capabilities approach is based at least in part on noting the impact of inequalities of gender. Sen's identification of the 'missing women' phenomenon - the hundred million women 'lost' globally to sex selective practices (Casey *et al.*, 2006) - was influential in the formation of the approach. Nussbaum focuses on women's capabilities and their difficulty in attaining a higher level of capability, as a problem of justice. She and Robeyns are equally feminist and capabilities scholars (e.g., Nussbaum, 1999, 2000; Robeyns, 2008).

In this study I draw on feminist thinking, for example on employment as a form of work and care as a public concern. In particular, I question how far social and policy preferences for formal employment and individual 'independence' serve the interests of people with intellectual and developmental disabilities. I explore instead the question of agency in a form theorised by feminist scholars. Although agency is a core consideration in the capabilities approach, it does not specify a particular conceptualisation of agency (Robeyns, 2017). For this study, I draw on feminist accounts of relational agency, especially those concerned with intellectual disability and capabilities (Mackenzie, 2014, 2019; Davy, 2019; Tucker, 2019). Mackenzie and Davy focus on agency and people with intellectual and developmental disabilities, while Mackenzie takes a capabilities approach. She argues following Sen (1999) that fostering the autonomy of 'vulnerable' people is a social obligation, not a private matter, and that the capabilities approach provides the most promising theoretical framework to articulate this claim. Chapter 2 discusses this view of relational agency.

Research aims and questions: Thesis structure

This research aims to see how far working with PA support, outside the constraints of paid employment, furthers the capabilities and agency of young people with intellectual and developmental disabilities, specifically the capabilities of learning and social participation. The research questions address:

1. Social participation under personalisation
    a. Why and how did young people with intellectual and developmental disabilities come to work in public settings?
    b. How far did personalisation promote or support this choice?

2. Participatory learning and capabilities
    a. *What kinds of participatory learning do participants identify?*
    b. How far did the work and the learning involved enhance the capabilities of the young people?

To address these questions, the thesis has three opening chapters. First is disability and the personalisation context (Chapter 2); second, employment and work (Chapter 3); and third, learning and participation (Chapter 4). These chapters build a thesis that is examined in the findings and discussion chapters. Chapter 5 outlines the methods and methodology. Chapter 6 presents the findings in two parts, as narrative portraits of participants and as an examination of cross-cutting themes. Chapter 7 contains the discussion, while Chapter 8 draws conclusions.

In this thesis I explore in depth five cases of young people with intellectual and developmental disabilities who work in ways that suit their preferences and abilities, in various settings, with the support of a PA. Using video footage of each to support discussion of their work, I explore the perspectives of the young person, the PA, a family member and the co-workers or supervisors concerned. I focus on the socio-cultural learning identified in discussions. On this basis, I consider how far these arrangements enhance the capabilities of the young people in the current social, policy and funding context.

Chapter 2 Intellectual and developmental disability: Language and difference, capabilities and agency

In this chapter I discuss intellectual and developmental disability as a category within disability, considering language and theorisation, difference and accommodation to difference. I address social inclusion as a social and political aspiration for disabled people, and consider the policy framework for social care in relation to that aspiration. I then turn to the capabilities approach to disability and the rationale for using it. As the capabilities approach takes the agency of people as a primary concern, I explain the adoption of feminist conceptions of relational agency within a capabilities approach. I end by considering personal assistance as an aspect of personalisation, and in connection with relational agency.

2.1 Language and people

The term 'intellectual disability' can refer to a diverse set of people, and is often poorly understood. Defining it in terms of 'impaired intelligence' (e.g. World Health Organization, 2020, n.p.) is problematic, since 'intelligence' itself is a contested concept and, in important respects, a tainted one (see Nisbett *et al.*, 2012). Many definitions of intellectual disability still refer to scores on tests of IQ, though this kind of testing is widely seen as inappropriate (see Williams, Swift & Mason, 2015) and is known to be inaccurate by its own standards (Sansone *et al.*, 2014). It is also relevant in the present context that 'intelligence' is beginning to be understood as a dynamic property that fluctuates across the lifespan, in interaction with environmental factors (Rinaldi & Karmiloff-Smith, 2017), rather than a static possession of individual brains. In addition to intelligence, the World Health Organisation (WHO) definition refers to difficulties in understanding 'new or complex information' and to a 'reduced ability to cope independently' (World Health Organization, 2020, n.p.), and I follow these understandings of intellectual disability.

Vocabulary in relation to disability is a contested issue. The now-rejected term 'mental handicap', was a matter for discussion in WHO terminology as recently as 2011 (Salvador-Carulla *et al.*, 2011). This fact and the current diversity of terminology illustrate how far notions of disability are social constructs and subject to revision (Jarrett & Tilley, 2022). But it is also problematic to avoid naming. Referring to any social grouping involves selecting for and focusing on certain characteristics above others and, as disability scholars have suggested, in this sense is a form of stereotyping. But membership of a group for one purpose does not define an identity for all purposes, and processes of de-stigmatisation and inclusion are likely to require action beyond changes in language. Indeed, a strong focus on the power of language and cultural representation can deflect attention from the ways in which changes in material realities impact on discourse (Feely, 2016).

Practical and ideological matters influence my choice of the term 'intellectual disabilities' in this thesis. The first issue is clarity. The UK-preferred term 'learning disability' is used in the US for specific learning difficulties such as dyslexia and ADHD, which can also be recognised as disabilities (Sedgwick, 2018). The International Classification of Disease 10th revision (ICD-10) employs the term 'intellectual disabilities', giving this term international currency. Intellectual disability is often associated with neurodevelopmental characteristics, especially with autism. This can be a further source of misunderstanding. The boundaries between intellectual disability and autism are not entirely distinct (Thurm *et al.*, 2019), and in the literature on intellectual disability it is not always clear when autistic people are included. Highlighting autism alongside intellectual disability is an important task. Selection bias against intellectual disability in autism research means that there is little knowledge about autistic people with intellectual disability, though they may comprise approximately half of autistic people (Russel *et al.,* 2019). Autism is also relevant when considering social inclusion, as autistic people may have distinct ways of relating socially (Heasman & Gillespie, 2019), so may have different conceptions of what kinds or levels of social contact are desirable. For these reasons, I have drawn on literature on intellectual disability and autism as separate and joint categories in this study.

The term 'people with intellectual and developmental disabilities' is person-first language, while some advocate for disability-first language, especially in the case of autism. There are valid reasons for preferring 'person-first' or 'disability-first' language - people may want to identify first as people, or they may want to highlight how social conditions disable them, or they may feel that their disabled identity is primary and inextricable. In the present case, disability-first language is unwieldy ('an intellectually and developmentally disabled person'). Nevertheless, it is an important task to foreground ways in which social arrangements and social conditions disadvantage people and to seek a positive identity for disabled people.

Some scholars refer to people as 'labelled with a learning [intellectual) disability' in order to highlight the historical contingency of constructions of disability. Goodley and Runswick-Cole (2015) embrace the doubt that this terminology implies as useful to recognise and maintain definitional 'confusion and complexity', because 'this fits most readily with our understanding of humanity' (p. 2). They seek to reject the 'othering' of people by labelling, but from my perspective 'labelled with' risks implying that difference is a (mis)construction of ideology and discourse. There is a fine line, too, between objecting to the labelling of intellectual disability and objecting to the phenomenon itself. The problem should be with the devaluing of an identity rather than with the naming of it. Intellectual disability is a complex and multidimensional construct, but a shared terminology is needed to conceive of common interests or collective identity. There is evidence that exploring shared characteristics can provide a positive foundation for self-understanding (e.g., Gordon *et al.*, 2015). In the case of autism, self-advocates argue for embracing an autistic identity, which includes reclaiming previously stigmatised behaviours (Oredipe *et al.*, 2022).

Of course, the fact that a characteristic such as intellectual disability can be the basis for a group identity does not imply that it defines the people included in every respect or at all times. I argue here for people excluded from employment to have the choice to participate in the public sphere in ways that take account of difference and for them to have access to identities and relationships based on characteristics other than disability.

The group 'people with intellectual and developmental disabilities' is a broad one. As I noted in Chapter 1, this study focuses on young people who might be said to fall in the middle of the spectrum of intellectual disability. Klotz (2004) argues that the sociocultural study of intellectual disability has focused on the lives of people with mild disability, using their experiences as the basis for conclusions about the nature of intellectual disability as a whole. He contrasts the research evidence that has resulted with the lived reality of people whose impairments are severe, profound and multiple. From a research design perspective, one group is familiar but requires methodological adjustment; the other calls for rethinking the theoretical and methodological tools of sociocultural research (see also, de Haas *et al.*, 2022). Klotz (2004) argues, justifiably, for attention to profound disability, but in making this case, he passes over another group – those between mildly and profoundly disabled, that I see as overlooked in research and policy. They are less easily included in research than the first group but require moderate methodological adjustment, rather than a complete reconsideration of tools. The methods of inclusive qualitative research can fit poorly with people in this group. For example, they may use concrete, transactional forms of speech and be competent in other kinds of 'beings and doings' (Sen, 1992, p. 40), but a focus on accessing voice and verbal accounts of experience is problematic for them. Inclusive research has brought in hitherto excluded voices but, as Klotz and others suggest (de Haas *et al.*, 2022; Nind, 2011), this has involved a bias towards people who have particular verbal skills and a capacity for this kind of research activity, 'those who have already found their voice and a way to use it' (Nind, 2001, n.p).

There is also a longstanding tendency to focus on people with milder levels of intellectual disability in employment activation policy and in supported employment, as I argue in Chapter 3. The middle group does not fit easily into formal schemes, which entry requirements and offer kinds and levels of adjustment that do little to address their needs. By failing to fit into such schemes, their potential for social participation outside employment remains untapped. Chapter 3 explores this topic.

Admitting difference

The process of reforming deficit-focused 'medical' models of disability is now around 50 years old (see Jarrett & Tilley, 2022). The thinking behind the social model of disability has played a significant role in this process, influencing the form of the UNCRPD (2006, Article 1) and UK government policy, for example. The UK social model is shaped by its origins in the disability rights movement of the 1970s and 80s and the social context of the period. It had a political and tactical focus on social arrangements and their disabling effects, while 'impairment' – previously the sole focus of attention – was kept as a private matter, separate from disability (Morris, 2007). The main disabled people's movement and this social model made the case for deinstitutionalisation and 'independent living', prioritising personal agency or 'choice and control' in matters of care and support. In the UK and in other high-income countries these themes feature prominently in the rhetoric of personalisation policy and in public accounts of arrangements for people with disabilities. In this sense personalisation echoes the language of disability rights. But critiques of personalisation highlight the disproportionate impact of austerity on disabled people, broadening analysis to the relationship between personalisation and a neo-liberal cost-cutting agenda (e.g., Mladenov *et al.*, 2015; Power, Coverdale, *et al.*, 2021).

Though the social model is largely superseded by social relational (Thomas, 2004) and bio-psycho-social models (World Health Organization, 2002), it still has influence. The UK Government Office for Disability (2020, n.p.), for example, aims to 'encourage the use' of the social model of disability. Major disability charities subscribe to it, such as Scope. From the perspective of people with intellectual and developmental disabilities, two connected aspects of the social model are problematic: its focus on physical sources of disability; and its resistance to discussion of embodied experiences of impairment (Morris, 2007; Vehmas & Watson, 2016). I explore below the social model and features of it taken to support social and policy biases and preferences.

The social model undoubtedly led to changes in attitudes towards disability, but the focus of the model on physical disability and its dissociation of disability from impairment have been questioned (for example, Shakespeare, 2006; Vehmas & Watson, 2014). Arguments for independent living, adaptation of the physical environment and freedom from stigma depended on forceful assertions of personal independence and minimal needs for accommodation. Morris saw the model as having an implicit preferred version of disability: a ‘young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment’ (Morris, 2007, p. 9). Morris notes how this presentation misrepresents significant dimensions of disability – the bodily experience of vulnerability, cognitive forms of impairment and, the associations with age. In other words, it offers a partial image of disability, favouring youth, cognitive strength and an individualised form of agency. As more than one third of adult social care spending goes to working age adults with a ‘learning disability’, and the largest proportion goes to older people’s services (National Audit Office, 2017), such a representation of disability has significant gaps.

In 2017, the UN reported on violations to the rights of disabled people by UK government policy. The government’s response affirmed its acceptance of the social model and claimed that the UK was ‘committed to thinking how to remove physical, social and environmental barriers to enable disabled people to realize their aspirations and potential’ (OHCHR, 2017). This claim refers to the idea that simple, low-cost adjustments to environmental and social conditions can mitigate the disadvantages of impairment (‘Reasonable accommodation in most cases does not incur costs or incurs just a minimal cost’, United Nations Department of Economic and Social Affairs, 2019, p. 166). The concepts of ‘reasonable adjustment’ or ‘accommodation’ that appeared in the UK in the Disability Discrimination Act (1995) and Inequality Act (2010) reflect this conception of the intersection between employment and disability. For example, the policy paper ‘Valuing People Now: Real jobs for people with learning difficulties’ (Department of Health, 2009) connects low employment rates among people with ‘moderate and severe learning difficulty’ to stakeholders’ lack of knowledge about how to make reasonable adjustments and the lack of ‘a shared understanding of the social model of disability’ (p. 26).

The social model’s reconfiguration of the relationship between impairment and disability unwittingly served the policy purpose of minimising the implications of disability for employment, relying on the idea that impairment is fixable: ‘An individual with an impairment who lives and works in a suitably adjusted environment may not be considered as disabled under this model’ (Government Statistical Service, 2020). For the group of people taken as the subject of this study, at least, this language and the concept of ‘removing barriers’ oversimplify the relationship between impairment and environment, ignoring the wider local and global factors that influence the extent to which contemporary employment is accessible or can accommodate people with cognitive impairment. Chapter 3 expands on this issue.

In its evasion of intellectual or ‘cognitive’ impairment, the social model adopted an attitude that is widespread in society and runs throughout academic and philosophical thought, which Carlson (2001) describes as ‘cognitive ableism’. She points to the ‘profound othering’ of cognitive impairment, citing how it has served in philosophy as an exception to or test for theories of personhood and justice. In other words, in philosophy it has served to outline where the boundaries of humanity might lie. She argues that this process establishes a ‘prototype effect’, where ‘one type of “cognitively disabled” individual (for example, mildly disabled, profoundly disabled) becomes representative of the whole category’ (Carlson, 2001, p. 141), making a more granular exploration of people and their traits unnecessary. In this way much philosophical literature has systematically overlooked the heterogeneity of people with intellectual and developmental disabilities and the personhood of individuals.

Proponents of critical disability theory also note how certain forms of difference – ‘radical linguistic difference’ and ‘cognitive disabilities and related communicative differences’ – tend not to feature in disability studies (Erevelles & Kafer, 2010, pp. 212-213). Erevelles and Kafer (2010) see the field as having invested in the voice of the disabled scholar and activist to the extent that the inclusion of people with intellectual and developmental disabilities (and those with mental illness) might seem to threaten that cause.

Similarly, in autism research and activism, people with intellectual disability tend to be missing from autistic self-advocacy (see McCoy *et al.*, 2020) and from participation in autism research (Russell *et al.*, 2019). In employment terms specifically, autism is often presented as conferring cognitive advantage (‘Many people… have higher-than-average abilities; [with] special skills in pattern recognition, memory, or mathematics’ (Pisano & Austin, 2017, p. 96). The phenomenon of cognitive ableism and its persistence within the field of disability indicate high levels of social investment in the idea of individual cognitive ability. It is an idea that permeates social arrangements, operating powerfully within the education system and across employment in adult life (e.g., Grover & Piggott, 2015; Slee, 2019).

Social relational models of disability handle the impairment/disability divide by embracing the understanding that ‘everyone is impaired, in varying degrees’ (Thomas, 2004), a proposition repeated in the outlining of the WHO’s *International Classification of Functioning*, *Disability and Health (ICF)*. Though the system sets out to gauge the functional impact of impairment for the purposes of international comparison, its authors display confidence in the concept of ‘reasonable accommodation’ and what it can achieve. For example, the ICF guide states that types and levels of impairment are ‘not an accurate predictor of receipt of disability benefits, work performance, return to work potential, or likelihood of social integration' (WHO, 2002, p. 4). However, statistics suggest that differences of degree and type of impairment are materially consequential, especially with respect to employment. Intellectual disability and mental health conditions impact greatly on employment probabilities, and more so than other forms of disability (ONS, 2019). Statistically, people in these categories are more likely to be in receipt of benefits and to be socially isolated.

In these constructions, employment for disabled people seems to depend less on accommodation and more on the existence of technical and procedural fixes to eradicate difference. The notion that society can manage disability with minimal investment and without disrupting existing employment priorities and norms is supported both by a desire for impairment's effects to be erasable and, specifically, by cognitive ableism.

The question of support needs, their recognition, and responses to them in society can serve as an introduction to the topic of social exclusion: 'a state in which individuals are unable to participate fully in economic, social, political and cultural life, as well as the process leading to and sustaining such a state' (United Nations, 2016). Social *in*clusion for people with disabilities is a consensus target globally, for example in the UN sustainable development goals that the UK has committed to deliver (United Nations, 2016).

The terms of inclusion

Reducing the number of people 'excluded from mainstream society' has been a principle of social policy in the UK since the 1980s. 'Inclusion' has been a key tenet of service provision for people with intellectual and developmental disabilities since *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001). The phenomenon of social exclusion is the subject of a large literature, especially in connection with poverty, unemployment and forms of deprivation. Disability and poverty are highly correlated: people living in poverty are more likely to become disabled, and people with disabilities more likely to be poor. In the UK around 35% of people with disabilities are thought to be living in poverty, almost twice the rate of the non-disabled population (18%), and this is a consistent gap (Joseph Rowntree Foundation, 2022). There are also higher levels of families in poverty where there is an adult or child with a disability. The contributing factors are higher costs of living associated with disability, lower levels of education and qualification among disabled people, and lower levels of employment and earnings. The key point is that both poverty and disability are strongly associated with social exclusion (Levitas, 2006). This relationship is often thought to hinge on reduced rates of employment among disabled people. Chapter 3 discusses this relationship.

Social inclusion is, however, a multidimensional concept distinct from poverty, and is a major focus of policy and literature on intellectual and developmental disabilities. In the intellectual disability literature, inclusion tends to overlap with related social terms such as social interaction, integration, belonging, social capital, community participation and independent living (Amado *et al.*, 2013; Bigby *et al.*, 2017; Cobigo *et al.*, 2012). As this overlap suggests, there is debate about what constitutes social inclusion, how it can be assessed and how far people can be assumed to want it. In the intellectual disability literature, inclusion is often defined and measured in terms of 'independent living' and participation in community-based activities (Cobigo *et al.*, 2012), and these understandings are reflected in personalisation policy (Power, 2013). This can seem to be a limited or even prescriptive understanding of inclusion, which disregards differences and preferences in what matters to people socially. Some people may have reasons not to prefer 'independent living' (see Bigby *et al.*, 2017). Also, the presence of a functioning community with activities to be joined cannot be assumed (Roulstone *et al.*, 2014; Roulstone & Morgan, 2009). Some discussions of social inclusion suggest a communitarian view of society, implying the existence of a cohesive mainstream community whose values those on the outside share or aspire to share (Mouffe, 1991). Significantly, inclusion research tends to focus on people with the ability to articulate their perceptions of being or not being included, so that little is known about the perspective of people without this ability (Clifford Simplican & Leader, 2015), which may be different. Discussion of inclusion often overlooks the fundamental differences in the time commitments and priorities of employed people and people who are not in employment. As far as community activities take place outside working hours, they cannot address the central issue for those with intellectual and developmental disabilities of what happens during the 'working day'.

Cobigo, Lysaght and colleagues (Cobigo *et al.*, 2012; Lysaght *et al.*, 2012) offer an account of social inclusion that considers identity and active roles for people with intellectual and developmental disabilities. They define it as a series of complex interactions between environmental factors and personal characteristics, providing opportunities to:

- Access public goods and services,
- Experience valued and expected social roles of one's choosing based on age, gender, and culture,
- Be recognized as a competent individual and trusted to perform social roles in the community,
- Belong to a social network within which one receives and contributes support.

(Cobigo *et al.*, 2012, p. 82)

All but the first are intimately connected with working roles ‘in the community’, though not necessarily with employment (see Lysaght *et al.*, 2012). The authors see inclusion as a process, which increases dynamically with opportunities to interact and participate with others in jointly valued activities. This might imply a learning element to inclusion, or at least that participation and reciprocity might be important. I return to this possibility in Chapter 4. Simplican *et al.* (2015) propose an ‘ecological’ model of social inclusion that involves ‘organizational’ and socio-political factors; that is, factors beyond the reach of the community activities suggested in policy. They highlight positive self-representation – being seen and known in participating roles – as a means to develop inclusion, suggesting again that inclusion might involve active and interactive processes rather than being something granted or withheld by a community.

Though its definition is contested, ‘social inclusion’ is an important concept in disability research and policy, both in its own right and for its links with a significant ‘exclusion’ literature outside disability. In this study, I use the term to connect with this discourse. I also use the term ‘social participation’ to denote a specific aspect of ‘social inclusion’ – a participatory social role that is not confined to domestic and disability-specific settings. Participation is also the term used in socio-cultural learning literature (for example Matusov, 1998; Rogoff, 1995), and it can bring together the theme of learning, the public activities of work and a particular view of social inclusion. I discuss this view of participation in Chapter 4.

Personalisation policy is supposed to promote social inclusion; that is, personalised social care supposedly replaces collective and segregated forms of care with community-based care. This is the focus of the next section.

The purposes of personalisation

In the UK and in many high-income countries personalisation is a policy project and long-standing theme in health and social care (Power *et al.*, 2009). The UK policy agenda for the past two decades has been based on promoting ‘social inclusion, civil rights, choice and independence’ (Department of Health, 2001, p. 14) to deliver ‘an integrated, community-based approach for everyone’ (Carr & Dittrich, 2008, p. 2). Personalisation takes elements of its vision directly from the disabled people’s movement, while other components follow neo-liberal principles: minimising the role of the state, and emphasising individual responsibility and market solutions to social issues. Many critics note the tendency of marketisation to dominate over social justice elements (Mansell, 2005; Mladenov *et al.*, 2015; Power, Hall, *et al.*, 2021). Roulstone and Morgan (2009) characterise personalisation as a move from the ‘enforced collectivity’ of old-style day care to an ‘enforced individualism’ that embodies individualist conceptions of autonomous agency. As a result, individual people can become isolated, occupying themselves with ‘short periods of time in the “high street”’ and ‘a great deal of time at home’ (p. 342). Another persistent theme in critiques has concerned the ways in which the social and economic agenda of personalisation limits rather than extends social justice (e.g., Ferguson, 2012).

Claims have been made for the success for personalisation as a mechanism for realising ‘choice and control’ (Harkes *et al.,* 2014; Turner & Giraud-Saunders, 2014) as conceived within the disabled people’s movement. There are, however, specific doubts over its application to people with intellectual and developmental disabilities (Harflett *et al.*, 2015; Malli *et al.*, 2018), for example about how choice and control can result from a personal budget that may need to be managed by others (Turnpenny *et al.*, 2020). Decades into this process of personalisation, a review of the literature concluded that, in addition to underfunding, people with intellectual and developmental disabilities had lost social support and were experiencing increased isolation, while family carers had greater demands made on their time, with negative effects on both their role as carers and their own labour market participation (Malli *et al.*, 2018).

Studies involving people with intellectual and developmental disabilities in a number of countries where personalisation has taken place illustrate vividly the problem of under-occupation – the lack of desired or meaningful activities and roles, and the consequences of this (for example, Ashley *et al.*, 2019; Charnley *et al.*, 2019; Luthra, 2019). In Australia, Merrells *et al.* (2019) found that a history of receiving personalised care did not mitigate the experience of social exclusion and employment rejection, even for comparatively socially advantaged young people. Rather, young people reported frustration and boredom, with persistent difficulties in finding and sustaining employment, nothing to do and limited social contact outside the family.

Several analyses of the impact of personalisation have concluded that the policy entrenches inequalities, since the benefits of the system depend on the resources – social capital and personal support – available within individuals’ family networks (for the UK, Carey *et al.*, 2019; in Europe, Dursin *et al.*, 2021). In the US, Johannes (2017) found that half a century of changing practices of inclusion had had little impact on how people with intellectual and developmental disabilities described their lives. Before and after deinstitutionalisation the ‘language, images, and concepts of segregation’ remained ‘hauntingly the same’ (p. 42). A capabilities assessment of the impact of personalisation (Burchardt *et al.*, 2015) provided empirical findings whereby disabled people had not gained ‘choice and control’ but continued to be more likely to experience ‘constrained autonomy in all respects’, with those in lower socio-economic groups or lacking educational qualifications accruing additional risks. Burchardt *et al.* (2015) singled out for criticism the instrumental motive for promoting choice - to position recipients as consumers of care (what they characterise as ‘choice as choosing’, p. 45). They highlight how this interpretation misses the point of choice in capabilities terms - its intrinsic value as a dimension of ‘autonomy’.

In personalisation, the key mechanism for delivering self-directed support is the personal budget. This is the amount of money that a local authority will pay for a person’s social care, and is decided through a needs assessment. Local authorities are legally obliged to offer funding in this form to eligible people, incorporated in a care and support plan that promotes ‘well-being’ (Department of Health and Social Care, 2018). The recipient should have a key role in deciding how the budget is used. It should outline what is important to them, and what personal assistance they need to achieve their ends. Participation in work, education or training are conceived as possible uses.

In the case of people with intellectual and developmental disabilities, personal budgets were envisaged specifically as having potential to increase rates of employment (‘Personal budgets can and should be used for this’, Department of Health, 2009, p. 47). Nonetheless, a review found little use in practice (Watts *et al.*, 2014). The review identifies a culture within social care that discounts employment as a possibility. It cites families making their own arrangements, giving the lack of interest among staff as their reason for doing so. The recommendations suggest that such a focus on ‘care and support needs’ can be incapacitating (p. 54). Hence, minimal accommodation is envisaged outside social care; within it, there is an exclusive focus on care.

The idea of personal assistance has origins in the independent living and civil rights movements (Christensen, 2009; Mladenov, 2012), and it is defined as a human right in the UN Convention on the Rights of Persons with Disabilities (Article 19). Personal assistance and the means to finance it were key demands of the ‘choice and control’ agenda put forward by the independent living movement. A PA was to be employed by the disabled person and, importantly, chosen by them. It became ‘one of the most significant innovations in disability policy in the Global North over the last several decades’ (Mladenov, 2020, p. 3).

Mladenov (2020) sees the arguments for personal assistance as a means to renegotiate the meaning of autonomy for disabled people, specifically to rethink perceptions of their ‘dependent’ status. Considering a consensus statement on personal assistance drawn up by grassroots organisations in Europe, he sees it as contesting ‘existential-ontological and socio-political intuitions’ inherited from the Enlightenment. In a Kantian conception of the individual, women, children and salaried workers were taken to be unfit to participate in public affairs on account of their ‘dependency’. The same logic has been widely applied to people with intellectual and developmental disabilities, in philosophy (Carlson, 2001) and social contract theory (e.g., Rawls, 1993, pp. 18-20; see also Putnam *et al.*, 2019). If autonomy is construed as a particular form of interdependence, as conceived in the statement, disabled people can be autonomous – both ‘dependent and fully human’ – and therefore ‘entitled to participate in the public sphere’ (Mladenov, 2012, p .11). Conceptions of personal assistance as reconfiguring the potential for social participation have pervasive implications for the freedoms of people with intellectual and developmental disabilities.

Personal assistance requires funding, and there has been a justifiably critical focus on the underfunding of social care under personalisation (e.g., Malli *et al.*, 2018; Pearson & Ridley, 2017). Disabled people are disproportionately reliant on such funding and so are additionally disadvantaged by cuts. However, under-occupation, an absence of things to do and be – which is not a direct consequence of underfunding - also fundamentally undercuts the project of promoting wellbeing and agency. For example, an extensive package of PA support, awarded in the context of high support needs, might not result in meaningful occupation or increased social participation for the supported person. People with PA support are ‘not necessarily doing what I would consider to be good, structured activities or even just leaving the house’ according to social care commissioners (Coverdale, 2020). In capabilities terms, the resource of personal support does not necessarily convert into capabilities in such a case. Further, even if markets in care are accepted as a basis for provision, services may be too thin for money to be spent. In the words of another care commissioner: ‘There aren’t the choices available in the area for people to spend their money, whether their money is Direct Payments, personal health budget or self-funded’ (Coverdale, 2020). The failure to conceive of sustainable means to achieve well-being or social participation are core weaknesses in the conceptualisation of personalisation and what it can offer to people with intellectual and developmental disabilities.

In policy, personal budgets can enable young people with intellectual disability and their allies to employ PA support specifically for participation in work, following the wellbeing principle of the Care Act (2014). This might address widespread under-occupation and social exclusion. In practice social care does not support this option, due to a lack of awareness and information among professionals and recipients and the ‘belief that employment isn’t a social care outcome or priority’ (e.g., Watts *et al.*, 2014, p. 24).

There are key differences between self-generated supported work and supported employment, as I discuss in Chapter 3. Research to date on employment within a supported scheme suggests that flexibility and ‘fit’ to individual interests and circumstances might be better achieved through employment supported by PAs (Stevens & Harris, 2013; Watts *et al.*, 2014). This alone suggests that personal assistance might be better suited to expand the capabilities of people with intellectual and developmental disabilities than formalised schemes. The roots of the capability approach in philosophy and economics lead to a focus on what matters to people and on the social and economic factors that constrain or enable them in pursuing what matters to them. In this study, I take ‘what matters’ to be evident in the things that people choose to do and those they avoid engaging in. The following section considers the capabilities approach as a framework for analysis.

2.2 Capability and disability

I consider disability, work and learning using a capabilities approach. The approach is concerned with evaluating the quality of lives that people can lead. Sen’s focus is on enhancing individual freedom, while Nussbaum’s is on respect for human dignity. The approach is widely used to address questions of poverty, social justice and human development, for example in cross-national development contexts, such as the UN's Human Development Index. However, Sen (1992) conceived it as relevant to capability deprivation in high-income contexts, noting that ‘the extent of capability deprivation can be quite remarkably high in the world’s most affluent countries’ (p. 114). Sen (1992, p. 115) highlights lack of ‘social care’ as a factor producing deprivation in such high-income contexts. I take people with intellectual and developmental disabilities in the UK to be among those deprived of capabilities. The focus on what people are able to do and what lives they are able to lead, and their freedom to make choices in these respects, captures what is most often missing in the lives of people with intellectual and developmental disabilities in the UK. Capabilities scholars have argued for the advantages of this framework over other models of disability, in particular over the WHO’s International Classification of Functioning (ICF) (e.g. Mitra, 2006; Terzi, 2005; Trani *et al.*, 2011), on the grounds of its focus on ethics, democratic participation and what matters to people.

Disability is understood in the capabilities approach as a ‘deprivation’ of capabilities that occurs when an impairment deprives a person of valuable opportunities (Burchardt, 2004; Mitra, 2006), in other words, as a particular form of capability-poverty. The approach highlights the complexity of interactions between people’s personal characteristics, their material and social resources, and their environments - physical, social, economic, and political, while maintaining a strong focus on what people value doing and being. Research has focused on a range of people considered to be capability poor, such as disabled students in higher education in South Africa (Mutanga & Walker, 2015) and young people vulnerable to unemployment in the European Union (EU) (European Commission, 2013). The framework has been used to evaluate policies and social institutions in diverse geographical and cultural settings; examples relevant in this context include the design of the welfare state in affluent societies (e.g., Wolff & de-Shalit, 2007), and employment activation policy in the EU (Bartelheimer *et al.*, 2012).

Sen and Nussbaum developed the capabilities approach to counter what Sen saw as reductionist, top-down, economistic evaluations of human development. By contrast, a capabilities approach refocuses on the importance of individual people's lives, the possibilities or freedoms open to them and the duty of the state to protect and enhance these (Brunner & Watson, 2015). Equality in social arrangements is to be evaluated in terms of people's capabilities. The framework specifies that policy should be primarily evaluated 'according to the extent of freedom people have to promote or achieve functionings they value' (Alkire, 2005, p. 122). In this study I consider, work, learning and participation from a capabilities perspective. This chapter focuses on capabilities as a framework in relation to disability policy and relational agency.

The economic causes and consequences of disability are critical factors in assessing social arrangements in high-income countries, where formal employment demands a high threshold of competences and flexibility, and where welfare benefits are intended to support people vulnerable to poverty and social exclusion. A capabilities approach considers how people fare within social and economic systems. This allows attention to extend to what is usually underplayed in individualised models of disability, including the biopsychosocial model: 'a profound understanding of structural constraints and enablements as they relate to individuals' (Wallcraft & Hopper, 2015, p. 83; see also Terzi, 2005).

Pervasive diversity

A strong acknowledgment of human diversity is a key principle of the capability approach, and part of the rationale for its development. Alternative approaches are found to rely on assumed norms and to downplay the impact of differences. According to Sen (1992, p. 114), investigations of equality… that proceed with the assumption of antecedent uniformity miss out on a major aspect of the problem. Human diversity… is a fundamental aspect of our interest in equality'. Accounting for diversity is the starting point in a capabilities analysis, because differences are understood to have material consequences and implications for equality (see Sen, 1999, pp. 69-70). Specifically, diversity matters because 'equal consideration for all may demand very unequal treatment in favour of the disadvantaged' (Sen, 1999, pp. i-xi). Capabilities scholars see inter-individual differences as producing inequality, and hence as having important implications for policy. Sen describes socio-economic status as an important source of inequality, but argues for a more broadly based consideration of difference. He cites diversities in 'productive abilities' and in resource need (for example, in cases of disability) as sources of serious inequalities (Sen, 1992, p. 120). These kinds of difference are material in the present context and have particular significance in economic environments where productivity is sought after and measured.

The capabilities notion of conversion factors – differences in people's ability to convert available means into valuable opportunities or outcomes (Robeyns, 2017, p. 48) – captures the meaning of demanding favourable treatment for disadvantaged people. Conversion factors can be personal, environmental or social, and may be modified by both policies and choices. Personal conversion factors are internal to the person, and may include physical condition or cognitive capacities. In the present context, reading skills, for example, determine the extent to which a person can take advantage of written information. Social factors include public policies, social norms and discriminatory practices. Environmental factors derive from the physical and built environment, including the available means of transport and communication (Robeyns, 2017). Chapter 3 discusses these factors in relation to employment and social inclusion.

A core premise of a capabilities approach is that each person counts as a moral equal, to be respected as an end in themselves 'rather than simply as an agent or supporter of the ends of others' (Nussbaum, 2000, p. 57). In this sense capabilities pertain to the individual. The focus on the individual as an end is integral to the critique of priorities in welfare economics, especially to the top-down application of income as a measure of equality. For the purposes of this study, it is important to distinguish this kind of individual focus from ontological or explanatory forms, since the capabilities approach has been criticised for its 'individualism' (for example, Leβmann, 2020). Robeyns (2017, p. 185) identifies an underlying misunderstanding in this critique. She defends the position that the capabilities approach is 'ethically individualist' in accepting the moral worth of each person, but argues that this focus co-exists with an ontology that is not individualist in its understanding of social structures, social support or group identity. She insists that human agency, not markets or governments, is at the centre of the approach, while people and their opportunities are understood to be socially embedded (Robeyns, 2017, p. 185). She quotes Drèze and Sen's explanation of capabilities as a 'people-centred' approach:

> The crucial role of social opportunities is to expand the realm of human agency and freedom, both as an end in itself and as a means of further expansion of freedom. The word 'social' in the expression 'social opportunity' […] is a useful reminder not to view individuals and their opportunities in isolated terms. The options that a person has depend greatly on relations with others and on what the state and other institutions do.… We shall be particularly concerned with those opportunities that are strongly influenced by social circumstances and public policy.

(Drèze & Sen, 2002, p. 6)

Sen writes in *Development as Freedom* (1999) that to confront the problems of development 'individual freedom' must be taken to be a social commitment (p. xii), and that this understanding is the basis of the approach.

For Nussbaum, human wellbeing ('flourishing') is dependent on relations with others, including relations of care. *Frontiers of Justice* (2006) is concerned with social responsibility for respecting human dignity in the context of disability. The ten central capabilities that she specifies as the minimum requirements for justice include the capability for affiliation, which she define as 'Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction' (Nussbaum, 2006, p. 76). Importantly in the context of devalued identities, affiliation includes 'the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others' (p. 76). Nussbaum and Sen's view that capability development must be a societal not an individual commitment has important implications for employment policy and for personalisation in social care, which will be discussed in Chapters 3 and 4. This view also informs Mackenzie's (2014) capabilities approach to relational agency, which is the focus of the next section in this chapter.

The capabilities understanding of the relationship between the individual and the social is important in relation to social inclusion and to the 'enforced individualism' critique of personalisation policy (Ferguson, 2012; Power, Coverdale, *et al.*, 2021; Roulstone & Morgan, 2009). The analysis of inequality at the group level is an explicit aim of Sen's approach. Such analyses are essential to provide information on the 'intergroup variations' required to identify group-level inequality (Sen, 1999, p. 117). Attention to group-level factors is evident in the capabilities literature in work on the position of women, unemployed and disabled people (Garrels & Sigstad, 2021; Mitra, 2006; Nussbaum, 1999). In education, the capabilities approach has been proposed as an ethical framework to guide inclusion in education, which can be understood to aim to build 'communities that are characterised by… the development of capabilities' (Reindal, 2016, p. 8). These interpretations of capabilities will inform the study's analysis of individual participants' capabilities, and discussion of group level capabilities for people with intellectual and developmental disabilities in the personalisation context.

The companion concept to capabilities is 'functionings', or what people are actually achieving in terms of 'beings and doings'. The difference between the two reflects freedom to make choices and to have agency. The distinction captures the difference between what it is possible to do – the range of opportunities that are available – and what is being done. Sen (1992) uses the example of religious fasting versus being subject to famine, where the functioning is the same, yet the capabilities differ, since religious fasting is a choice. In this respect, the conception of agency captured in the notion of capabilities has some common ground with ‘choice and control’ as originally conceived in the disabled people’s movement (see Burchardt, Evans & Holder, 2015).

Analyses using a capabilities approach can be made in terms of either capabilities or functionings (Robeyns, 2017, p. 9), though capabilities are more commonly used. In this study the focus is on the capabilities of young people with intellectual and developmental disabilities; that is, it is concerned with their agency, with the options open to them and with the kind of life that they can pursue.

There are notable differences between the capabilities specifications of Sen and Nussbaum (see Robeyns, 2017). Nussbaum (2006, p. 75) developed a list of ten capabilities that she considered essential for a life of dignity, arguing that ‘a society that does not guarantee these to all its citizens, at some appropriate threshold level, falls short of being a fully just society’. Sen (2004) by contrast made a virtue of the ‘underspecified’ nature of the capabilities framework, seeing it as a non-prescriptive philosophy open to debate and public reasoning, and respecting the diversity of settings, people and purposes: ‘To have such a fixed list, emanating entirely from pure theory, is to deny the possibility of fruitful public participation on what should be included and why’ (p. 4). I follow Sen’s approach in arguing for the capabilities relevant to this study – the capability to work (discussed in Chapter 3), to learn and to participate socially (discussed in Chapter 4). Where relevant I also draw on Nussbaum’s list and her conception of central capabilities.

The distinction between capabilities and functionings, and the focus of most applications of the approach on capabilities, signals the significance attached to questions of agency in capabilities reasoning. The capabilities approach has a strong focus on freedom to achieve wellbeing, but wellbeing is secondary to the priority for agency. Sen (1999, p. 190) claims that, though there is substantial overlap between the two, assessing ‘agency achievement’ is a broader exercise than the evaluation of wellbeing since people ‘act or refuse to act and can choose to act one way rather than another’ at any level of wellbeing. This distinction captures how pervasive is the question of agency in everyday human activity and in the choices that people make about what they do. People may choose to act against their own wellbeing. Sen gives the example of a person pursuing altruistic work despite personal risk (1992, p. 62). Claassen (2017) notes that agency is itself a capability (‘it is rather surprising that [this] has not been noted more often’, p. 1283), and that, as with other capabilities, individual agency is ‘to a large extent’ a social achievement (p. 1285). Examining the conception of ‘choice and control’ found in personalisation policy, Burchardt *et al.* (2015, p. 44) found a shallow interpretation in personalisation, and an absence of choice ‘in the deeper sense of autonomy’. These claims indicate how agency, autonomy, and choice are conceived in a capabilities approach as fundamentally important to distinguish a 'good life' from one where a person is forced into a particular life, 'however rich it might be in other respects' (Sen, 1999, p. 121). In the lives of people with intellectual and developmental disabilities and the policies concerning them, capabilities and agency have particular significance given the history of paternalism in social arrangements and social care (Mackenzie, 2014).

The capabilities approach is not committed to a particular account of agency, so that those using it should choose a preferred account (Robeyns, 2017, p. 64). I take feminist theorisations of relational agency to explain how people, including people with intellectual and developmental disabilities, attain agency through interpersonal, social and institutional scaffolding. I draw mostly on the accounts of relational agency by Laura Davy and Catriona Mackenzie (Davy, 2019; Mackenzie, 2019). Both apply their accounts in the context of intellectual disability and see promoting personal autonomy as a vital concern for care.

2.3 Agency and relational autonomy

Sen's concept of agency is simple: 'what the person is free to do and achieve in pursuit of whatever goals or values he or she regards as important' (1985, p. 203) or 'what a person can do in line with his or her conception of the good' (p. 206). In capabilities terms, capability and agency are closely related, and both are connected to notions of autonomy (Burchardt *et al.*, 2015; Claassen, 2017). For a more complete theorisation, I turn to feminist conceptions of relational agency. Feminism has provided a body of work concerning disability, especially philosophical treatments of disability, the ethics of care and the distribution of responsibility for care (e.g., Fineman, 2013; Silver, 2020). There is a strong feminist strand in the philosophy and theorising of disability, including work by disabled women and by the mothers and sisters of disabled people (e.g., Davy, 2015; Garland-Thompson, 2011; Kittay, 2011). Considerations of gender and disability inform the original writings of the capabilities approach by both Sen and Nussbaum (Nussbaum & Glover, 1995; Sen, 1999). In her assessment of the capabilities approach, Robeyns (2017, p. 115) characterises it as 'favourably regarded' by feminist scholars and by academics concerned with care and disability. The link here relates to a shared critique of mainstream moral and political philosophy, and within it, 'the relative invisibility of the fate of those people whose lives did not correspond to that of an able-bodied, non-dependent, caregiving-free individual who belongs to the dominant ethic, racial and religious groups' (p. 115).

Feminists have highlighted how disability, especially intellectual disability, has been side-lined as a concern of philosophy, and have played a key role in bringing disability to the foreground

(Carlson, 2016). Feminists and scholars of disability share a concern for the recognition of rights for women and disabled people, but also recognise that care responsibilities are gendered and neglected in mainstream economics and theories of well-being and social justice. They have questioned assumptions in philosophy (e.g., Mackenzie, 2014, 2019), in economics (e.g. Robeyns, 2019) and in law (e.g. Fineman, 2013) about the methods and priorities of treatments of 'vulnerability', care and interdependence. In particular, they recognise how the constraints imposed by caring responsibilities and by paid employment conflict, and are different for men and women (e.g. Kittay, 2011; Robeyns, 2008; Standing, 2009). This conflict affects people with intellectual and developmental disabilities and their families, as it tends to reinforce gender inequalities and the association between disability and poverty (e.g., Levitas, 2006).

The feminist accounts of agency introduced here are not additional to or separate from the capabilities approach but are a necessary element within it. The account of agency is based on the capabilities account given by Mackenzie (2014, 2019). Mackenzie draws on feminist and capabilities thinking to argue that 'vulnerability' is a construct that covers multiple underlying causes, including impairment and disability, and gives rise to moral and societal obligations. The argument for such obligation rests on the function of caregiving as an unrecognised subsidy to society: 'Without aggregate caretaking, there could be no society… it is caretaking labor that produces and reproduces society' (Fineman, 2013, p. 19). Mackenzie (2014) proposes that certain understandings of vulnerability have served to underwrite paternalistic and coercive forms of policy, and, for this reason, the state's duty of protection should be shaped by an overall aim of promoting autonomy. She disputes the view that vulnerability and autonomy are opposing states (for example, Fineman, 2010), and sets out the relational view that autonomy is a learned skill. Rather, fostering the autonomy of people vulnerable to the control of others must be a shared social and political task, as it involves developing social, economic, legal and political institutions that support the development of 'autonomy competences and capabilities' (Mackenzie, 2014, p. 34).

Relational theorists consider people to be fundamentally relationally and socially constituted. Development proceeds through embodied social interaction with other people, with whom we exist in various relations of dependency. Peoples' identities and sense of self are taken to depend on these relationships, and processes of enculturation into linguistic, political and historical communities. Agency is understood to be a cognitive capacity (Davy, 2015) that develops dynamically in relation to opportunity and interpersonal, social and institutional scaffolding. Mackenzie (2014) and Davy (2015) give the example of a woman in an abusive relationship, who may have capacity to leave it only with access to various kinds of legal, institutional and social protections and supports. Social policy and norms can enable autonomy or entrench vulnerability

(Scully, 2014). Hence autonomy is a socially constituted capacity, the development and exercise of which require extensive societal support. A policy that tends to increase social isolation or excludes people from participation in the practices of their culture fails at a basic level to support their agency.

By understanding autonomy as enabled with and through others, for all people, support can be seen as a practice that is not disability specific. Relational understandings acknowledge that in intellectual and developmental disability the care and support may differ in both quality and extent. In contrast to some conceptions of human interdependence (e.g. Kittay, 2011), relational theorists avoid conflating the interests of care givers and care receivers (as Shakespeare (2006) suggests that Kittay's conception does) by balancing support needs with respect for individual personhood. Referring to her sister's non-verbal mode of communication ('unique vocal, facial, and physical cues that require long-term familiarity… to interpret'), Davy (2019, p. 134) describes how her sister can achieve a public voice through the intercession of 'engaged others'. She sees the giving of support and the promotion of agency as mutually sustaining, because 'autonomy cannot be enabled without care, and care cannot be enabling without respect for autonomy' (p. 102). This notion of relational autonomy can serve as a benchmark for assessing a personal assistance role. It is qualitatively different from the kind of support envisaged and offered in supported employment, as Chapters 3 and 4 will discuss.

Relational theories can also serve to rethink the target of independence ('relying on one's own efforts, resources, judgment, and abilities, without requiring support from others' (Sandjojo *et al.*, 2019, p. 38). They derive from a feminist critique of philosophical and social understandings of self-determination prevalent in liberal democracies, where autonomy is individualised as a 'freedom' from dependence on others and from the constraints of social bonds (e.g., Mackenzie, 2019, p. 11). Fineman (2013) sees this ideal as a 'foundational' myth. In her analysis of public policy in relation to poverty among women and children (2013, p. 13), she makes the case that public institutions assume that 'all the activities that manage human dependence' will take place out of public sight in the domestic sphere. This allocation of responsibility supports the public myth of individual autonomy and conceals the fact of collective needs that must be met for society to survive and reproduce itself. She argues for the redistribution of responsibility for dependency among the family, the state and the market. This issue – the distribution of responsibility between these institutions - is at the core of personalisation and debates about its impact in the UK. The 'responsibilisation' of individuals under personalisation shifts the care task further onto families and into the private sphere (e.g. Malli *et al.*, 2018), whether intentionally or unintentionally, thereby disconnecting disabled people from each other and from the shared sphere of public activities.

As Fineman's arguments suggest, independence, in the sense of acting without support, is a value that is deeply embedded in society. It is assumed that adults are self-sufficient, and 'significant discursive and material pressure is exerted on encouraging them to become so' (Davy, 2019, p. 105). Targets relating to independence are ubiquitous in policy and practice for people with intellectual and developmental disabilities (Department of Health and Social Care, 2014; Liebrecht, 2021), even though the task at hand is to manage departures from this supposed norm, that is, to manage cases where the need for additional support is evident. Personalisation could be interpreted as promoting the ideal of individual self-determination (in the form of choice, control, and independence 'as far as possible'). It can also be seen as covertly drawing on the private ideal of the 'assumed family' (Fineman, 2013), embodied in the carer whose social importance is partially recognised in the Care Act (2014). The Care Act marked a step towards recognising the social role of unpaid carers and providing limited financial support to them. However, in practice, the system can operate differently. The amount of care provided by the carer may be deducted from the budget allocated to the cared-for person (Mitchell *et al.*, 2014, p. 7), thereby limiting 'choice and control' for both parties. In policy and practice personalisation reflects a widespread tendency to overlook the complex dynamics of care-giving relationships and to conflate the needs and aspirations of carers and the people they support (Mitchell *et al.*, 2014). In other words, the policy supports this relationship at the expense of wider social connections.

The capabilities of people with intellectual and developmental disabilities depend on successfully navigating the demands of care and personal agency. A key underlying issue is that of access to participation in a society where participation is largely a matter of formal employment. Robeyns argues from her feminist and capabilitarian position that caring and unpaid labour should be seen as fundamental economic activities, because carer and cared for are tied together economically through their relationship to work and earning:

> Income might reveal much of the well-being of an idealised independent individual who is working full time, who is in good health and good physical and psychological condition, and who has no major caring responsibilities. But for an unemployed person, or a care-taker, or a dependent person, other dimensions of well-being might be much more important for their overall well-being... the more a person deviates from the idealised model… the more other factors influence the mapping from income into well-being.
>
> **(Robeyns, 2008, p. 88)**

Her analysis underscores the limitations of employment as a measure of wellbeing success for people with intellectual and developmental disabilities. This issue is the subject of Chapter 3.

Participation in public shared endeavours is supposed to be key to social learning and the development of agency (Biesta *et al.*, 2008; Billett, 2008; Illeris, 2006). Billett (2008) identifies a relational interdependence or bidirectional relationship between individuals and the social practices that comprise their workplaces. The experience of work involves interaction between people, their capacities and subjectivities, and the norms, practices and values of particular work settings. Personal agency is required to make sense of the social experience the workplace presents. Applying this aspect of relational agency to work by people with intellectual and developmental disabilities, I understand both the work situation and the PA support to have potential to offer support for the development of agency.

In the ways outlined above, the issue of relational autonomy is a significant aspect of a capabilities analysis and central to the questions of this study. It conceptualises the impact on capabilities of relations between people with intellectual and developmental disabilities, their PAs and others encountered through work. The conceptions of relational autonomy rooted in feminism derive from a critique of social arrangements that idealise individual self-determination and confine matters of care and support to the private sphere. Relational autonomy provides a means to evaluate the quality of personal support, alongside robust arguments that supporting the autonomy of people vulnerable to subjection is a matter for society and for social policy. If relational support promotes the autonomy or agency of the person, it has the potential to serve a foundational purpose in what they can do or be.

The theorisation of relational autonomy brings together ideas of personhood and its development which emphasise the significance of social participation and social policy. I consider next its implications in connection with the disability notion of personal assistance.

Personal assistance and personalisation

A language of choice, autonomy and personal responsibility dominates personalisation policy. It specifically tasks people receiving social care with the responsibility for their own support and provision, promoting independence ‘as far as possible’ (Department of Health and Social Care, 2018). The individual autonomy that it celebrates is a central tenet of liberal politics. It also harmonises with the political agenda of a small state and reduced expenditure (see Ferguson, 2012; Mladenov, 2015; Needham & Glasby, 2015). Davy (2019) notes how, in these circumstances, autonomy becomes an individual ‘problem’ for disadvantaged people to negotiate, and how this issue deflects attention from the social, economic and cultural conditions that constrain their freedoms.

In the case of people with intellectual and developmental disabilities, many have noted (e.g., Davy, 2019; Mackenzie, 2019) how responsibility for care is transferred jointly to the individual and the individual carer. Personalisation aims to promote choice and control over support, yet there are recurring concerns in the research literature that this comes at a high price for the individual and close relatives (e.g. Brookes *et al.*, 2017; Malli *et al.*, 2018). The system requires a high level of skills and resources - to negotiate the administrative burden and managerial responsibilities, including those involved in employing a PA (e.g. Carey *et al.*, 2019; and from a capabilities perspective, Dursin *et al.*, 2021). While policy aims to support informal connections in the community, such connections can be unpredictable and do not occur spontaneously. Rather, ‘complex and sustained work’ is required to facilitate them (Power, 2013). A capabilities framework and feminist accounts of relational agency serve to interpret these factors in the working arrangements of participants in this study, and how far such arrangements enhance their capabilities.

The PA role might increase the scope for care and support to be socially distributed, reducing social isolation and the monopoly of family and disability as reference points and markers of identity. In this way, support outside the family might be an important enabler of autonomy. PAs might also function as bridge between supported people and the public social world in the ways suggested in the theorising of relational autonomy. Supporting communication and relationships in work contexts might be important to mitigate the social exclusion often reported in employment contexts, especially since social difficulties are often the cause of a breakdown in employment arrangements (Beyer, 2012). Personal assistance might then prove to be ‘a major condition for the possibility of disability equality’, as claimed (Mladenov, 2012, p. 4).

These possibilities are distinct from the kinds of employment support envisaged in supported employment or in the concept of reasonable accommodation. An example might be found in the question of language. Variations in the speed and fluency of language processing have extensive implications for people with intellectual and developmental disabilities in public settings. One accommodation that is often recommended is ‘easy read’ (e.g., Department of Health and Social Care, 2014), a simplified and illustrated version of written information. Research suggests that, in practice, easy read text does little to improve understanding (Buell *et al.*, 2020; Chinn & Homeyard, 2017); rather, what makes information meaningful for people with intellectual and developmental disabilities is personal support - familiarity with the person’s language-processing capacity and life experience (‘relating text content to the lived experience of the reader,’ Buell *et al.*, 2020, p. 228). Davy writes that if people with intellectual and developmental disabilities are to be represented in the public sphere, ‘engaged others’ may need to ‘translate, interpret, and communicate their needs and perspectives’ (Davy, 2019, p. 109). Such relational support tasks might be among those undertaken by PAs and be part of a process of scaffolding mutual understanding. Personal assistance for work can be conceived as having potential to ‘activate’ the autonomy of the individual by enabling a life outside the networks of family and disability settings. Feminist accounts of relational agency in a capabilities framework offer a means to unpick these possibilities.

Personalisation policy acknowledges that institutionalisation and paternalistic day care arrangements are incompatible with autonomy - this is the basis of the call for ‘choice and control’ by the user. Davy (2019) speaks of long-term familiarity with the supported person as the foundation for promoting relational agency. The capacity to find a compatible PA may be a significant advantage of personal budget schemes. Sharing ‘common ground’, shared knowledge, joint experiences and personal familiarity have been cited as means to establish relationships of equality between the supported person and their PA (Williams & Porter, 2017). Problems of availability and pay and conditions for PAs (Scourfield, 2005; Woolham *et al.*, 2019) may make that potential advantage more difficult to achieve.

2.4 Summary

In this chapter I have discussed language and concepts central to the discussion of disability and people with intellectual and developmental disabilities, arguing for labels and language that acknowledge meaningful differences between people, and that both group identity and identity beyond disability are possible. A capabilities account of multidimensional difference and its insistence on the significance of diversity in considering equality inform these positions. I have outlined the case for a capabilities approach to evaluate participation in work in the public sphere, which focuses on what people can be and do in their lives. As agency is understood to have a core role in addressing capability deprivations, I have argued for feminist accounts of relational agency and relational autonomy. I have suggested why they might be appropriate in the context of this study, and how they might be applied.

Personalisation policy has changed how social care operates. The reforms have involved significant budget cuts and had distinct effects for people with intellectual and developmental disabilities. This study will examine its impact from a capabilities perspective. Specifically, I look at young people with intellectual and developmental disabilities and the use of personal budgets to employ personal relational support, exploring participation in the public sphere and related learning and social outcomes. Social inclusion and learning are important dimensions of participation in work that are considered further in Chapters 3 and 4.

In the next chapter I consider work and employment for people with intellectual and developmental disabilities from the points of view of policy and social participation.

Chapter 3 Employment and work

In this chapter I outline the employment context for people with intellectual and developmental disabilities, and argue for alternative approaches to attaining the benefits that are supposed to accrue from employment. Since the right to employment is fiercely defended, I spend some time doing this. Speaking for people with intellectual and developmental disabilities, Bates *et al.* (2017, p. 172), write:

> We must disavow work. We desire employment.… Work is a place where people with intellectual disabilities can craft identities that sit in counter-distinction to the passive subject positions afforded by the psychiatric and psychological literature: contrast, for example, 'I work' with 'I go to a day centre'. Labour has the potential to deconstruct intellectual disability. Labouring shows you are doing something: you are able. Work is enabling.

While I seek many of the positive outcomes cited, I argue against the assumption that employment is the way to achieve them, and I note the conflation of employment and work.

My argument draws on the literature concerning disabled people as a whole, on the special considerations for people with intellectual and developmental disabilities, and on the broader arguments against an 'employment-focused paradigm' in policy on capabilities grounds (Laruffa, 2020). I devote some time to the position of people with intellectual and developmental disabilities in relation to employment, given its dominance as an economic, policy and social ideal and, as in the quotation above, as a means to empower people with intellectual and developmental disabilities.

3.1 Disability and employment

In terms of employment disabled people are disadvantaged, both internationally and across the range of types and severity of disability. They are less likely to be employed, on average they are paid less and they are more likely to be in part-time, temporary or insecure forms of employment (Gunderson & Lee, 2016; Mitra & Kruse, 2016). They receive fewer opportunities for training and development than non-disabled people (Schur *et al.*, 2017). In the UK, a significant and increasing number of working-age adults (19%) are counted as disabled for employment purposes (Department for Work & Pensions, 2018b), and they comprise a highly diverse set of people, conditions and situations. With a current employment rate of c. 5% (NHS Digital, 2022), people with intellectual and developmental disabilities, alongside those with a mental health condition, are among the least likely to be employed.

As disability is defined in terms of a person’s ability to carry out everyday tasks and to participate socially (e.g., World Health Organization, 2020), the concept is intrinsically linked to both paid work and social participation. The terms ‘disability’, ‘unemployment’ and ‘retirement’ are linked historically, as they developed as related constructs in twentieth-century welfare states when work became concentrated in competitive industrial production, which was not sustainable in older age (Macnicol, 2011). In recent decades, population-level health and longevity have risen, and work disability has also increased (Macnicol, 2011). These connections suggest that finding and keeping employment entails a complex trade-off between physical and psychosocial wellbeing and the opportunities in the employment environment, and this is discussed below.

As employment is the central factor that structures adult lives and identities in high income countries, it is widely conflated with work. Yet employment is a recent form of work organisation, and is subject to a longstanding critique in terms of its ‘commodification’ of work (see Standing, 2009). From a feminist perspective, the historical shift to wage labour, in which the welfare state prioritised ‘full employment’ and a male breadwinner, drove an increasing de-recognition of women’s unpaid reproductive and care work (Ferguson et al., 2016). As women and, later, disabled people were absorbed into the workplace in high-income countries, employment became one of the main forms of social cooperation. In the UK, nearly 80% of working age adults are in paid employment, the majority of whom (c. 85%) are in full time employment (ONS, 2019b).[2] Such a majority and such a monopoly over the use of time is problematic for those not engaged in employment because of the scale of the divide that it establishes in terms of time patterns, experiences and social connections.

In recent decades, employment has become the priority of economic policy. Globally, social policy has been shaped around the goal of promoting labour-market participation, including by disabled people. The economist Guy Standing (2009) identifies this period as a ‘recommodification’ of labour in the wake of globalisation, whereby the welfare state’s protection from market pressures is reduced and active labour market policies incentivise maximum employment.

In the following sections, I consider evidence that in such markets the arguments in favour of employment for people with high levels of disadvantage are misconceived, and that the policies

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[2] Figures before impact of Covid-19.

and interventions to include them in employment have been ineffective. Fundamentally, I argue that employment is likely to constrain rather than to extend their capabilities. I understand that the people who are the subject of this study are eligible for a range of disability benefits and have care plans that support the employment of a personal assistant.

The employment monopoly and work intensification

Overall economic policy in high-income countries focuses on increasing economic competitiveness (e.g., European Commission, 2013). In the UK, there is an additional focus on addressing the national productivity gap (Taylor *et al.*, 2017). Both are thought to require investment in 'human capital' - retraining and reskilling for employment (Chapter 4 examines this topic). It is these policies rather than disability-specific policies that shape markets in jobs. To identify the source of unemployment in lack of reasonable adjustment or discriminatory attitudes among employers is to give insufficient attention to the structural barriers, that is, to the impact of competition and efficiency priorities in capitalist economies, evident in ordinary business practices to maximise profit (Russell, 2002).

Current labour market trends demand higher and higher levels of educational attainment in prospective employees (European Commission, 2013), and there is a shrinking pool of employment opportunities for less-skilled workers (Standing, 2009; Susskind, 2020). In such an economy, there is marked differentiation between people in terms of knowledge ownership (Goodley & Norouzi, 2005, p. 228). For all people there is a broad correlation between their level of educational qualification and the likelihood of being employed (European Union (EU), 2020). A knowledge-based economy, technological change and globalisation highlight particular skills and competences in employees. The value of adaptability is reinforced, such that 'lifelong learning' has been adopted as a policy to increase economic competitiveness (Colardyn & Bjornavold, 2004). In the UK, for economic and employment reasons, there has been a concerted effort to make basic skills an educational priority (see Bynner, 2017). There are few available statistics on the educational and qualifications of adults with intellectual and developmental disabilities, but they are likely to be among the 18% without a qualification at Level 2 (e.g., GCSE A*, A, B, C), sharply reducing their employment options. Further, a lack of qualifications has an added impact in the context of disability, which is intensified at lower levels of qualification. Disabled people with a degree-level qualification are c. 15% less likely to be employed than comparable non-disabled people, while the differential rises to 44% for people without qualifications, and this gap is thought to be widening over time (Berthoud, 2011).

Since the 1990s global socio-economic changes have driven work intensification, which has come to be regarded as a critical issue for employees in high-income societies (Paškvan & Kubicek, 2017). Intensification involves an accelerated pace of work, time pressures, increased effort, and an emphasis on individual performance. It is supported by zero-hours contracts and productivity- and performance-based employment schemes (Mauno *et al.*, 2022), and these result in yet higher demand for flexibility and adaptability - for a capacity to redeploy and learn new roles and processes in response to market fluctuations. Recent OECD forecasts report an increasing need for employees to switch jobs flexibly and to retrain extensively to remain in employment (OECD, 2019). Some examples of how these conditions affect the employment chances of people with lower levels of marketable skills are cited in research from the Netherlands examining the perspectives of private employers working with local government to support employment for disabled people. Staff outline the impact of the reconfigured labour market on their ability to find roles for the target group:

> In production companies such as ours, where low-skilled people often end up, you need to be increasingly versatile and employable.… For people with work impairments, this gets difficult. (Production company, private sector)
>
> We’re a knowledge-intensive organization.… We outsourced cleaning, we outsourced catering, and we could have hired a lot of people [with disabilities] for those tasks. (Public sector organisation)
>
> we scrape together tasks that match the target group. For us that’s the main challenge. We outsourced many tasks. And skill requirements become higher and higher. (Financial services, private sector, 3,000 employees)
>
> A ‘normal’ employee can work in three, four tasks. A person with disabilities only in two. So, for us, this person’s employability is low. (Tourism, private sector, 150 employees) (van Berkel, 2021, p. 539)

As these comments suggest, employers’ premium on skills, knowledge and versatility, combined with the outsourcing of lower-skilled functions, produce an environment that is hostile to people with intellectual and developmental disabilities.

First-hand experience of precarious employment conditions is reported in Australian research. As in the UK, policy in Australia is ‘personalised’, focusing on enhancing ‘freedom, life choices and participation of service users’ and emphasising ‘individualisation, choice and control’ (Sawyer & Green, 2013, cited in Merrells *et al.*, 2019). Choice and control are watchwords of personalisation, but these goals of policy are rarely instrumental in shaping access to employment for disabled people. Merrells *et al.* (2019, p. 16) present a picture of adverse conditions in which participants had pursued employment persistently, for up to six years, with limited success. A young woman who had managed to obtain insecure work clearing plates and washing dishes struggled with deadlines and lost out in the competition for shifts:

> I find it really difficult. Um, because I find it hard to keep up with everything because I know everything has to be done at a certain time…. So, um, yeah, so I phoned up, like, last week to see if there's any more shifts, and there haven't been any shifts for me, like, this week, so… yeah.

Participants' sense of difference and rejection from mainstream society was amplified by such struggles for access (p. 18). Productivity and efficiency demands are key employment obstacles for people with intellectual and developmental disabilities which operate regardless of diversity policies (see Moore *et al.*, 2018). The specific patterns of employment after globalisation disadvantage people with intellectual and developmental disabilities in multiple ways.

3.2 Employment activation – policy and research

Since the 1990s social policy in high-income countries has advocated for people's labour market participation and for human capital enhancement as a means to achieve it (i.e. investment in education, training, skills and experience) (e.g., Laruffa, 2020). Across Europe, unemployed people of all kinds have been increasingly pressurised to take work. Active labour market policies have been allied with reductions in social protection, squeezing budget allocations to benefits (Bartelheimer *et al.*, 2012; Reinders Folmer *et al.*, 2020). The policies are considered to align with the UNCRPD, since investment in the development of human capital is assumed to promote both quality employment and greater social inclusion for disabled people (ibid.).

Specifically, since 2001, UK policy has made increased employment its objective for people with intellectual and developmental disabilities (Valuing People, 2001). The policy case for employment was first made explicit in the government strategy paper 'Valuing Employment Now' (2009 to 2011):

> all people with learning disabilities, like all other people, can and should have the chance to work. To deny people that opportunity is a waste of talent for the individuals, employers, society, and the wider economy.… Government's goal [is] to radically increase the number of people with moderate and severe learning disabilities in employment by 2025.…We aspire to close the gap between the employment rate of people with learning disabilities and that of disabled people. Closing this gap in today's terms would mean 48% of people with moderate and severe learning disabilities in England in real jobs... employment is a fundamental part of life, and it is only when

> people with learning disabilities have the same opportunities as all other citizens that we will really be valuing people.
>
> **(Department of Health, 2009, p. 2)**

The argument deploys the language of rights and normalisation to present employment as a valuable opportunity: ‘the same opportunities as all other citizens’. ‘Valuing Employment Now’, followed a Green Paper (*No One Written Off: Reforming welfare to reward responsibility,* Department for Work & Pensions, 2008) that illustrates the logic of the government’s employment aspiration, linking employment with questions of skills acquisition and social responsibility. The then Prime Minister, Gordon Brown, argued that ‘rights’ would be met with ‘tough responsibilities’ to respect the rights of taxpayers as well as those claiming benefits’ (p. 5). The paper calls for individuals to strive to prepare for new markets in jobs and to ‘get the skills to progress in an increasingly competitive and globalised society’ (p. 5).

Current UK government policy is less ambitious specifically for people with intellectual and developmental disabilities. Instead, it focuses squarely on reducing the headline disability employment gap, that is, the difference between employment rates for people with and without disabilities. The gap is taken to be a key metric of equality, and reducing it is a requirement of the UNCRPD (van der Zwan & de Beer, 2021). The White Paper *Improving Lives: The future of work, health and disability* (Department of Health, Department for Work & Pensions, 2017) aims to halve the disability employment gap in the following decade (i.e., by 2027). The policy identifies the significant savings to be made: finding work for an additional 1% of Employment and Support Allowance claimants would ‘save the Exchequer £240 million and provide a boost to the economy of £260 million’ (Powell, 2020, p. 11). Yet, as the paper’s title suggests, the policy claims to rest on the argument that work has health and well-being advantages for the individual: ‘It keeps us healthy, mentally and physically. It enables us to be economically independent, and gives us more choices and opportunities to fulfil our other ambitions in life’ (p. 3). This and other employment activation policies construe employment as a means by which people can improve their health, wellbeing and socially marginalised position as well as their economic ‘independence’. Employment is a social obligation. Similar arguments are found in much research literature, including that specifically concerned with people with intellectual and developmental disabilities (e.g., Bates *et al.*, 2017; Emerson Hatton, Baines *et al.*, 2018; Reinders Folmer *et al.*, 2020). Attaining employment is understood to be empowering. Yet current employment trends make sustainable employment outcomes unlikely, and social and policy pressure for employment can have negative consequences. Research concerning the outcomes of active labour market policies in the UK in terms of capabilities has documented some of these. Unemployed people with ‘multiple problems and needs’, including intellectual disability, engaged in strategies supposed to increase their employability, building portfolios of ‘virtually meaningless’ qualifications and repeatedly revising their curriculum vitae (Dean *et al.*, 2005, p. 17). Echoing the experiences of employment rejection reported in the context of personalised services in Australia (Merrells *et al.*, 2018), they experienced repeated disappointments, which focused attention on other failures they had experienced, thereby maintaining ‘the corrosive pressures of their own and society's expectations’ (Dean *et al.*, 2005, p. 17). The claims that employment is empowering are undermined by such findings, and by other factors. I consider first the question of earnings, followed by health and social inclusion.

Earnings

The financial benefits from employment are generally agreed to accrue above 16 hours per week (e.g. Department of Health, 2009), yet the majority (two-thirds) of people with intellectual and developmental disabilities who are in employment work fewer hours (Parkin *et al.*, 2018). Indeed, employment for less than two hours per week is increasing (ONS, 2019). In addition to the earnings disadvantage of low hours of work, financial gain is limited by low rates of pay. People with intellectual and developmental disabilities are classified in Government statistics as people with ‘mental impairments’, the group that has the greatest pay disadvantage (c. 18%, ONS, 2019a). Yet this category also covers people with depression, ‘bad nerves or anxiety’ and specific learning difficulties, that is, people with less disadvantage in educational attainment. McDaniel *et al.* (2016) found that people with intellectual and developmental disabilities in the US had mean weekly earnings 24 to 39% below those of disabled people in other categories.

Of the minority of people with intellectual and developmental disabilities who are employed, therefore, most work too few hours and at too low rates of pay to become independent of state benefits (Public Health England, 2020; Ramsey, 2020), and the basic earnings rationale for employment does not apply.

Employment, health and social inclusion

A large literature links unemployment causally to negative effects on mental health (e.g., McKee-Ryan *et al.*, 2005; Paul & Moser, 2009). This link is thought to apply to people with intellectual and developmental disabilities (e.g. Emerson, Hatton, Baines *et al.*, 2018), yet there are reasons to doubt the health and social inclusion benefits of employment for such people. The relationship between health and employment is conditional, even for those in ‘good’ work. Key factors are thought to be autonomy at work and social support. The landmark Marmot Report (1991) on health inequalities among civil servants found a correlation between job grade and the health effects of work, with a ‘steep’ inverse relationship between mortality and type of work, whereby people in lowest status jobs had the poorest health outcomes. Monotonous work characterised by low control and low satisfaction was a key determinant of illness, while social support mitigated such effects. Casual and unskilled jobs were most associated with poor health outcomes, that is, the kinds of work most accessible to people with intellectual and developmental disabilities. By 2010, Marmot warned specifically on the flawed argument for activation policies: ‘Getting people off benefits and into low paid, insecure and health-damaging work is not a desirable option’ (Marmot *et al.*, 2010, p. 26). As this suggests, the health effects of precarious and low quality employment are adverse for all people, yet those with intellectual and developmental disabilities are much more likely to occupy such positions (Emerson *et al.*, 2018). Marmot’s findings on autonomy and control (see also Green, 2004) give empirical support to a capabilities conception of the importance of agency to wellbeing. They highlight the difficulty of turning employment to advantage as a person with intellectual and developmental disabilities.

One problem besetting research findings regarding the benefits of employment concerns the conflation of employment and work. Much research depends on comparing employed people to those seeking employment, without reference to people engaged in other forms of work, which might alter the patterns found. One exception is a review of the connections between poverty, employment and social inclusion in the UK (Levitas, 2006), which compares employment and alternatives to employment, including unpaid reproductive and care work. This review concludes that UK policy overstates the role of paid employment in delivering social inclusion, and neglects the specifically social aspect. Policy also neglects specific findings for people with intellectual and developmental disabilities in employment (including supported employment), which is that social isolation and exclusion are common experiences (e.g., Beyer & Robinson, 2009; Hall, 2004; Jahoda *et al.*, 2008).

I consider next government policies and interventions to extend the number of people in employment.

3.3 Supported employment

Between 1994 and 2014 the UK government established a range of interventions to facilitate the employment of disabled people, including people with intellectual and developmental disabilities. These included campaigns, landmark legislation (the Disability Discrimination and Equality Acts, 1995–2010; 2010–ongoing), employment support schemes and the Disability Confident Campaign for employers (2010, ongoing). Supported employment is a personalised model intended to help disabled people secure and maintain employment; schemes link disabled people and employers through a variety of government sponsored formats. Supported employment is described as the gold standard support for people with intellectual and developmental disabilities (Wehman *et al.*,

2014) and is the UN recommended option to increase the employment level of disabled people (e.g. United Nations Department of Economic and Social Affairs, 2019). But supported employment is also seen as having a strongly normalising ethos, seeking and training for compliance with employment norms for behaviour and productivity (Wilson, 2003).

The schemes operating to support employment in the UK can be categorised into four groups:

- National contracted employment support programmes, such as Work Choice, Specialist Employability Support and the Work and Health Programme
- Jobcentre Plus provision, including direct support from Work Coaches to gain a job, enhanced for those with more complex needs, and access to locally funded specialist disability support
- Grant-based employment support, such as Access to Work
- Initiatives targeting employer behaviour, such as Disability Confident.

(Learning and Work Institute, 2019, p. 2)

The initiatives operating between 1994 and 2013 for people with intellectual and developmental disabilities were reviewed and evaluated by Blamires (2014). She identifies limited local success stories, without an overall impact on employment rates. Blamires concludes that 'the current situation for people with learning disabilities appears bleak, with… little prospect of employment' (p. 163). Support schemes that targeted disabled people as a whole lacked expertise in the specific needs of people with intellectual and developmental disabilities, and those 'furthest from the labour market' (i.e., those with higher support needs) were underserved. Recent outcomes are similar. Around 82% of participants with 'learning disabilities' did not achieve a sustained job outcome through the Work Choice scheme (2010–2018) (DWP, 2020). In general, supported employment was not widely accessible. Work Choice, for example, offered too few places to meet demand (Powell, 2020). The main scheme for employers, 'Disability Confident', aimed to influence attitudes and advocate for the employment of disabled people. It was evaluated as vaguely specified and poorly targeted (House of Commons Work and Pensions Committee, 2017, p. 137). In the view of a leading specialist in work and intellectual disability, it represented an unbalanced, supply-side approach which paid inadequate attention to the employer role and job generation (Beyer, 2012). More recently, Bacon and Hoque (2022) note that only a tiny proportion (c. 0.5 %) of UK private sector businesses (sole traders were excluded) have adopted the scheme, even though this sector has the majority of UK jobs - above 75% (ONS, 2022). Ultimately, as noted earlier by Blamires (2014), employment statistics provide a basic assessment of supported employment. In the past decade there has been a small increase in the overall rate of employment among people with disabilities (Powell, 2020), yet the proportion of people with intellectual and developmental disabilities in employment has declined (Hatton, 2018).

A troubling verdict on the labour market activation of disabled people is given by the economist Macnicol (2011), who sees employment policy primarily as a tool to control inflation, thereby creating a stable environment for finance capital. The UK government, and in Macnicol's view specifically the New Labour government (1997–2010), deployed the 'emancipatory, post-civil rights social model of disability' to justify the labour market activation of disabled people. This rhetoric enabled employment to be presented as 'empowerment' through removal of the 'discriminatory barriers' said to prevent disabled people from working (p. 35). Macnicol is unusual in taking a sceptical view of what employment has to offer disabled people, but is in line with that of a minority of scholars of intellectual disability, who have argued for the right not to engage in paid employment (Grover & Piggott, 2015; see also Hall & McGarrol, 2012).

3.4 Employment, work and capabilities

Employment activation has been understood as an economistic approach that subjects the interest of people to economic policy, and so constrains the capabilities of people subjected to it. Capabilities scholars have argued against the priority given to transitions into employment, irrespective of quality and regardless of other factors, such as care responsibilities (Bartelheimer *et al.*, 2012; Dean *et al.*, 2005; European Commission, 2013). They have addressed the impact on marginalised groups of such policies. Egdell and Mcquaid (2016) consider the third-sector employment support programmes for young people from disadvantaged backgrounds. Some of these were interpreted as capability friendly, since young people had agency in the delivery and implementation of the support. The constraints on their capabilities were, rather, due to the limited opportunities available to them in the labour market beyond the programmes and in accessible education and training. There were few jobs or routes to jobs for which they qualified, partly on account of their prior educational opportunities. The authors concluded that 'structural inequalities continue to be important in shaping the trajectories' of these young people (p. 16), regardless of activation measures.

Comparing employment protection measures in the context of activation policies in Germany and Spain, Bartelheimer *et al.* (2012) argue that 'cash transfers' with few conditions, as opposed to schemes providing services and activation measures, can be capability-friendly 'by default' (p. 31). The absence of conditions enables benefits to be used actively to the person's benefit, adapted to their individual needs and circumstances. Their findings support the possibility that a personal budget at an adequate level and with few conditions might have similar capability-enhancing potential for a person with intellectual and developmental disabilities.

Bonvin and Laruffa (2016) argue for policies to give people choices beyond employment, as well as capabilities within employment, allowing them, for example, to opt out of an extended job search or education/training pathway to undertake caring or other personal priorities (p. 41). Their analysis highlights how increasing pressure for employment affects the capabilities of people with intellectual and developmental disabilities directly and indirectly by reducing the freedom of others to choose an unpaid caring role.

3.5 Social participation and the capability to work

I turn first to social care, examining the framework of personalisation in services for people with intellectual and developmental disabilities. Two key points arise in relation to the present study. The first is its low priority in government policy, indicated by the tighter restrictions on eligibility noted in critiques of personalisation (e.g., Forrester-Jones *et al.*, 2021) and the employment-focused paradigm itself. The second is that social care has its own culture and priorities, emphasising support need, with little focus on capacity for work or employment (Hall & McGarrol, 2012). Hence personal budgets, a key feature of personalisation, are little used for the purpose of work despite this being a part of the original conception (Watts *et al.*, 2014). Personalised social care is supposed to cultivate inclusion and 'belonging' in the community (Care Act, 2014; Power, 2013), yet little attention is given to the means by which it might be achieved. Despite the headline focus on promoting independence within 'mainstream' services and activities, there is no account of how presence in mainstream places and activities might result in participation and agency within them. Simplican *et al.* (2015), for example, describe activities that take place in mainstream community settings, but involve exclusively or mainly disabled people, as 'semi-segregated', since they typically feature only limited interaction with or recognition by the wider community.

People with intellectual and developmental disabilities may indeed prefer segregated spaces, since they may feel more socially comfortable and less stigmatised, as reported by Lysaght *et al.* (2017). Both segregated and semi-segregated settings may be reasoned choices, but they suggest that people with intellectual and developmental disabilities have unequal freedom to access the public sphere. This freedom, the 'capability to appear in public without shame', is identified as a critical general capability (Robeyns, 2017, p. 95). For people with intellectual and developmental disabilities active participation in mainstream settings, despite the challenges involved, may be the best opportunity for them to represent themselves to others as unique people and 'promote positive awareness about disability and inclusion' (Simplican, 2015, p. 24). Chapter 4 discusses participation and participatory learning in such settings, together with the scaffolding involved to support the challenge.

The social care policy underpinning the benefits system distinguishes two groups of disabled people eligible for Employment Support Allowance, the main income replacement benefit. The mechanism for doing so is the Work Capability Assessment (WCA), an employability assessment, which assesses whether an applicant:

- has limited capability for work – will not have to look for work, but will need to take steps to prepare for work, or
- has limited capability for work and work-related activity – will not be asked to look for or prepare for work.

(https://www.gov.uk/employment-support-allowance/eligibility)

Those in the conditional category ('need to take steps to prepare for work') are placed in the work-related activity group, while those in the unconditional category (who will not be asked to seek or prepare for work) are placed in the support group. The rules and processes of work capability assessments and claims for Employment Support Allowance are complex. It has been characterised as a 'controversial' and 'adversarial' process (Litchfield, 2013, p. 59). As intended, it produced from its inception a high proportion of 'fit for work' recommendations. Marmot's (2020) review of health equity in England noted that a large number of applicants deemed 'fit for work' had died within six months (p. 68). The assessment process is recognised as posing particular problems for people with intellectual and developmental difficulties, who may overstate their capacity for employment or understate the support they need as they try to cooperate with the interview process (Litchfield, 2013).

The sorting procedure is problematic in itself, yet the implication of the two-category policy is that those deemed to have limited capability for 'work and work-related activity' are effectively written off. As employment is the valued outcome, there is no conception of, or provision for, social participation by other means. As Hall and McGarrol point out, it is assumed that people in this group are incapable and unable 'to make a contribution to society' (Hall & McGarrol, 2012).

I have discussed how people with intellectual and developmental disabilities are multiply disadvantaged with respect to social participation: lack of employment and aspects of the personalisation process reduce the possibilities for taking part in the social and cultural activities going on around them. I now consider what work might offer in forms other than employment.

This section discusses the distinction between positive and negative aspects of work, drawing on economic and philosophical analyses and on the capabilities approach.

Social cooperation beyond the realm of economic productivity

From a capabilities perspective, Weidel (2018) makes a powerful case that a capability for meaningful work should be included in Nussbaum's (2011) list of core human capabilities (i.e., 'the ones that a minimally just society will endeavour to nurture and support' (p. 28). Noting how Nussbaum draws equally on Marx and Aristotle in her development of core capabilities, Weidel argues that she omits a central facet of Marx's focus: the importance of 'meaningful labour' in actualising the potential of human beings. Nussbaum's list supports instead equal right to employment, but this 'fails to connect to the non-normative "being or doing" upon which the capabilities approach is centred' (Weidel, 2018, p. 44).

Yeoman (2014) argues on capabilities grounds for 'meaningful' work to be considered as a basic human need, on account of its role in creating and sustaining values and meanings beyond economic productivity. Access to work that is 'meaningful' should not be seen as a private matter to do with personal preferences, without relevance to policy. Rather, the distribution of 'meaningful' work should be understood as a matter of social justice. Ghaeus and Herzog (2016) argue for equal access to the 'goods of work other than money'. If these goods are central to individuals' ability to lead flourishing lives, it is these, not employment per se, that should be the concern of social justice, and reflected in policy. If attention can be given to regulating the 'bads' of work, for example in policy on health and safety standards, then it should equally apply to accessing its 'goods'. These arguments are outlined here for their potential to clarify what, other than pay, might be gained by people with intellectual and developmental disabilities through participation in chosen work. For most people, work is the major occupier of time and effort, a process that has increased through work intensification. The need to work for a living makes it the crucial site for fulfilling our need for 'meaning', but 'work' is not equivalent to employment. Yeoman argues for a broad definition of work that encompasses 'all the activities which contribute to producing and reproducing a complex system of social cooperation' (2014, p. 236). She includes the kinds of unpaid care and support activities that are erased from accounts of work that focus on paid labour. In this wider definition, work functions 'to create and to sustain values and meanings beyond the realm of… economic productivity' (ibid.). For her, the need to experience life as meaningful is a fundamental human need, evaluated both subjectively and objectively. Her argument acts as a counterbalance to an employment-focused paradigm. It is particularly useful to consider what people with intellectual and developmental disabilities might gain through a working involvement in the 'complex system of social cooperation' of their setting.

Yeoman (2014) uses a capabilities framework to conceptualise her argument, understanding meaningful work as a process that develops agency and capabilities. If we are not able to experience life as meaningful through work, in her view, we are less likely to ‘develop the human capabilities necessary for equal participation over the life course’ (Yeoman, 2014, p. 238). Her arguments echo those of Weidel (2016) in seeing work as engaging people’s capacity for ‘practical reasoning’ and social co-operation, skills that develop as they are exercised. Weidel understands such capacities to be learned: they are not static but mature over time, ‘as we are able to connect with others and work together to meet our needs’ (p. 74). Yeoman’s terms differ, but her arguments also concern participation and the co-construction of meaning through socially and culturally valued activity. She may underestimate people’s capacity to experience meaning through earning itself (for example, the satisfaction of supporting oneself or others), but her linking of work to the development of important capabilities points effectively to the deprivation that can accompany a lifelong pattern of under-occupation and disconnection from the activities of social cooperation.

Social philosophers Gheaus and Herzog (2016) consider the goods of work ‘other than money’ from the point of view of theories of justice. They see analyses of work as being unduly focused on a single aspect of work: earnings. They argue that the non-monetary benefits of work are highly socially valued, driving motivation independently of ‘decent wages’ (p. 71). Following research findings from psychology and sociology and drawing on wider traditions of thought about work, they argue for four kinds of ‘goods’ of work besides pay: (i) attaining competence or proficiency; (ii) making a social contribution; (iii) experiencing community; and (iv) gaining social recognition (p. 71). For Ghaeus and Herzog (2015) ‘community… plays a role for all kinds of work’. These aspects of work, which emphasise social cooperation, are aligned with some views of what constitutes social inclusion. They share a core concern with the social roles in which people choose to engage (see Lysaght *et al*, 2016). In research tracing the intersection of inclusion and productivity for people with intellectual and developmental disabilities, Lysaght *et al.* (2017) address the issue of work beyond formal employment. They examine experiences of sheltered work, social enterprises and voluntary work, and find that these provide a sense of social inclusion, particularly in the socio-emotional sense of ‘belonging’. In their analysis, a critical element enabling this kind of social inclusion is the ‘fit’ between the person and the work context: ‘The experience of inclusion, particularly of belonging, depends on a successfully negotiated congruence between worker attributes and the social features and demands of the work environment’ (p. 922). Their findings underscore the importance of autonomous choice in work – the freedom to select suitable, preferred environments and tasks – and of work in concepts of social inclusion.

Putting together the ‘goods of work’ discussed by Yeoman (2014) and Ghaeus and Herzog (2016) and those identified by Lysaght (2017), the goods of ‘work’ and ‘social inclusion’ can be conceived in terms of their fundamental life opportunities or capabilities. These involve social and cultural recognition, reciprocity in relations with others and a sense of meaning or purpose through social participation. The qualities required of work that can deliver this seem to be:

- *fit between person and environment* (‘a successfully negotiated congruence between worker attributes and the social features and demands of the work environment’, ‘social roles of one’s choosing’, belonging)
- *developing competence, attaining agency* (‘attaining various types of excellence’, ‘[be] recognized as a competent individual’, ‘development of capabilities’)
- *social recognition* (‘gaining social recognition’, ‘experience valued and expected social roles’, ‘trusted to perform social roles in the community’,)
- *reciprocal social relations* (’to belong to a social network within which one receives and contributes support’, ‘experiencing community’, ’making a social contribution’ ‘equal social participation’).

(Adapted from Lysaght *et al.* 2016, Yeoman, 2014, and Ghaeus & Herzog, 2016)

In analysing the work of the primary participants in this study, evidence of these processes and characteristics of their work is explored. These features of work serve as a measure of value to assess the extent to which the work that participants do enhances their capabilities.

The capabilities approach seeks to offer an alternative to approaches to development and social justice where income and economic growth are the first priority - the employment-focused paradigm is an example of such an approach (Laruffa, 2019). To conclude this examination of employment and people with intellectual and developmental disabilities, I consider alternative proposals by those who reject labour market activation and the small state model. These address the capabilities and autonomy of people in relation to labour markets, supporting choice beyond employment. A number of economists advocate for basic income schemes, which pay a government guaranteed minimum income to individuals whether or not they are employed. Standing (2009) advocates for a Universal Basic Income (UBI), a public programme for ‘payment sufficient to meet a person's basic needs, without a means test or work requirement’ (Bien Network, n.d.). For him, the importance of meaningful work and the difficulty of obtaining it in a globalised market system justify the introduction of such an income.

Other economists anticipate a future world with less paid work, as technological progress reduces the availability of employment. Susskind (2020) anticipates two salient outcomes: a need to create social solidarity by other means, and the vacuum of ‘meaning’ in under-occupied lives. He advocates a version of a basic income that is conditional, recognising voluntary work or community service as social contributions. Laruffa *et al.* (2022) advocate for a 'participation income'. This proposal combines a capability approach with an 'ethics of care' for the environment, in which policy emphasis shifts from economic production to 'social reproduction and environmental reparation' (p. 508), and so prioritises the choice of care work. From a feminist perspective, a basic income offers a means to address both the inequalities of gendered care responsibilities and the female disadvantage in employment (Gheaus, 2009). For people with intellectual and developmental disabilities and their allies, basic income proposals might offer significant advantages: relief from the discriminatory and stigmatising conditionalities of disability benefits and the psychosocial and administrative burden of claiming them.

3.6 Summary

A capabilities analysis focuses on the benefits, other than pay, of work that may be available to people with multiple disadvantages in relation to employment. A powerful social and moral imperative is created by an employment-focused paradigm, yet work intensification and the persistently low employment rates of people with intellectual and developmental disabilities make employment inaccessible. Disabled people are trapped, not only between unattainable employment and reduced benefits but also between unattainable employment and societal redundancy. Claassen (2015) argues that the sense of uselessness that often accompanies unemployment in contemporary society indicates that a basic capability for agency has not been met, 'even where it is well compensated for financially by social benefits' (p. 231). Freedom from the employment constraint provides a level of choice of type of work and environment, while support in work might help to establish successful participation and reciprocal relationships in work. The question remaining is the extent to which such work outside of employment is both accessible and acceptable to people with intellectual and developmental disabilities.

Chapter 4 Learning, work, inclusion

In this chapter I explore connections between learning, work and the social inclusion of people with intellectual and developmental disabilities. These connections are implicit in participatory theories of learning, and have been little explored. I begin by addressing theories of learning, specifically the implications of cultural and participatory views of learning in the context of this study. I discuss the idea of reciprocal learning and mutual adaptation in the context of work by people with intellectual and developmental disabilities. I then consider the significance of social and relational support for learning within these theories, and how these factors intersect with questions of agency.

The links between learning, work and social inclusion that I refer to are implicit in approaches that construe learning as an integral part of social practice and participation to be the crucial learning process (e.g., Lave & Wenger, 1991, p. 51). In the participatory view, learning and selfhood are fundamentally relational. These accounts suggest that people learn and develop through their changing engagement in the sociocultural practices valued in their communities, that those practices change over time through this participation and that these processes are a core expression of human identity.

Tomasello (2016) argues for the importance of social-cognitive skills for participating and exchanging human knowledge in cultural groups. From an evolutionary perspective, collaboration and collaborative learning are at the heart of cultural learning and drive the creation and evolution of cultures. Individual learning and culture creation are ‘mutually constituting’, formed from the efforts of people working together (Rogoff, 2003, p. 51). Working constitutes shared experience on common ground, which has a ’strong and sustained’ impact on social closeness to partners (Wolf & Tomasello, 2020). From this perspective, the fact that most young people with intellectual and developmental disabilities lack significant experience of participating with others in work is a crucial disadvantage for learning and inclusion. Segregated or semi-segregated settings limit basic opportunities for social and cultural learning, both compounding the disadvantage of having a cognitive impairment and establishing a significant divide between the life experiences of people with significant support needs and the working majority. Theories of learning that see it as a process by which cultural practices are shared and modified underline how social segregation eliminates opportunities for such adaptive processes. From this follows the potential of supported participation in work.

4.1 Learning, participation, inclusion

To begin this discussion, I consider Kolb's (Kolb, 1984, p. 31) definition of learning as 'an holistic process of adaptation to the world'. This terminology connects learning with evolutionary processes of adaptation, as a means to enable people to become better able to live and flourish in their specific environments. His conception that learning is the central process of human adaptation - that it always involves and commonly begins with concrete experience - provides a starting point for considering the social and cultural experience of people with intellectual and developmental disabilities. Kolb sees immediate experience as the focal point for learning, because it is embodied and imbued with both personal and social significances, giving 'life, texture, and subjective personal meaning to abstract concepts', while providing a 'concrete, publicly shared reference point' (Kolb, 1984, p. 21). It entails transactions between the person and the environment that involve the whole person 'thinking, feeling, perceiving, behaving' (ibid.) and is inherent in situations where there is challenge.

In these senses, Kolb sees knowledge as situated in place and time and learners as active participants. He draws on the models of Dewey (1938), Lewin (1946) and Piaget (1970), and cites Bruner and Freire extensively to support his conception. These emphases contrast with the cognitive and behaviourist models of learning dominant at the time of his writing, and in his view have significant implications for understanding the relationship between learning, work and other life activities (Kolb, 1984, p. 20). In this study I draw on learning theories developed in anthropology, psychology and education that take everyday experience not as the starting point for learning, as Kolb does (Illeris, 2011, p. 105), but as the core of learning.

The 'root theoretician' for this family of accounts is Lev Vygotsky, for his emphasis on social, historical and cultural aspects of learning, activity and social interaction (Matusov, 2015, p. 316). In Vygotskian sociocultural learning, human learning originates in social, historical and cultural interactions. Cultural tools, particularly language, are held to have a significant mediating role, and learning occurs primarily within the learner's 'zone of proximal development'. This is defined as the area between the 'actual developmental level of the learner', or what they can do without support, and the level of 'potential development', which is what can be achieved with guidance or in collaboration with more capable peers (Vygotsky, 1978, p. 86). Importantly for people with intellectual and developmental disabilities, this definition implies a need for both a level of challenge and for the support of more experienced others. Learning is therefore conceived as inseparable from specific social, cultural and historical context and to involve performance with relational support (Matusov, 2001). In other words, learning requires access to the cultural setting and to the support of a more practised person with understanding of where manageable challenge might lie in a particular case.

The participatory learning literature explores how ‘novices’ – children, young people and other kinds of newcomer (Rogoff *et al.*, 2016) – are inducted into the practices, knowledge and beliefs of their cultures by taking part in them, with appropriate guidance, following pathways of increasingly central participation over time. Induction is a process of negotiation and adaptation rather than one of transmission of skills and knowledge. The various positions that people take in relation to their cultures influence practices, so that practices are remade in the image of changing participants (Rogoff, 2003). Rogoff describes the process as ‘people contributing to the creation of cultural processes and cultural processes contributing to the creation of people, so that individual and cultural processes are mutually constitutive’ (2003, p .51). This kind of cultural learning provides the basis for cultural practices to continue, but also to modify and evolve, according to who takes part. Participation is a precondition for learning and for contributing to these processes. One outcome of the marginalisation of people with intellectual and developmental disabilities is that processes of adaptation cannot take place. Consequently, people inhabit ‘a cultural, political and intellectual world from whose making they have been excluded (Abberley, 1999, p. 15).

4.2 Learning to be part of a greater whole

Participatory accounts of learning define themselves in conscious opposition to conceptions of learning as an acquisitive process that proceeds ‘inside the skull’ of individuals (e.g., Rogoff, 2003, p. 271). The mind and individual processing skills are not the central issues of learning; by contrast, learning processes are understood as intensely social in nature. An influential early paper (Sfard, 1998) discusses the divide in terms of two metaphors of learning that underlie a variety of theories of learning, as they appeared at the time of writing. She explores how one – the acquisition metaphor – implies the possession or accumulation of some*thing* (e.g., knowledge, learning or concepts). The ‘thing’ may be conceived as received passively, acquired by development, or as actively constructed, depending on the writer’s theoretical perspective, but there is a shared assumption of ‘gaining ownership’ over some kind of entity or commodity (pp. 5-6). She refers (p. 6) to a transformation taking place as the metaphor of participation gained ground, in which the active and fluid notion of ‘doing’ (participation metaphor) replaces the stability of ‘having’ (acquisition metaphor). The doing of participatory learning is not solely metaphorical, as participation entails embodied engagement with practice. In other words, it involves modes of learning that are accessible and sustainable to people with intellectual and developmental disabilities in ways that abstract, disembodied and verbally mediated forms of learning may not be. Sfard unpicks the implications of this metaphorical shift:

> 'Participation' is almost synonymous with 'taking part' and 'being a part,' and both of these expressions signalize that learning should be viewed as a process of becoming a part of a greater whole.… Just as different organs combine to form a living body, so do learners contribute to the existence and functioning of a community of practitioners.... the [participation metaphor] shifts the focus to the evolving bonds between the individual and others… [and] gives prominence to the aspect of mutuality characteristic of the part-whole relation. (1998, p. 6)

Sfard's summary spells out how viewing learning as a participatory process involves becoming/learning to become part of a social whole, through reciprocal relations with other participants. Rogoff (2003) sees collaborative partners seeking a common perspective or means of communication to co-ordinate their efforts, so that understanding occurs between them and involves modifications in each person's perspective (p. 285). More recently, Tomasello and colleagues have highlighted the roles of shared intentionality, shared experience and common ground in cultural learning and culture creation (Tomasello, 2016; Wolf & Tomasello, 2020). The implications for this study are that successful participatory learning should involve a reciprocal impact on persons with intellectual and developmental disabilities and the perception of those with whom they interact and collaborate. I take these ideas to be significant for the question of learning by people with intellectual and developmental disabilities, and to have important implications for questions of social inclusion.

4.3 Individual differences

By focusing on social processes, participatory accounts have been seen as underplaying individual differences between learners and individual learning. For example, Sfard (1998) takes the position that participatory theories do not adequately account for learners' unique learning history and leave open the problem of how learning can be 'transferred' from one situation to another. This point relates to a longstanding theoretical assumption that learning by doing, as opposed to more abstracted forms of learning, produces a context-bound, literal understanding that is not 'portable' to other times and places (e.g. Scribner & Cole, 1973). The issue is significant here, as the learning histories of people with intellectual and developmental disabilities are likely to have distinctive features. For example, the competitive ethos of schooling may have communicated their marginal social status as learners (Slee, 2019), they may have experienced social rejection in school (Juvonen *et al.*, 2019) and/or been tacitly prepared throughout schooling for a dependent life in welfare services (Gustavsson *et al.*, 2021). From a capabilities perspective, these aspects of education jeopardise one of the critical tasks of learning: to challenge ‘adaptive preferences’, the tendency of disadvantaged people to modify their aspirations according to their situation (Robeyns, 2017, p. 137).

Hodkinson *et al.* (2008) argue that participatory accounts of learning can incorporate the influence of unique learning histories by taking a view of learning that integrates the individual and the situation within the theory. They invoke Bourdieu’s (1977) concept of habitus, and his insistence on its influence on learning. Habitus brings together the deeply ingrained, subconscious habits, skills and dispositions that develop from a person’s social position. Bourdieu’s focus is on social class, yet his argument can be applied equally to social positioning in other terms, in this case disability. The solution that Hodkinson *et al.* (2008) propose returns, effectively, to a version of ‘mutual constitution’: that people influence and are part of learning cultures, just as learning cultures influence and are part of individuals. They propose integrating individual and social views of learning by considering ways in which the social is simultaneously external and internal as people navigate the social world, ‘existing in and through interaction, participation and communication’ (p. 38). In this way, learning can be characterised as a process of ‘becoming’ that it is always situated but ‘transcends’ both individual situations and situated learning cultures in its ‘dispositional impact’ (p. 43). Their argument implies that successful participatory learning may have an enduring impact on the ingrained, culturally developed dispositions acquired by people with intellectual and developmental disabilities. Successful learning, therefore, might modify adaptive preferences. This kind of potential is largely absent from the undemanding leisure activities and passive occupations typically available to people with intellectual and developmental disabilities (see Charnley *et al.*, 2019; Verdonschot *et al.*, 2009).

4.4 Collaboration, communities, practice

In participatory accounts, learning must be situated in social co-participation within authentic activity; that is, it involves shared and jointly valued goals that matter socially. The communities of practice concept involves common ground - ‘mutual engagement’ in ‘joint enterprise’ (Wenger, 1998, p. 2): ‘people who share a concern for something they do’. It embeds learning in ongoing social relations as people ‘learn how to do it better as they interact regularly’ (Wenger, 2011, p. 1). Learning is conceived to take place through embodied activity, for example through mimetic processes (observation, imitation and action) (Billett, 2014), with limited verbal mediation. The key concept of ‘legitimate peripheral participation’ makes participation accessible - there are ‘varied, more-or-less engaged and inclusive ways of being located in the fields of participation’ (Lave & Wenger, 1991, p. 37).

Tomasello’s studies of social cognition and cultural learning explore specifically human cognitive characteristics. Tomasello (2016) describes the ability to participate in collaborative activities as a uniquely human characteristic that is at the heart of cultural learning and cultural creation. He identifies collaboration as the key means by which cultural practices are transmitted: they are co-constructed as individuals interact with others in common circumstances, especially those which are work-like, where organisational conventions and other kinds of social norm structure activities. Learning in this way is essentially relational. He emphasises the dual-level structure of shared intentionality involved in collaboration, in which participants attend to shared goals, yet have individual roles and perspectives, which are also shared. The cognitive representations resulting from this kind of situation assimilate something of the perspective of the interactional partner, and this new perspective continues to guide the learner after the original learning experience has ended. Moreover, the human motivation to collaborate ‘leads people to work harder and persist longer on a problem, and enjoy it more, than if they work at it on their own’ (p. 648).

Wolf and Tomasello (2020) establish how shared experience on common ground, even if minimal, develops social bonds. Such experience and its outcomes can be seen as the positive counterparts to the processes involved in out-group bias and social devaluation (Markus & Kitayama, 2010), establishing a further argument for collaborative social participation. Finally, the ‘mutual constitution’ of cultures and selves describes the dual social and individual impacts of participation: how people ‘contribute to the creation of cultural processes and cultural processes contribute to the creation of people’, so that ‘individual and cultural processes are mutually constitutive rather than defined separately from each other’ (Rogoff, 2003, p. 5). The daily situations and practices of work are key sites for this process of negotiations between practices and cultures and the characteristics of those taking part (Markus & Kitayama, 2010).

Lave and Wenger’s (1994) account of a form of participatory learning, apprenticeship in communities of practice, further develops the notion of links between learning, work and group membership. The authors refer to situations of collaborative effort where people are involved in ‘collective learning’ in a ‘shared domain’ (Wenger, 2000, p. 1). Apprenticeship generally combines elements of learning and work participation or ‘on-the-job’ learning. This understanding of apprenticeship combines metaphor and historical examples of apprenticeship. The relevance here lies in the conception of being part of a learning community. I take the concept to be applicable to the ‘micro-cultures’ of work settings to be explored in this study.

Learning that is situated in 'communities of practice' draws significantly on Lave's research on tailors' apprenticeships in Liberia, West Africa. According to Lave, the concept intentionally blurs the divisions between people (or between their minds, bodies and emotions), their activities and the world (Lave, 1991, p. 64). She traces how, through their apprenticeships, the apprentices she studied learned the mechanical skill of making trousers, which was the object of the apprenticeship, yet within this cultural setting they also gained wide knowledge in social and cultural matters, such as social identities and divisions in Liberian society, how to navigate them and how to 'make a life' as well as a living (p. 150). The master tailor's role, according to Lave, is not to teach, but to provide legitimate access to a purposeful community and its practices (p. 69). Learning is then an emergent property of active participation in shared goal-directed practices. It depends critically on admission: 'increased access of learners to participating roles in expert performances' (Lave & Wenger, 1991, p. 17). Lave and Wenger's theorisation suggests that access to legitimate, participating roles might have significant potential for both learning and social participation in the case of people with intellectual and developmental disabilities.

Participatory learning theory can also guide thinking on the question of PA support. This is an area little explored in research. There is no research specifically concerning work by people supported by PAs. As described in chapter 2, such support is considered in principle to be crucial to supporting the agency and social inclusion of disabled people (Mladenov, 2012). Disabled people themselves consider PA support to enable their autonomy (Mladenov, 2020). Other research addresses relationships between PAs and disabled people. These are found to have emotional dimensions that are neglected in instrumental understandings of the role (Shakespeare, Porter & Stöckl, 2017). Disabled people describe their relationships with PAs as having some of the dimensions of friendship, including attachment and shared interests (Mladenov, 2020).

From a sociocultural learning perspective, PAs can be understood as acting to support learning in the role of 'more knowledgeable other', acting as a bridge between the current knowledge and skills of the person and the expectations of the work situation. PA support could also be understood as a form of peer learning in the work situation (see e.g., Nind *et al.*, 2020). Peer learning is supposed to promote cooperation and thereby reduce inequalities of power (Boud & Middleton, 2003). Developing more equal relationships between support staff and people with intellectual and developmental disabilities has been described as key to developing the latter's agency (Fish & Morgan, 2021). In their role as peers and 'more knowledgeable others', PAs could provide significant support for learning and relational agency.

Participatory accounts have a dual personal/social focus: people are supposed to develop through their changing participation in the activities of their communities. The anthropological and cross-cultural focus of participatory theories resulted in a critique of 'Western' individualist understandings of thinking as happening ‘inside the skull’ (p. 271). Rather they take a view of thinking as produced between people, institutions and tools, within cultures and communities and across time. It is a defining characteristic of the ‘apprenticeship’ idea that identity (as a member of a community) and learning are inherent in the same process, with identity within the community motivating, shaping and giving meaning to learning. Learning situated in communities of practice is supposed to construct a conceptual bridge between the development of ‘knowledgeable skill’ and identity, in what Lave and Wenger (1991, p. 55) describe as the ‘common processes inherent in the production of changing persons and changing communities of practice’. Admission to learning in community of practice is not conditional on productivity or achievement: legitimate participation can be peripheral, as long as it involves access to a broader view of what the community is about. Becoming an established practitioner involves sustained engagement as much learning proficiency. It is a mark of this form of learning that, although the setting must be ‘authentic’ (sheltered employment, for example, might not meet this specification), the learner and the activity together produce the learning ‘curriculum’. Progress is evident in the process of work itself (p. 68), so that more successful participation is a mark of learning. Rogoff (2003, p. 74) points out that in the cases that she discusses, for example the practice of midwifery, there appear to be no ‘devastating structural barriers’ to prevent newcomers from gradually becoming established. Learning, or ‘changed understanding’, is forged in cycles of work (Lave & Wenger, 1991, p. 82), so that participation is the means of learning, while the object is more intensive participation. The notion of participation gives people with intellectual and developmental disabilities access to learning as legitimate co-participants in collaborative systems without the competition, predetermined goals and verbal mediation inherent in formal educational processes.

Rogoff’s (1995) concept of ‘guided participation’ follows similar principles. She refers to processes and systems of involvement between people as they communicate and coordinate activities, including side-by-side participation and more distal arrangements of guidance, highlighting that participation is also guided by sociocultural tools, culturally defined goals and social arrangements for joint activity: the beliefs, values and tools of the culture in which a person develops. Learners themselves shape their learning engagements within these parameters. Rogoff often focuses on child engagement in adult activities, contrasting their involvement in adult activities with North American formal practices of schooling. The learning processes that are embodied, social and distributed suggest a mode of learning that is accessible and relevant to people with intellectual and developmental and that construes learning as a reciprocal process of social adaptation to group membership.

Guidance refers to guiding cultural and social values, as well as social partners. The procedures, values and practices are navigated (learnt about, not acquired) and themselves inform understanding and behaviour. Like Lave and Wenger, Rogoff (1995, p. 142) notes the central and socioculturally situated connection between learning and identity, seeing in learning ‘a process of becoming’: ‘Individuals change through their engagement in a valued activity, so that they handle a later situation in ways prepared by their own participation in the previous situation’. Rogoff’s research on learning patterns in indigenous-heritage American communities identified cultural practices that support learning that emphasises the process of integrating learners into important purposes of the community, in what might be termed their inclusion. She characterises the social experience of the individual learning in the community settings that she describes as one of involvement and belonging, including personal and emotional commitment to the community (Paradise & Rogoff, 2009).

These conceptions of learning are based in ethnographic observation of learning embedded in practice and developed through engagement over time in pursuit of shared goals. Knowledge becomes a matter of competence in valued endeavours, while knowing consists of participating with others in such endeavours; that is, in active engagement in the social and cultural world. Participation, learning and ‘work’ are seen as operating synchronously and producing a combined effect. While these authors are not specialising in intellectual and developmental disability, they are concerned with inclusion and participation, the accessibility of learning opportunities without barriers to entry.

Everyday participation and interdependence

It is significant that the focus on learning in this tradition emerged from an anthropological concern with everyday activity in communities rather than special learning arrangements. The theory emphasises how learning is unavoidably involved when engagement with others is substantial and sustained over time and when relationships are interdependent. Hence, according to Lave (2011, p. 150), when people engage ‘for substantial periods of time, day by day, in doing things in which their ongoing activities are interdependent’, learning is part of their ‘changing participation in changing practices’. Participatory learning makes the case for relational learning and a relational understanding of agency.

One theme is the way in which children and young people in many cultural traditions are integrated into the economically and socially valued activities of the adult community, contributing to these endeavours in real ways as they learn about their shared economic and social reality. By contrast the educational and childcare practices of North America, for example, keep young people apart in separate institutions without exposure to the practices of adult life.

People with intellectual and developmental disabilities experience significant difficulty in achieving or being accorded either adult status (e.g. Midjo & Aune, 2018) or access to adult activities. Paradise and Rogoff (2009) address how participation in mainstream economic activities and social relationships enables young people to begin to negotiate meaning within a community. Educational separation denies them the rewards of participation and limits their opportunities to make sense of adult life: 'Useful and purposeful integration' into the social sphere of work and community life allows for 'an underlying coherence and groundedness' (p. 106) in the experience of learning, which is a defining characteristic of this mode.

Moreover, Paradise and Rogoff discuss the relationship between the modes of communication dominant in 'Western' schooling and those available through participatory learning. They understand the reliance on 'talk' in schooling to be a by-product of segregation from community activity, pointing to the limits of language as a medium. They cite Scribner and Cole (1972, p. 556), pointing out that when language 'becomes almost the exclusive means of exchanging information, then "the amount of information available to the learner is restricted"' (Paradise & Rogoff, 2009, p. 118). For people with intellectual and developmental disabilities, participation in the work of their communities might involve more holistic means of understanding work and community life, something difficult to access through schooling. The embodied forms of learning involved might bring additional advantages in broadening the available communicative modes beyond language.

4.5 Social participation

Though participatory learning is an established approach to learning and has an extensive literature, it is not the view embodied in educational policy and institutions, and its implications for people with intellectual and developmental disabilities have been little explored. Social and cultural learning theory understands humans to learn and develop through their changing participation in the sociocultural activities of their communities. This implies that people with intellectual and developmental disabilities are deprived of basic capabilities by exclusion from key social practices. Not having the capability to participate in socially shared endeavours entails exclusion from cultural learning. In its focus on integration within the shared world of adult activities, it has implications for achieving adult status and for negotiating meaning in the adult social world. Its focus on embodied experience might have advantages as a concept of learning with fewer restrictions for people whose impairments are cognitive, and for learning that is not primarily verbally mediated. In reconfiguring learning as a reciprocal social process of inclusion in a community, it legitimises forms of competence that are not dependent on individuals' capacity to achieve goals without support, whether the goals are in learning or in work participation.

Ceasing to privilege individual achievement and solo activity (Matusov, 1998) has extensive implications for the agency of people with intellectual and developmental disabilities, who are still hampered in education and social care policy by the restrictive goal of independence. Collaborative activity in everyday work contexts is conceived as the basis for mutual constitution, the process whereby participants shape practices that come to embody new normative standards (Tomasello, 2016).

The concept of legitimacy acknowledges the public or community acceptance of a work situation and role within it. Legitimacy denotes inclusion and recognition within those structures. Additionally, it recognises ‘situatedness’, or how a specific setting plays an active role in shaping activities and relationships and in fostering ‘belonging’ in ways often omitted from work on social inclusion (Wilton *et al.*, 2018, p. 248). Learning inherent in participation in work could make a significant difference to the capabilities of people with intellectual and developmental disabilities, both intrinsically and as a fertile capability to give access to further capabilities, such as the capability for affiliation.

The understanding of participatory learning theory as egalitarian and inclusive emerges from a re-evaluation of the functions of learning in human societies from anthropological, evolutionary and cross-cultural perspectives. In common with a capabilities approach it has a focus on the diversity of people and values and the impact of specific social and cultural settings on people’s opportunities. There is also an underlying concern for equality. Lave (1996, p. 149) refers to her motivation to explore learning in ways ‘that do not naturalize and underwrite divisions of social inequality in our society’, arguing that theories of learning that highlight individual performance and individual and group differences in learning performance create hierarchies that are necessarily exclusionary. By reducing learning to matters of individual mental capacity/activity, such theories ‘blame marginalized people for being marginal’ (p. 149). Most importantly in the current context, participatory accounts explain how learning and social and cultural inclusion can be mutually sustaining and conceived as core capabilities, with particular significance for people with intellectual and developmental disabilities.

4.6 Informal learning

The concept of informal learning draws on and overlaps with the literature and theorisation of participatory learning. While participatory learning includes elements of guided learning and instruction (e.g., Tomasello, 2016), informal learning highlights unplanned learning that is not supervised by an educator (Colley, Hodkinson & Malcolm, 2002) and in some definitions encompasses all forms of learning after formal education. First-language learning is the key example cited in theory (e.g., Callanan, Cervantes & Loomis, 2011), as it signifies the assumed cultural and evolutionary significance of such processes. Key theorists show that informal learning is omnipresent and how it is the 'natural' and indispensable element of learning (e.g. Billett, 2010), in contrast to the supposed artifical forms and limited applications of formal education and training (see e.g., Rogoff *et al.*, 2016b; Coffield, 2000). However, understanding informal learning as 'natural' may be the product of a cultural bias towards formal education, which means that other ways of organising learning are not explored (Paradise & Rogoff 2009).

Whereas formal learning has a high profile, recognised through its institutions, teachers, curricula and assessment, informal learning is construed as ubiquitous yet invisible and elusive. A number of theorists use an iceberg metaphor in which formal learning is the visible tip of a hidden mass of informal learning (Livingstone, 1999; Coffield, 2000). Informal learning is under-recognised by both learners themselves and society (Eraut, 2004; Cullen *et al.*, 2000), because it is integrated in activities or events that are significant for other reasons (Callanan, Cervantes & Loomis, 2011; Rogoff *et al.*, 2016) and is not scrutinised or measured to the same extent. Whereas participatory learning draws on anthropological and ethnographic research, the informal learning literature largely addresses learning in late-twentieth and early twenty-first century high-income contexts, often focusing on social change: economic (learning to skill up for globalised markets in jobs) or social and cultural change (learning in response to retirement or by special interest groups).

In the 1990s learning in adult life, especially informal and lifelong learning, became the subject of government interest and of large-scale international initiatives (UNESCO, 2000; OECD, 2001). According to the OECD, informal learning is a means to establish 'lifelong learning for all', thereby 'reshaping learning to better match the needs of the 21st century knowledge economies and open societies' (OECD, n.d.).

An extensive literature on lifelong and informal learning accumulated, in which informal learning came to be seen as an accessible means to increase skills, assets and influence at the individual and social level (e.g., Bélanger, 2015; Werquin, 2012). The literature on informal learning draws on participatory learning for its critique of formal learning practices however the focus on induction and participation in small-scale communities is reconfigured: often, learning is understood as individual and social capital, both in terms of economic value and community empowerment, or its potential to develop the agency of marginalised groups. Three strands of literature are well developed: that on informal learning in the workplace (e.g., Eraut, 2004; Billett, 2002) and in community engagement (e.g., McGivney, 1999; Coare & Johnston, 2008). The third strand, also extensive, links learning after education and employment as a means by which people can improve their employment status and earnings. These strands can contribute to exploring the relationships between learning, work and social participation for people with intellectual and developmental disabilities.

4.7 Formal versus informal

Formal and informal learning have been positioned as competing paradigms (Colley *et al.*, 2002), with informal learning often seen as the neglected powerhouse. Claims for the superiority of learning informally date back to Cole and Scribner (1973), who argued that 'school… requires and promotes ways of learning and thinking which often run counter to those nurtured in practical daily activities' (p. 533). Researchers in the field comment on the lack of attention to informal learning and the status accorded to formal learning (e.g., Knowles, 1973; Paradise & Rogoff, 2009; Field & Tuckett, 2016). Lave (1996, p. 150) sees the informal practices that she found in traditional societies as 'so powerful and robust' as to raise questions about formal educational practices in the Global North. Rogoff *et al.* (2016) refer to the 'factory model' of formal education and the prevalence of 'assembly line instruction' in North American schools. Colley *et al.* (2002) summarise the contrasts in terms of 'ideal-types' of formal and informal learning (Table 4.1).

Formal Learning	Informal Learning
Teacher as authority	No teacher involved
Educational premises	Non-educational premises
Teacher control	Learner control
Planned and structured	Organic and evolving
Summative assessment/accreditation	No assessment
Externally determined objectives/outcomes	Internally determined objectives
Interests of powerful and dominant groups	Interests of oppressed groups
Propositional knowledge	Practical and process knowledge
High status	Low status
Education	Not education
Measured outcomes	Outcomes imprecise/unmeasurable
Learning predominantly individual	Learning predominantly communal
Learning to preserve status quo	Learning for resistance and empowerment
Pedagogy of transmission and control	Learner-centred, negotiated pedagogy
Learning mediated through agents of authority	Learning mediated through learner democracy
Fixed and limited timeframe	Open-ended engagement
Learning is the main explicit purpose	Learning is either of secondary significance or is implicit
Learning is applicable in a range of contexts	Learning is context-specific

Table 4.1: Possible ideal types of formal and informal learning, adapted from Colley *et al.* (2002, pp. 14–15)

Many scholars of informal learning refer to some contrasts cited here, yet most also caution that the two forms are neither mutually exclusive nor dichotomous. Rather, learning is supposed to sit somewhere on a spectrum of formality (Colley *et al.*, 2002). The polarity nevertheless points to the ways in which the properties of formal learning, its individual focus, measurement and documentation continue to dominate in policy and practice. I discuss first the workplace literature, then community engagement strand and, finally, lifelong learning.

4.8 The workplace as a site for learning

The workplace learning literature extends into organisational management, human resources, industrial training and business management. It often focuses on personal, organisational and social economic advantage through learning. The literature does not engage with work by people with intellectual and developmental disabilities, though there is some focus on people with 'low skills' (e.g., Illeris, 2006). It is relevant here for the discussion of the kinds of situations and processes that promote learning and why learning might particularly pertain to work. Work is viewed as fundamentally connected to learning or as a privileged site for learning (Manuti *et al.*, 2015). Boud and Middleton (2003, p. 194) state that 'Learning at work constitutes a large part of the learning undertaken by adults during their lives'. Reviewing the literature as it was in 1999, Stern and Sommerlad (1999) classify levels of separation in the literature between 'learning' and 'work': the workplace as a site for learning, as a learning environment, and learning and working as inextricably linked (p. 2).

Looking at research involving business and accounting, engineering and healthcare, Eraut (2011, p. 8) addresses three questions: What is being learned at work? How is learning taking place? What factors affect the amount and direction of learning in the workplace? Eraut interprets social and situational factors as catalysts for learning. His participants cite two modes of learning as important: learning from the challenge of the work itself; and learning from other people. When learning is crucial to task achievement, the learning is much greater. There is increased investment of effort and significant cycles of learning, and the effort maximises the learning. In an echo of the criteria for successful inclusion proposed by Lysaght *et al.* (2017), Eraut (2011) highlights the learning inherent in situations where it is possible to contribute and where contributions can be recognised. He finds that reciprocity in work shapes patterns of behaviour and influences how people conceive of themselves in relation to others. Fundamentally, his research foregrounds how work provides opportunities for people to learn by being present in situations where they can contribute and be recognised. His findings provide empirical support from ordinary UK workplaces, suggesting that rich opportunities for learning are inherent in working situations, and that such learning is a stable feature of workplace participation.

The second strand of informal learning literature focuses on the grassroots level. Research explores the potential of informal learning to promote the concerns of community groups (e.g., Surfers Against Sewage, Cullen *et al.*, 2000) and populations on the periphery of the economy, for example on learning by older people (Hafford-Letchfield & Formosa, 2016), women (Foley, 2001) and ex-offenders (Cullen *et al.*, 2000). The social and cultural advantages of learning for agency and social cooperation are significant themes. To be effective for older men in Australia, for example, learning situations need to be accessible and social: 'local, practical, situated, and in groups' (Golding, 2011, p. 103). Collaboration on shared priorities is understood to bring together individual learning and social change. Informal learning is construed as a means to address social exclusion and social isolation (e.g., Cullen *et al.*, 2000; B. Golding *et al.*, 2009; B. G. Golding, 2011).

Cullen *et al.* (2000) provide a definition of informal learning (e.g., by ex-offenders) as co-extensive with widening participation. Both involve 'the active engagement by citizens (including those… who have to some extent been stripped of their citizenship) in the construction, interpretation and… re-shaping of their own social identity and social reality' (n.p.). Their focus on increased participation and reshaped identity as outcomes of learning, rather than on individual skills, attributes and knowledge, is characteristic of this strand. Indeed, participants often do not perceive themselves to be learning; rather, the learning serves other emergent priorities. The focus in this strand on people who are 'to some extent stripped of their citizenship' and on outcomes in terms of agency, reshaped identity and social reality suggest the potential of informal learning for people with intellectual and developmental disabilities.

The final thread of the informal learning literature relates to lifelong learning. 'Lifelong learning for all' was adopted as a guiding framework for education policy by the OECD in 1996. Initially, lifelong learning was conceived inclusively, as a means to extend opportunity after schooling, especially for those who had missed schooling earlier (OECD, 2001) This thread departs farthest from participatory theory. First, it includes formally taught 'abstracted' forms of learning as well as informal and work-based learning. Second, an important element of 'lifelong learning' was the drive to recognise and validate informal learning, using processes of measurement and accreditation characteristic of the formal end of the spectrum (Colardyn & Bjornavold, 2004; UNESCO, 2012). A changing labour market and the increasing dominance of the 'knowledge economy' drove interest in the concept (Noy *et al.*, 2016). Learning for employment and economic gain came to dominate the agenda. An OECD employment outlook report summarises the message:

> Change is required in the well-ingrained behaviour of individual workers, companies, social partners and, above all, in policies.… we should move away from a model of front-loaded education… to a system in which skills are continuously updated during the working life to match changing skills needs.
>
> **(OECD, 2019, p. 7)**

A number of writers (e.g., Bynner, 2017; B. Golding *et al.*, 2009) comment on the dominance of economic over wider social learning goals. The economistic bias of understanding learning this way – as a means to support the economy – already disadvantages people with intellectual and developmental disabilities, as it reaches into formal education through the competitive and employment-focused orientation of learning (see, e.g, Gustavsson *et al.*, 2021; Slee, 2019). The contrasts in Table 4.1 underscore how the top-down aspects of formal processes, and their quantification in terms of content, measurement and accreditation, give them policy value, while the ‘organic and evolving’ and ‘imprecise/unmeasurable’ aspects of informal learning keep its status low (see Golding *et al.*, 2009).

In the UK, Coffield (1999, p. 480) refers to this approach as ‘social control’. He draws up a sceptical list of what he calls the consensus view that is embodied in the OECD position:

- A nation's competitiveness in global markets ultimately depends on the skills of all its people.
- The new economic forces unleashed by globalisation and technology are as uncontrollable as natural disasters and so governments have no choice but to introduce policies to 'upskill' the workforce.
- Education must be modernised and become more responsive to the needs of employers. In some formulations, education becomes the mere instrument of the economy.
- The responsibility is passed to individuals to renew their skills regularly to ensure their employability.
- The model for educational institutions to follow is that of British business.

There are evident parallels between this learning consensus and an ‘employment focused paradigm’; indeed, employment activation schemes commonly draw on informal/lifelong learning discourse (Coffield, 1999). The responsibilisation of individuals noted by Coffield is shared with personalisation policy, so that employment, learning and care and support are individual concerns. While the workplace learning and community action threads of informal learning literature maintain the principles of participatory learning, lifelong learning and, specifically, the recognition and validation of informal learning return to the strongly individualist conceptions of learning that the theorists of participatory learning sought to undermine.

The social focus of informal and participatory learning provides a view of learning that recognises fluid boundaries between self and others, so that ‘thinking’ can be viewed as distributed among individuals rather than concentrated exclusively within them (e.g., Cole & Engeström, 1993). This gives scope for people with intellectual and developmental disabilities to take meaningful roles in situations where outcomes result from the pooled input of individuals, cultural tools and technologies.

The concepts of ‘distributed cognition’ (Flor & Hutchins, 1991) and ‘distributed competence’ (Goodley & Rapley, 2003) elaborate on this possibility. Work in psychology, anthropology and computer science since the 1970s has illustrated how no analysis at the level of the individual, without reference to the other people, tools and technologies that have a role in the task at hand, can adequately explain how people learn or work (e.g., Nardi, 1993). In distributed cognition the system is the central unit of analysis: the collection of individuals and artefacts and their relations to each other in a particular work practice (Rogers & Ellis, 1994). The approach explores how systems have capacities distinct from those of their participating individuals. Importantly, it is assumed that individuals vary in their knowledge, with gaps in expertise as well as overlaps and redundancy, and that systems can compensate for such gaps. Looking at working situations at the systems level strengthens the argument that people with intellectual and developmental disabilities can occupy ‘legitimate’ roles when resources are pooled to accomplish tasks. Research has mainly addressed complex systems and sophisticated technologies, yet it also illustrates the capacity for different and variable individual contributions to contribute within a working system.

4.9 Mutual constitution: Evolving norms

In participatory learning, the learning process is not conceived as unidirectional, from the socio-cultural situation to the individual. Rather, the character of social practice fluctuates according to the psychological and cognitive makeup of the individuals who participate and how they interrelate. People ‘collaboratively co-construct’ normative rules with others in their culture, with new members not conforming to normative expectations of the cultural group and contributing to the creation of new normative expectations (Tomasello, 2016). Hence social practices change over time according to who participates, where and how (Rogoff, 2016). As these norms are mediated within social relationships and in learning situations, so successful cultural participation has the potential to be a means through which people who have not previously participated might contribute to shifting norms in society about the possible social roles of people with intellectual and developmental disabilities.

In the employment literature concerning people with intellectual and developmental disabilities, learning arises primarily as skills acquisition, consisting of getting or keeping skills that are marketable to employers. Some authors refer to the missed opportunities for personal development that are embedded in work (e.g., Redley, 2009), and for social inclusion as an aspect of productive work (e.g., Lysaght *et al.*, 2017). But often, adults with intellectual and developmental disabilities are assumed to require learning in forms that are highly didactic, especially in relation to work. Dee *et al.* (2006, p. 2) recommend methods of teaching that combine 'learning in real-life settings with the development and practice of specific skills in controlled settings, using a variety of methods', adding that the transfer and generalisation of skills must be planned for, meaning that the learning is controlled by the teacher or instructor with little room for learner agency. Hence, young adults may be subject to prolonged preparation for employment, sometimes taking basic skills courses multiple times, regardless of prior failures. They can be effectively 'stuck in transition' to employment, without that employment outcome becoming a realistic prospect (Butcher & Wilton, 2008; Hubble, 2012).

The view of learning as a process of normalisation extends into the field of supported employment. Research in this area favours embedded learning 'on the job' (the 'place and train' model), but learning is conceived as a didactic and even coercive process. Systematic Instruction in such contexts is described as highly effective in such contexts and is commonly used in the UK by job coaches in supported employment settings (Stevens & Harris, 2013). The system is based on behaviourist principles, that is, on 'breaking tasks down into stimulus: response chains and using prompting hierarchies and reinforcement' (Beyer & Robinson, 2009, p. 11) as mechanisms. Seeking to assess young adults' learning across supported work experience placements in the UK, Beyer and Meek (2009) report their participants' progress in terms of changes in scores on what they call 'transferable work skills', such as 'lift, carry and push things' and 'walk, move easily' (see Figure 4.1). Using Likert-scale questionnaire responses, they operationalise learning as change in performance across placements, as scored by employers (from 5, performing 'Very well', to 1, 'Not at all'). The learning results are visualised in Figure 4.1.

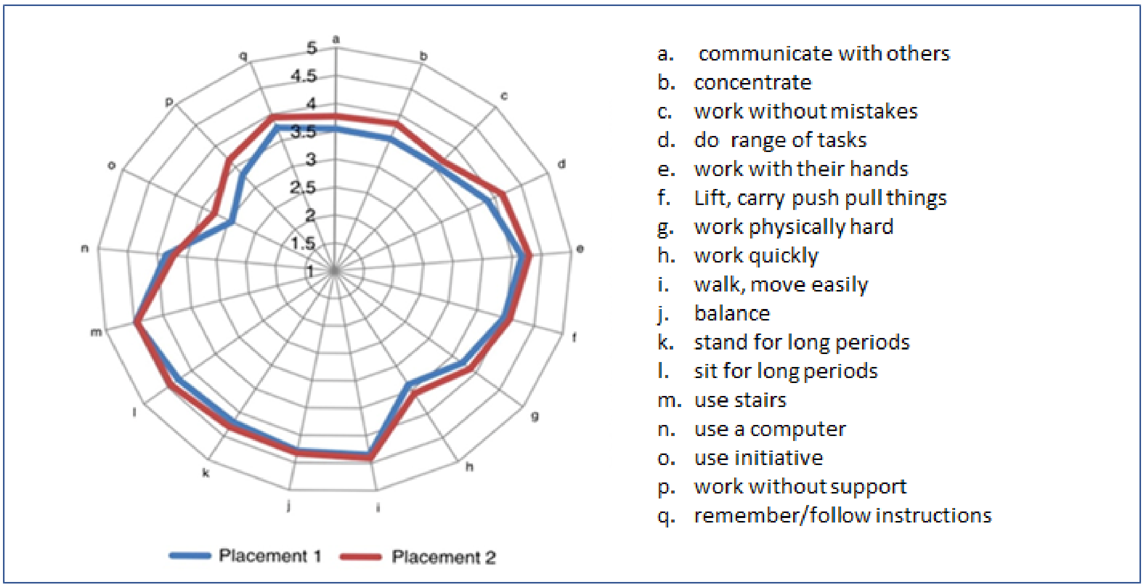

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Figure 4-1 Showing ‘the difference in performance on a number of work skill indicators on the young person’s first placement compared to their second placement’ (adapted from Beyer & Meek, 2009)

Using these methods, a succession of short-term (five-week) placements was judged to have demonstrated the value of learning in supported work experience and to have contributed to participants’ transitions to adulthood. This work shows learning and inclusion as processes in which people with intellectual disabilities learn by didactic means to approach norms of performance as a condition of participation.

According to the contrasts in Table 4.1, although it takes place in a work setting this learning has the characteristics of formality, including measured outcomes, individual learning and a fixed timeframe. The other characteristics of formal learning are the ways in which such learning precludes any agency for the learner: ‘teacher as authority’, ‘teacher control’, ‘externally determined objectives’ and ‘learning mediated through agents of authority’. Although support is seen in this case, as elsewhere, as being critical to successful work participation by people with intellectual and developmental disabilities, it has none of the characteristics necessary to promote agency. In Mackenzie’s argument, a relational approach that provides some policy responses to existing vulnerabilities serves to ‘entrench or exacerbate’ them, so that ‘the obligations arising from vulnerability’ extend ‘beyond protection from harm to the provision of the social support necessary’ to the development and exercise of autonomy (Mackenzie, 2014, p. 17). In this conception of learning, the subordinate position of the disabled person, rather than being challenged, is enacted.

As Mackenzie suggests, protection from risk and challenge is a common feature of attitudes towards people with intellectual and developmental disabilities and provision for them (Seale, 2014; Seale *et al.*, 2013). Yet protection can undermine the learning and motivation that occur through experiences of risk and reward. Eraut (2000) found a triangular relationship between challenge, confidence and support in the workplace for non-disabled newcomers. He relates learners' confidence to take on challenges to the extent to which they feel supported. Challenge and support together underpin confidence and motivation to learn. This triangular relationship, like the notion of relational autonomy, conceives support as being necessary to agency, rather than as evidence of any deficit of agency. Research on how people with intellectual and developmental disabilities are perceived suggests that attitudinal change in society hinges on how far shared experiences allow them to be perceived as competent participants (Scior, 2011), again implying the primacy of adequate support.

The theorising of participatory learning can be understood to draw important links between social participation, socially and culturally 'legitimate' work settings, and reciprocal learning. In capabilities terms, both learning and social inclusion can be understood as matters of extending capabilities (Reindal, 2016), which are the 'objects of value' at the centre of the capabilities approach. In capabilities and social and cultural terms, participation in social practices is fundamental to how individuals make sense of and act on the world, meaning that it concerns equally both learning and agency, which lie at the core of capability conceptions of what matters for social justice.

Participatory learning has not been explored in research for people with intellectual and developmental disabilities; on the contrary, learning for people with intellectual and developmental disabilities has often been conceived as needing to be configured more strictly in terms of top-down didactic processes. Several emphases of participatory learning have particular significance for people with intellectual and developmental disabilities, including embodiment, reciprocity and distributed learning, and group membership. The important role given to social support and social context, specifically to the guidance of a more experienced person, suggests that there is potential for relational support and the relational agency that it can confer.

I will apply these concepts to understanding the role of personal assistance in the learning processes. The literature on informal learning provides a way to understand learning in ordinary work settings and for people who are socially marginalised. The formal-informal division suggests how learning informally might have substantial advantages over learning in educational settings in terms of the possibility for agency. These learning perspectives supply an established framework that can be applied to a new population and in novel circumstances.

Chapter 5 Methodology and methods

This study explores work and learning by young people with intellectual and developmental disabilities who are participating in work appropriate to their interests, and who are supported by a PA. The funding mechanisms of personalisation enable eligible people with social care needs to employ PA support, and I chose young people as they are most likely to be using personal funding for novel purposes. As I explore capabilities and agency, their work had to follow participants' own interests and preferences, as far as they were understood. The aim is to understand how and why such arrangements are made and how far they have potential to extend the capabilities of the young people involved in the present context of inaccessible employment, capability deprivation and the responsibilisation of individuals for their own social care.

To address the research questions, I explore in depth a small number of cases (five) of young people working in this way. I address the research questions using a bespoke design based on video-stimulated interview methods and adapted for these participants and this project. Additional modifications were made in the light of the Covid pandemic, which interrupted fieldwork.

The design entailed first video recording the people working with PA support. This footage was shared with young people and with the key stakeholders in their work arrangements: the family carers who had co-constructed work arrangements; the PAs supporting the work; and the co-workers and supervisors with whom they worked. This footage was used to support and stimulate collaborative discussion with each stakeholder, focusing on motivation and pathways to the arrangements, the outcomes of work participation and the learning recognised for young people and others in the work situation.

The design of the study followed from the priority for the methods to be engaging, collaborative and accessible. A bespoke design evolved, bringing together participatory elements, methods established as useful in workplace and informal learning research, and reflective methods used to research pedagogy.

In this chapter I outline the methodology and rationale for the design. The first section revisits the parameters of the study, looking at the inclusive research paradigm, participatory methods and the capabilities framework from a methods perspective. The second section gives the steps of the research process. The final two sections explain the process of analysis and discuss validity.

Parameters for the study

The focus of the study follows from the multidimensional significance of 'work' in adult lives in high-income societies and the failures of policy measures to increase employment levels for people with intellectual and developmental disabilities. In the absence of paid work, stable but paternalistic collective provision for people with intellectual and developmental disabilities has been replaced with 'personalisation,' a narrative covering personal-level funding and devolving responsibility for care and support to the individuals. Many see this 'transformation' as disadvantageous for people with intellectual and developmental disabilities, yet the provision of funding for personal assistance might make work attainable. In the absence of employment, working might be a means of social and cultural co-participation, and workplaces are thought to be key sites for adult learning (e.g., Eraut, 2007; Billett, 2008). Supported participation is an opportunity made available by personalisation reforms that invites exploration.

A capabilities approach is used here for its concern with questions of equality, and its attention to the significance of human diversity. Important questions in the lives of people with intellectual and developmental disabilities – social participation, learning, and agency – can be brought together in the capabilities concept of what it is effectively possible for them to do and be. A capabilities approach supports no specific methodology, but participatory methods align closely with its ethical and democratic orientation (Clark, Biggeri & Frediani, 2019).

To recap, the research questions driving the research design concern social participation under personalisation and participatory learning and capabilities:

> Why and how did the young people with intellectual and developmental disabilities come to work in public settings?
> How far did personalisation promote or support this choice?
> What kinds of participatory learning can the young people and those they work with identify?
> How far did working enhance the capabilities of the young people concerned?

As this exploration concerns the significance of working, learning and participating for the young people taking part in the study, the processes were designed to engage them and maximise possibilities for them to contribute their own perspectives. As I assume a relational view of selfhood and seek a rich and layered account of participation and learning, I sought the perspectives of others involved in the social reality of their work, as people 'competent to debate a particular question' (Puigvert *et al.*, 2012, p. 514). I also wanted to bring my own understandings as researcher and 'alongsider' (Carroll, 2009; Chalachanová *et al.*, 2020) into the dialogue. I therefore characterise the video-stimulated interactions as discussion rather than interview. The object of study is thus based in the reflections and interpretations of all the participants, across the research processes. In this way, the approach is grounded in a communicative perspective on reality, with knowledge understood as constructed through interaction and dialogue (Puigvert, Christou & Holford, 2012).

5.1 The inclusive paradigm: Aims and ethical considerations

The topic and methodological approach and topic of the study bring it within the ‘inclusive research’ paradigm. Inclusive research uses methods and practices grounded in valuing the agency, experience and intentions of people with intellectual and developmental disabilities (Walmsley, Strnadová & Johnson, 2018). Researchers are therefore to some degree politically oriented. The balance of priorities – for activism or for research quality – is a matter for debate.

There is now a substantial body of literature on inclusive research that discusses methods to involve and capacitate people with intellectual and developmental disabilities, which includes treatments of the ethics of inclusion (Tilly, 2020) and the epistemic value added through inclusion (Nind & Vinha, 2012; Walmsley, Strnadová & Johnson, 2018), and inclusive research as a site for lifelong learning (Nind, 2016). Inclusive research has significantly extended the active participation and ‘voice’ of people with intellectual and developmental disabilities in the research concerning them.

Ongoing debate about the nature of the role of researchers with intellectual disabilities, for example, includes how far their contribution is ‘unique’ and dissimilar to that of non-disabled researchers (Walmsley, Strnadová & Johnson, 2018). One outcome of inclusive research has been the tendency to involve the section of the wider population that can contribute a ‘voice’; that is, self-advocates and people with milder levels of intellectual and developmental disability (see Jones, Ben-David & Hole, 2020; de Haas *et al.*, 2022). Here I focus on people with higher levels of support need and on autistic people, including people who are not easily engaged in conversation, especially on abstract topics not of their own choosing. This focus had significant implications for the research design, modifying how the discussion was approached and the focus on collaborative methods.

The understandings and priorities of primary participants are critical to assessing the capabilities that matter to them and their agency, or their ability to pursue their own preferences and interests, which are the chief concerns of this study. Nevertheless, I characterise the methods as collaborative more than ’participatory’. The latter can invoke rankings of participation, such as the widely referenced ‘Ladder of Participation’ (Hart, 1992), with research initiated and directed by the participant group presented as the target to be achieved. This approach can seem to follow a normalising ethic, assuming that participants share an interest in research procedures and that they will find following them empowering, which may not be the case (see Woelders *et al.*, 2015). Bourke (2009) notes that in health research, non-disabled participants are selective about how far they take part. Gallacher and Gallagher (2008) suggest that using participatory approaches with children may involve 'processes that aim to regulate them' (p. 499) and see a danger that participatory methods are seen as '"fool-proof" technology' that enables research to achieve ethical and epistemological validity. Gallacher and Gallagher (2008) suggest, instead, that participants can have agency in research encounters in other ways. In this study, I have aimed to design processes that present opportunities for participants to present, by performing and communicating, their chosen work, and that accommodate their own forms of agency as contributors. I have highlighted a relational view of selfhood, and therefore see the contributions of the other participants as enriching rather than diluting the central focus on the people with intellectual and developmental disabilities (Davy, 2019; de Haas *et al.*, 2022). This approach does not take a romantic view of the participant as an authentic voice, or of the interview as a means to access to 'the interiority' of social actors' (Whitaker & Atkinson, 2019). Rather I see participants as jointly examining cultural understandings of work and learning through particular filters of personal experiences (to use the terms of Crotty, 1998, p. 83).

In debate within the inclusive research community, inequality of power and privilege between researcher and researched is an important concern, including the question of any direct gain from such research, such as obtaining a doctorate. Participants in this research were not paid for their participation; however, the primary participants were pleased to be filmed and to have their work represented to others. They understood the filming and research process to suggest that their work was worthy of attention.

Shaping research processes to fit the participants

Learning embedded in work is notoriously difficult to 'get at', as argued in Chapter 3, and must be inferred. In the field of informal learning, interview is the method underpinning most research (Eraut 2004; Sawchuk, 2008). Theories developed by Illeris (2006) on learning by low-skilled workers and identity formation, and Eraut's (2011) foundational research on workplace learning are based on interview methods. The methodological difficulty of 'capturing' learning embedded in other activities – of knowing when learning is occurring and when it is significant – is widely discussed in the research (for example, Eraut, 2011). Eraut reports describes how self-reports of learning show respondents' difficulty in recognising their own learning, and how formal conceptions of learning tend to dominate in responses. In our own research on learning in the context of personalisation, learning was often tacit (Nind, Coverdale & Croydon, 2020). In this study, I have used the support of the video footage and the perspectives of people with different positionalities to try to ‘get at’ the learning. In discussions, I briefly introduced key ideas of social and cultural learning theory to broaden the discussion beyond work-specific skills. I gave some concrete examples and asked, for example, about learning by people in the workplace. In some cases, I referred to instances of learning that were tacit in descriptions of other things.

Given the characteristics of primary participants, the research methods had to consider how to support conceptual understanding of the topics and communication about them. Specifically, they needed to engage primary participants in thinking about learning and participation. In previous work with children and young people with language and communication needs, I had used photo elicitation methods to investigate experiences of residential special schools. The stimuli were bespoke to the project, and designed to explore aspects of the participants’ life at school (Pellicano *et al.*, 2014). The images had effectively established a shared attentional focus between researcher and participant that allowed participants to respond spontaneously and with little verbal elaboration. This provided a starting point for the research design.

I hoped that making and using video of participants at work would enrich this engaging and stimulating effect, especially since the video would showcase the participant and the activity of importance to them. This property is discussed further in Chapter 7. Harper (2010) sees photo elicitation – using a photograph as an interview stimulus – as a method to instigate collaboration, eliciting more information and a different kind of information; it ‘mines deeper shafts into a different part of human consciousness’ than purely verbal interviews’ (p. 23). Nind and Vinha (2016, p. 9) discuss using stimulus materials with people with intellectual and developmental disabilities and how this can result in ‘imaginative and creative interactions with data’ and, importantly, how ‘moving away from pure talk’ facilitated active engagement in discussion.

Moving away from talk while enabling primary participants to be active in the ‘construction and negotiation of meaning’ (Willig, 2013, p. 89) presented a dilemma. Interview methods are approached theoretically in differing ways, but rely on respondents’ voluntary recall and linguistic and conceptual dexterity. For example, quotations of participants’ words often frame the findings in qualitative research. The inclusive research question of how to counter rather than contribute to the marginalisation of participants with intellectual and developmental disabilities (Walmsley & Johnson, 2003; Nind, 2014), is complicated by the relationship between quotation and findings, as people with intellectual and developmental disabilities may not convey their competence effectively in words. In aiming to privilege the perspective of primary participants as a source of knowledge about themselves and their lives, researchers encounter the problem of highlighting their verbal contributions. In this study the video stimulus provides one part of the answer as it acts as a form of non-verbal representation. The perspectives of primary participants are also enriched through the relational representation of others. Davy offers a critique of over-reliance on the ‘voice’ of the participant as a constraint, that forecloses ‘deeper conversations about the possibility and conditions of ethical speaking-with’ (Davy, 2019, p. 108). While it cannot be assumed that different parent participants, PAs and co-workers have the same level of knowledge and ethical sensitivity in their ‘speaking with’, I take their views to be valuable as contributions to the collaborative discussion.

The methodology assumes communication and understanding to be co-constructed, as understood in participatory learning theory. Rogoff (2003, p. 285) describes learning as occurring between participants and involving modifications in each person's perspective. This idea can be applied to the collaborative processes of this research, where the intention was not primarily to ask participants for their views but to ask them to recall and reflect on changing social dynamics, for example, or changes in how work was approached or allocated. No participant type is taken to be the sole authentic author, able to ‘narrate the story that is uniquely [theirs] in that only his or her own voice can articulate it authentically’ (Gubrium & Holstein, 2003, p. 36).

The PA and co-worker perspective

The role of the PA was a key factor in the conceptualisation of learning through participation in work. The first-person perspective of PAs would be critical in extending, modifying or challenging others’ interpretations of how work might extend the capabilities of primary participants. PAs had a mediating role between the individual and the work situation, thus a unique position in the dynamics of the participation, well placed to notice changes in attitudes or behaviours that might be imperceptible to other participants. The co-worker was assumed to be familiar with the workplace culture, pre-dating the participation, and could give an account of the primary participant as a contributor or as a team member at the level of the task and or the broader culture. As I was interested in reciprocal learning – the workplace impact of the young person’s participation – co-workers could reflect on their own developing understandings of the person, their work and the PA’s role.

The large literature touching on the role of family in the lives of people with intellectual and developmental disabilities includes positive accounts of support and advocacy (Pérez, Alcover & Chambel, 2015; Giesbers *et al.*, 2020) and more ambivalent accounts of controlling and sheltering functions (Almack, Clegg & Murphy, 2009; Brennan *et al.*, 2016). It was clear from the literature and personal experience that families would have a substantial role in setting up and sustaining work arrangements that were independent of employment services and in managing the use of personal budgets. As criteria specified that participants must be pursuing their own interests in their work, I expected parents to be informative about the motivations for work, as well as possibly learning and social outcomes.

Collecting multiple perspectives on a subject in this way can enrich understanding of the dynamics in complex relational arrangements (Zartler, 2010; Vogl, 2016), and is part of the collaborative process of interpretation in this study. I am conscious of the risk of downgrading or distorting the views of the people at the centre of this study by the greater volume and articulacy of other voices. The non-verbal evidence of the video footage represents a counterweight to this risk, and signals the acceptance of different kinds of agency (see de Haas *et al.*, 2022).

Visual methods and interviews

Typically, qualitative research relies on interviewees' verbal fluency and conceptual understanding to provide the quality and depth of response that qualifies as 'rich description' and this, in turn, supports the validity of qualitative research (Lewis & Porter, 2004). Through using visual and creative methods, researchers in the field of intellectual disability have sought to reduce reliance on verbal mediation in interview (e.g., Seale *et al.*, 2015; Hill *et al.*, 2016; Kaley, Hatton and Milligan, 2018). In participatory research, this may involve participants creating artefacts as a means of expression, particularly photographs. In photovoice, participants take photographs to 'illustrate' the research problem or question, which are supplemented by interview. Photovoice sets out to convey, or to 'give voice', to the point of view of the person holding the camera (Booth & Booth, 2003). It can be engaging and accessible as a method, and is widely used with people with intellectual and developmental disabilities (Povee, Bishop & Roberts, 2014; Cluley, 2017; Overmars-Marx, Thomése & Moonen, 2018). However, the invitation to 'share the story the picture evokes for the person who clicked the shutter' (Booth & Booth, 2003, p. 432) brings significant problems of interpretation and intentionality. Piper and Frankham (2007) invoke debates in semiotics and art history to problematise the 'reading' of images in photovoice research.

Video has a clear place in studies involving people with intellectual disabilities as a medium that gives people who cannot read fluently access to data (Williams *et al.*, 2010), with control over the time to take in the information (i.e., it can be paused and rewatched). An information video (described later in this chapter) was made for participants in this study on this basis. Conversely, in the form of 'I am…' video stories, it can give an account 'beyond words' (Wood-Downie *et al.*, 2021) of a person with limited 'voice', such as an autistic child involved in educational transitions. Video data has also served researchers interested in the 'multimodal character' of social interaction (Jewitt, 2012) in a variety of paradigms. As demonstrated by its currency in workplace studies (Sawchuk, 2008), video can capture efficiently the co-operative and contextual aspects of workplace learning. On the basis of these characteristics, it has acted as a medium to stimulate and support discussion pf pedagogy, building on its advantages as a means to explore thinking and learning underlying observable events (Nind, Kilburn & Wiles, 2015). The potential of video to connect the viewer and researcher is a key strength; Jewitt (2012) describes it as providing a sense of 'being there' together.

Using video records of workplace participation offered a range of advantages for this study. First, it was meant to engage primary participants in the themes of the research, allowing a concept like collaboration to be pointed to rather than explained. I hoped that the focus on videos about themselves and the activities that were important to them would be rewarding. Its portability could be useful, enabling sharing and reviewing as needed or desired. It could revive a memory of events while allowing them to be experienced from a novel perspective. It would allow participants to establish joint attention on an event or sequence without needing to explain or describe the event verbally. Lastly, I hoped that familiarisation with recorded episodes and participants' wider knowledge would help to make complex and elusive phenomena more amenable to collaborative analysis.

Researchers in the field of disability have advocated for the use of video in inclusive research, but it remains little used (Kaley, Hatton & Milligan 2018). In this context, the capacity of video to communicate information non-verbally (e.g., Jewitt, 2012) and to capture non-verbal communication, including facial expressions, gestures and embodied interactions, is critical. It can be used as a tool in various methodologies, and clearly has advantages for collaborative research. The potential of video to connect the viewer and researcher non-verbally is a key strength; Jewitt (2012) describes sharing video as providing a sense of 'being there' together. Video is also easy to distribute and makes possible repeat viewing, so that information can be accessed at the viewer's preferred pace.

There is a tradition in research of using video documentation to unravel or deconstruct sequences of behaviour such as interactions between people, which can be fast-moving and complex. Jewitt (2012) sees methods using video to support scrutiny of events as particularly useful to generate accounts of how 'invisible' phenomena operate. The technique is particularly applicable in contexts where a phenomenon may be 'invisibly buried in the routines of day-to-day' (Schubert, 2006, cited in Jewitt, 2012, p. 4), such as learning.

It is this 'deconstructing' function of video that has led to its use in research in workplace studies, specifically in studies of 'informal' learning in the workplace (Sawchuk, 2008). These contexts capitalise on the ability of video to support detailed attention to complex events within relatively short chunks of time. Sawchuk (2008) warns that, while video provides the capacity for this kind of ‘micro-analysis’ of complexity, this strength can lead to distortion whereby small details and minor events are magnified and brief time scales take precedence over a longer time perspective. This possibility informed the development of interview protocols for this study, which were designed to conclude with summarising or ‘focusing out’ questions, which invited reflection from a more distanced perspective and over a longer time scale.

The version of video elicitation methods specified as Video Stimulated Recall Reflection and Dialogue (VSRRD) (Nind, Kilburn & Wiles, 2015) has particular emphases – on mutual recall, reflection and dialogue, collaboration and informal interview methods – that had potential to strengthen my research design.

Video Stimulated Recall Reflection and Dialogue (VSSRD)

VSRRD evolved from stimulated recall methods (e.g., Moyles, Adams & Musgrove, 2002) as a more dialogic and reflective approach, for example, to enable teachers to consider their own teaching, with a knowledgeable partner (Moyles, Hargreaves & Merry, 2003). VSRRD is a retrospective ‘think-aloud’ interview technique, designed to enable the interviewee to relive an original situation with vividness and accuracy. The video acts as a stimulus to prompt reflection and dialogue between participants and researcher about what is visible in the video and what can be inferred or reconstructed of the internal invisible processes. It is supposed to help make visible what is hard to see and know for both researcher and participant, and combines data about participants’ behaviour in context and the thinking that comes with that behaviour (Nind, Kilburn & Wiles, 2015).

In this study the researcher and video-taker were the same person, so the ‘reliving’ of events was shared by the researcher/interviewer and participant. The method was adapted for the purposes of this project to include further participants who may feature in parts of the video, such as co-workers, and others such as parents and some supervisors who do not feature in the video yet are stakeholders in the arrangement.

Characteristics of video as a record and as a stimulus for interview make video methods well suited to research collaborating with people with intellectual and developmental disabilities. First, the stimulus is engaging and accessible. It can be reviewed as much or as often as necessary or desired (Jewitt, 2012; Goldman *et al.*, 2014). Second, it reduces the dependence of interviews on purely verbal mediation – actions like pointing and rewinding are effective non-verbal means of signalling where the interest lies or comments belong. Video records of non-verbal forms of communication and behaviour preserve communicative modes that may be important expressions for people with intellectual and developmental disabilities. These features might enable participants to ‘see’ aspects of their behaviour that they do not have access to ‘in the moment’, meaning that involvement in research processes might offer some learning opportunities (Nind, 2016).

VSRRD provides a means to support reflection and dialogue that supports the involvement and interaction of people with intellectual and developmental disabilities, strengthening the collaborative research paradigm. The research was designed to enable the video footage to act as a shared resource for discussion and to keep the person and work concerned at the forefront of thinking. I reviewed video separately with each type of participant (primary participant, parent, PA, co-workers) as I wanted the sessions to have an intimate character in which participants could communicate personal responses and evaluations as they arose. In particular, I wanted to work with primary participants on a one-to-one basis as far as possible.

As each interview proceeded, I shared ideas and interpretations of what was shown in the video for the participants to consider. I see the methodological approach – the co construction of knowledge – as fitting closely with a socio-cultural view of learning, participatory methods and a relational understanding of the self. The sharing of thinking in interaction with video evidence may prompt recall and perhaps reinterpretation of memory and support recognition of learning processes that are otherwise elusive. Indeed, VSRRD can be characterised as working as a form of distributed cognition, as it depends on the thinking arising between individuals, artefacts and their relations to each other in a particular work practice (Rogers & Ellis, 1994).

Figure 5-1 James reviewing his video, giving his thumbs-up greeting

Figure 5-2 James reviewing his video, watching attentively

I have discussed the methodological framework, the inclusive research paradigm and the rationale for collecting data using a bespoke form of VSRRD data generation. I now outline the steps of data generation.

5.2 Data Generation – the steps of the research process

Participant selection criteria and recruitment

Once ethical approval had been obtained, I began the recruitment search, contacting individuals and organisations in the field of intellectual disability by email, telephone and posting on forums used by people with intellectual and developmental disabilities. Potential participants and their allies were referred to a project website (https://findingawaytowork.info/; see Appendix B) that explained the research and hosted a short film outlining the processes of participation in accessible terms. Information sheets were also made available to participants and carers. [Appendix A].

Recruitment was difficult: many organisations referred me to supported employment initiatives. Some argued, incorrectly, that personal budgets could not be used to support work. The British Association for Supported Employment objected to unpaid work on the grounds that it might undermine the employment market for other workers. Still others referred me to preparation for work training programmes. The difficulty reflected the small numbers of people working with PA support and the fact that arrangements were not associated with disability organisations.

Participants were selected as young adults (aged over 18):

i. with an intellectual and developmental disability;

ii. using state funding to employ a PA to access work opportunities

iii. working in public (not domestic or sheltered) settings.

Five people were recruited, in the South East, South West and Derbyshire; their roles and affiliations are shown in Table 5.1.

	Organisation	Region	Workplace	Role
Anna	National animal protection charity	Surrey	Local cat rescue centre	Cattery assistant; cat socialising
Ciaran	Community co-operative	Berkshire	‘Ethical supermarket’	Co-operative member; shop duties
Fiona	Area Library services	East Sussex	Branch library	Library assistant; shelving books
James	National heritage conservation charity	Derbyshire	National Park estate	Groundsman
Greg	National environmental charity (affiliated)	Somerset	Village centre	Community litter picker

Table 5-1 Participants and work.

Consent and ethical considerations

After viewing the informational film and discussing the project with family, the participants signed a visually supported simplified consent form. Each (accessible) consent statement on the form featured a still from the information video to confirm which activity was referred to [Appendix B].

The research design required; consent from the workplace for video to be recorded and for co-workers or supervisors to take part; consent from PAs to be filmed and to participate; and consent from parents to participate. Separate consent forms were made for each case (see Appendix A). Information letters were sent to employers as a first step, followed by email contacts or meetings, as preferred by the employer, to answer questions and establish a way of working (for example, in public locations a ‘warning’ notice was used to alert people that filming was taking place).

The means to include and collaborate with primary participants was central to the research design and to its ethics. For reasons explained above, I chose video methods to engage participants and support collaboration with them. The first ethical question concerned obtaining properly informed consent, which had additional importance as I was asking for a substantial commitment of time and effort to collaborate on the project. The information video was an important part of the consent approach. Its role was to ensure that primary participants understood the purposes of the project and the processes that they were being asked to take part in. It also acted as an introduction to me, the researcher, with whom they would need to collaborate. The steps of the research were demonstrated by my daughter, which tacitly introduced my motivation and positionality. The dedicated website was designed to have a clean and simple interface with small amounts of text. Embedding the video in this website gave potential participants the option to spend time considering the proposal. It also hosted a picture and text version of the research steps (Appendix B) for additional clarity.

Participants were young adults over 18 years. According to the Mental Capacity Act (2005), people working with people with intellectual disability must comply with the Code of Practice: ‘Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.’ Individuals should be supported to make their own decisions and professionals must ‘make every effort to encourage and support people to make the decision for themselves’ (Principle 2). The information film, the demonstration of research processes and accessible website followed this principle.

The use of video methods, where identities cannot easily be anonymised, also raised questions of confidentiality (Wiles *et al.*, 2008). Participants were offered anonymisation in written material and given a veto over the use of video featuring them. In practice, they did not choose to be anonymised: each participant preferred to have their own name used. They were keen to be recognise for their work roles, for video clips to be shown publicly and for their ‘stories’ to be known. Parents shared this outlook, seeing primary participants as modelling the possibilities for others in similar positions.

The wider ethical framework was set by using collaborative methods. The bare outline of research methods underplays the ongoing processes of developing relationships and exchanging information. The extra years of the research process, and the fallout of pandemic and lockdowns, added dimensions of shared experience and contributed to a longer-term and more varied research trajectory. The sharing and testing of interpretations took place throughout the research, informally in conversations, during filming and more formally during the VSRRD discussions. The member check procedure was a key stage by which participants learned more about the circumstances and experiences of other participants and how I was synthesising findings. In this sense participants have given their assent to the broad outline of findings and conclusions.

Moving into fieldwork

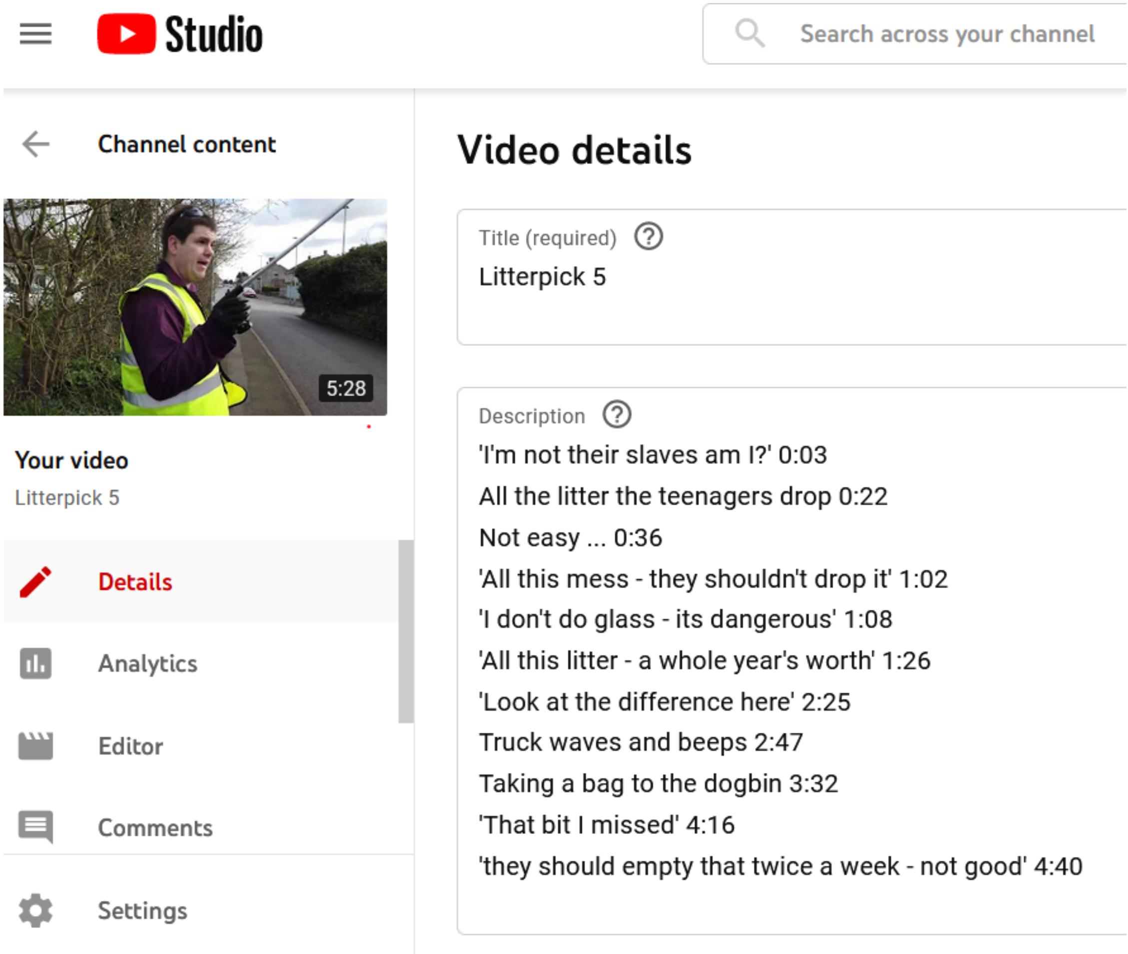
A first research meeting was arranged with participants and family, and this took place at their home. We revisited the information video, which allowed me to explain and introduce my rationale for the research. We discussed the workplace and working arrangements, and I asked about motivation and the processes of choosing and gaining access to the work. I asked participants to identify the moments of the day, activities or situations that they regarded as a priority for filming and checked in each case there was anything that they particularly did or did not want to be captured in the video.

A video planning document was produced collaboratively, reflecting these preferences. I familiarised participants with the camera – a small (pen-sized) camera (a DJI Osmo Pocket 3-axis stabilised handheld camera) that was unobtrusive, easy to use and made good-quality video. At this stage I also opened fieldnote files for each participant and workplace. These were used to record observations, store photographs, accounts of meetings and decisions made. They provided the basis for the participant and workplace profiles for use during analysis. Dated notes were added between meetings to record comments and ideas arising as the data collection proceeded. For example, I noticed in the course of data collection how much interest and variety I found in the personal and working lives of participants in comparison with the 'special' settings and relationships of disability services.

Arrangements for filming

The next stage was a short visit to the workplace to introduce myself and finalise the practicalities of video within each specific environment. For example, in some public locations notice had to be given that filming was to take place. Filming was to be conducted on three separate occasions to cover a range of different work situations, such as fluctuations in work demand, pace, participant state of mind and similar factors. The aim was to gather at least three hours of video from three separate visits. This would allow for some cutting to reduce any repetition prior to review.

The aim was to collect video footage of events as they occurred, not to select and highlight particular events. Dates and times for making video were allocated by workplace, according to what suited it and the primary participant. The arrangements meant that I did not control what was captured on film. The content therefore reflected a kind of random sampling. I kept the primary participant in frame as far as possible, keeping up with changing locations and activities as best I could, sometimes following instructions such as ‘That’s important, don’t miss that’. In this sense I acted as camera operator, not as director of the film, with minimal control over content or framing.



Title (required)
Litterpick 5

Description
'I'm not their slaves am I?' 0:03
All the litter the teenagers drop 0:22
Not easy ... 0:36
'All this mess - they shouldn't drop it' 1:02
'I don't do glass - its dangerous' 1:08
'All this litter - a whole year's worth' 1:26
'Look at the difference here' 2:25
Truck waves and beeps 2:47
Taking a bag to the dogbin 3:32
'That bit I missed' 4:16
'they should empty that twice a week - not good' 4:40

Figure 5-3 Screenshot showing video labelling.

After each video session I uploaded the content to a private YouTube channel that I had set up for the project. Initially I segmented video into short episodes of less than 5 minutes, each with a brief descriptive label to help participants and myself to navigate the contents. As the process of saving and uploading short sections was time consuming, I later used time stamps with labels to make larger chunks of video navigable (Jewitt, 2012) (see Figure 5.3). I labelled words or the actions taking place or, when this was not appropriate, I gave content a descriptive label. In the video elicitation discussions, I made it clear that descriptions were personal responses that were open to discussion.

When each session was complete, I sent a video link to the participant for them to review the material in their own time. The first filming sessions took place immediately prior to the first Covid 19 lockdown, at which time fieldwork was paused.

Covid 19

Progress was considerably slowed by lockdown. All participants but one ceased to work, fieldwork came to an end, and I reworked the project timetable alongside switching to part-time registration.

To collect some data, I arranged remote interviews with parents who, like many at this time, were pushed to pivot to online methods (Nind, Coverdale & Meckin, 2022). These were Zoom interviews, lasting 40 minutes to one hour, and they were recorded on video. I had planned to interview parents after video-supported sessions with primary participants; however, participant interviews had to have video support and to take place in person. The change of process allowed me to draw on parents' knowledge of how the loss of work had affected participants, to understand better how and why working arrangements had been made. This was an additional element of data as later the originally planned video supported interviews took place.

Previous literature on VSRRD suggests that review and discussion should take place as close as possible to the events videoed (Nind, Kilburn & Wiles, 2015), and this was no longer possible. However, the delays allowed me to keep in touch with participants and families over a longer period of time, and throughout the adjustment of losing and returning to work. These changes gave the methods more of a longitudinal and ethnographic character, producing a more complex picture of young people's experiences over time and in differing circumstances. In three cases it allowed participants to consider the video footage that was recorded before and after lockdown.

The VSRRD procedure with participants

VSRRD sessions took place in participants' homes and in workplaces. Two interviews (one PA, one supervisor) took place remotely with video screen-sharing. Participants had access to the labelled and chunked video footage of their case, and had reviewed video beforehand. For the VSRRD session, a large screen was set up for video review, and a camera set up to capture both the video screen and participant. This setup enabled responses, both verbal and non-verbal, to be captured simultaneously with the video that elicited them.

I intended the discussion of video to be conversational and discursive, but I took a list of broad question areas to ensure that there were no topic gaps. Clips could be selected by the participant or by myself. The first and final questions were intentionally 'zooming out' questions, as explained, although in practice discussion naturally zoomed in and out from the specifics shown in the video to wider questions. Each session took around 40 minutes, with short breaks between sections.

5.3 Analysis and findings

The videos of work and VSRRD sessions were transcribed using Trint video transcription software. This produces a rough draft synchronised with video replay, which required amendment. This is a time-intensive process, which enables immersion in the data. A criticism of the use of transcripts for analysis is that the emotional tone of the participant's account is lost (Beail & Williams, 2014). Here, the process of replaying video while revising transcription minimised any such loss. Provisional themes and patterns emerged which fed into the member check process with participants.

First report and validity check

The purpose of a member check (also known as participant or respondent validation procedure) is primarily to see how far patterns identified by the researcher are seen as valid by the participants and resonate with them (Saldana, 2013; Thomas & Magilvy, 2011). Such a procedure was planned as a part of the collaborative research paradigm, and took place in the early stages of interpretation of the data before the final coding process. It was intended to extend collaboration, to serve the purposes of transparency and to provide opportunities for participants to respond to initial findings. There was also an ethical dimension to the exchange, in that given the time invested, participants deserved to see what was done with their participation. As there was no communication between cases, I felt that participants might also benefit from seeing their own arrangements and outcomes in the context of other participants'.

For these purposes, I needed to present a concise and readable account of emerging findings. I had planned for the report to take the form of a list of key points, in an easy-read or PowerPoint presentation, to be accessible to primary participants. My developing understanding of them led to a change of course. First, the points that I wanted to make were not reducible to easy read without significant loss. Moreover, some primary participants might see an easy-read document as patronising, while others would not understand it. On the other hand, other types of participant – parents, PAs, people in the workplace – had also invested significantly in the project, and transparency required a more complete account of findings than possible in easy-read. I settled on a newspaper-style report, in which headlines, images and their captions might be meaningful and informative to primary participants, while longer, textual accounts of findings would give a fuller picture to those motivated to read further. The member check report is attached as Appendix C.

Responses to this report were gathered by telephone and email. There were minor corrections and suggestions, and much recognition. Feedback to the report informed the next stages of analysis and is incorporated in Chapter 6.

Analysis and coding

Early stages of analysis were embedded in the research process, in the VSRRD sessions and member check procedure, as emerging ideas were discussed with participants. The formal analysis process involved uploading all data to computer-assisted qualitative data analysis software.

Data (53 files) were uploaded to NVivo (Release 1.6.1), comprising:

- Transcripts of interviews conducted with parents (five x 50-minute video-recorded Zoom meetings)
- Transcripts of videos of primary participants at work (*c*. 12 hours of original video)
- Transcripts of the VSRRD sessions (28 x *c*.40-minute video-recorded interviews)
- Labels for video clips with relevant hyperlinks to video footage.
- Fieldnotes (14 files).

(Note that the research design was modified when fieldwork was paused for Covid 19, so that parents were interviewed twice, first before filming was complete and a second time in the VSRRD session.) Analysis involved a mix of deductive and inductive coding, as detailed below. I planned to present findings in the form of narrative portraits of primary participants and their contexts, followed by an account of cross-cutting themes.

The data was organised by primary participant. Considering the importance of personal characteristics and personal histories to a capabilities analysis, I decided to construct narrative portraits of primary participants, their work and support situations (Rodríguez-Dorans & Jacobs, 2020). Each case first was analysed separately. The narrative portraits outline each individual in the context of their family setting and support network. The work niche, learning and participation elements in each case are set out to preserve ‘the local web of causality’ (Miles & Huberman, 1994, p. 151) that can be lost in a thematic account. This would ensure that the detail of individual circumstances was not lost or subsumed under overarching themes. This method is intended to allow participants’ unique personal qualities and wider social contexts to be seen holistically (ibid.). Each portrait finishes with a brief description of the contents of the participant’s film, to provide an outline of the material used in the video-stimulated interviews, and an impression of the primary participant at work. Initial drafts were made before the completion of VSRRD sessions and revised in the course of analysis.

The narrative portraits are followed by a cross case analysis seeking patterns and divergences within the data set (Silverman, 2015). First, a basic template reflecting the two research questions was applied to organize the data (see Appendix D). Coding was initially directed by the research questions in a basic labelling process (Rapley, 2011). I coded highlighted material as relevant to one of the two research areas, i.e., regarding work arrangements or participatory learning and capabilities.

I then passed through the data as a whole, coding passages with a large number of brief descriptive labels, reflecting topics and themes as they emerged (Willig, 2013, p.185), which were tentatively allocated to research questions. These were revised and simplified in multiple passes through the data, in a process of consolidating and integrating material into larger chunks using a more interpretive coding approach. I initially coded key passages simultaneously, as the content seemed to connect with more than one code, but increasingly prioritised some connections over others as the outline of patterns became clearer in subsequent passes. Some separate codes were merged into an overarching new theme. For example, material related to 'supported employment', 'day services', 'paid work' and other aspects of service provision formed a single, multidimensional 'critique of services' theme, as I recognised that disparate descriptive codes were linked in this way. Some codes moved into themes related to the theoretical framework of the project, as I began to see conceptual links between them and the terms and concepts in the theoretical framework. Hence the theme of 'legitimacy', relating to 'legitimate peripheral participation' (Lave & Wenger, 1991), came to replace the inductive codes 'authenticity of work', and 'making a contribution' which picked up references to ways in which the work was 'real' rather than 'special' or tokenistic, and genuinely useful. The wider theme of legitimacy allowed the inclusion of other material relating to the importance people placed on being part of a 'mainstream' working organisation, as well as fitting the theoretical learning framework in an informative way. Similarly, the content of a code labelled 'adapting behaviour for work' and one labelled 'collaboration/collaborative learning' produced the theme of 'mutual adaptation', which better fitted the processes described. Codes and emerging themes were reviewed and modified, and this process continued until I felt that a coherent thematic account of the data had emerged, which was oriented to the specific research questions.

There were five main themes for motivation and arrangements for work (i.e., to address the first pair of research questions): critique of services; PA support makes work viable; structure and agency; access to participation; and purpose and meaning. For the second pair of questions, regarding participatory learning and capabilities, five key themes were identified: support enables agency; legitimacy; effort and recognition; affiliation and social bonds; mutual adaptation. These themes and details of subthemes are shown in Appendix D.

The analysis therefore proceeded in the following stages:

1. I organised files first by participant case to support the production of narrative portraits. Focusing on features of interest highlighted within the transcripts, field notes and video label data, I sought to identify the key elements of primary participants' characters and contexts. These were then compared across participants and simplified to produce consistent subheadings for the portraits.
2. Moving on to cross-cutting themes, I worked first with material highlighted as significant in the course of transcription and discussion. I labelled this with descriptive and emergent thematic codes, categorising these as relevant to one or more of the questions. I also established a category code for material relating to the use of video, as a resource for consideration of the methods.
3. I then worked through the data line by line, annotating the transcripts and labels with initial comments and ideas and generating a large number of codes. These were a mixture of brief topic labels (e.g., 'supported employment'; 'pay'), and emergent thematic concerns (e.g., 'reciprocity/common ground'). The theoretical framework and collaborative discussions informed this process, but codes were not established a priori, with the exception of the Camera/film category.
4. The coded data was reviewed and collated in stages into larger groups of working themes. These were further modified and refined in an iterative process to produce the themes and subthemes shown in Appendix D.

Questions of Validity

Questions regarding the validity of findings in qualitative research generally have been widely debated. The plurality of methods and diversity of epistemological perspectives used have resulted in factionalism (Silverman, 2010), so that validity procedures have been arranged by paradigm assumption (Creswell & Miller, 2000), with particular validity practices 'belonging' in certain paradigms. I follow Hammersley (2007) in seeking to establish the validity of this study in 'common principles' that permeate questions of design and methodology. The research design, data collection and interpretation follow a consistent logic of collaborative processes, shared resources and mutual enquiry. I start with the question of collaboration.

Collaboration and validity

I have sought to work closely with primary participants on a topic of mutual interest – their chosen work. Collaboration and shared resources were intended to draw all participants into the issues and processes of the research, as we revisited and interpreted events in which they had participated. The research design brought together a multiplicity of perspectives, including some divergencies of view, which are supposed to contribute towards convergent validity (Creswell & Miller, 2000). Incorporating the reflections of the other stakeholders helped to develop 'deep, dense, detailed' description (Denzin, quoted in Creswell & Miller, 2000, p. 128) and so to offer a credible exploration. The intention was for our understanding of the topic to build across research processes, as suggested in critical communicative methodology, so that participants can 'convey their story' and 'consider how and why they have followed a certain path' (Puigvert, Christou and Holford, 2012, p. 523). The data generated from collaboration with participants and within an inclusive paradigm pay close attention to participants' subjective understandings. Creswell and Miller (2000, p. 128) see this as a validity lens, since it consists of 'building the participant's view into the study'.

The collaborative processes leading up to and including VSSRD and the member check procedure involved sharing and discussion of participants' views through the stages of the project. Through these processes there is joint ownership of key findings, synthesised and voiced by me. The details of interpretation are mine, shaped by my learning across the stages of the project, by my interests and positionality and the particular requirements of doctoral research.

In collaboration, the research process itself counters marginalisation, rather than contributes to it. In this study 'collaboration' is also intended to build relationships – between the participant and the researcher and the participant and the topic – that shape understanding over time. First, in the context of Intellectual and developmental disabilities, the quality and depth of participants' contributions to research depend importantly upon their trust in researchers (Nind, 2008; Kaley, Hatton & Milligan, 2018). I anticipated that primary participants' motivation to invest effort in this study's research topic – since it involved their selected work interest – should be high. In practice, primary participants were enthusiastic co-participants, endorsing particularly, as I have said, the account of their work produced in film. Personal and professional experience of adapting to communicate with young people with intellectual and developmental disabilities, and my fully disclosed personal interest in the topics, helped to make collaboration informal.

In the participatory/inclusive research tradition, researchers must negotiate participants' relative lack of power through their choice of methods (Nind, 2008), such as their exclusion from the interpretation of data. Conversely, as Seale (1999, p. 69) points out, the generation of accounts that 'do not challenge the common-sense evaluations of [participants] is one of the easiest tasks in social research', and may appeal particularly when researchers identify with their participants' perspectives. To count as valid, findings need to do more than record and report the 'voice' of collaborative partners as if they had privileged access to truth. To balance the competing demands of respect, empowerment and critical distance, I have tried to interweave participant and researcher contributions and the informed commentary of co-workers and PAs, albeit filtered through my questions, analysis and writing. Participants have taken a strong collaborative role in early analytical decisions, yet the synthesis of participants' data, the coding and the final analysis were researcher tasks. Preliminary findings were then re-presented in an accessible form to all participants in order to incorporate their responses in the final account. Offering participants the chance to respond to a researcher's interpretations of data has been described as the 'most crucial technique for establishing credibility' (Lincoln and Guba, 1985, p. 314), yet it can be undermined by superficial or compliant responses or be hijacked by considerations external to the research (Seale, 1999). The process of 'member checking' in this study followed logically within the collaborative design, taking advantage of participants' investment in the research topic and their interest in outcomes that involved them. Responses received in this process were integrated in later analyses but not treated as direct validation or refutation of researcher interpretations (see Silverman, 2010, p. 28). Rather, they were integrated as part of a wider agenda of reflexivity and transparency, as I discuss below.

Reflexivity and transparency

The process of documenting research procedures can contribute towards a study's validity by enabling a reader to assess claims to truth. This approach is reflected in recent appeals for transparency that have grown in response to the 'reproducibility crisis' in scientific methodology (Munafò et al., 2017). Applying the lessons of this crisis to qualitative research, Haaker (2018) recommends transparency in data collection, analytic transparency and production transparency; that is, providing access to the full body of data analysed, describing precisely which evidence supports which claim and explaining in full how data were collected. I broadly follow these recommendations. I have given the rationales for the research design and data collection processes, and for modifications made to them as events unfolded. Hence, the video footage, originally intended to serve only as a resource for discussion, has come to assume a greater role as participants' views of its status as evidence became clear. Full access to video recordings is not possible in the current thesis; hence a brief description of the contents of each participant's film is given as part of the narrative portrait.

With respect to analysis, I have outlined collaborative and researcher-led aspects of this. I also have caveats: clean distinctions between evidence and its interpretation fit awkwardly into a collaborative exploration of complex social phenomena. Informal conversations with participants, for example, have a valid place in a collaborative process and may inform interpretation of data, but are not accessible as data.

Final ethical considerations

In this project, I wanted to contribute to thinking and debate about significant limitations imposed on people with intellectual and developmental disabilities by their treatment in social care and in policy. Concerns about the ethics of employment policy and personalisation policy were a significant motivating factor. The collaborative design and methods to elicit effective participation by people with intellectual and developmental disabilities also follow from ethical considerations about the treatment of such people by society and by research (see Nind & Vinha, 2014).

The capabilities approach that I adopted sets out to provide an ethical framework, to evaluate equality in the lives people can lead, focusing on capabilities as the ‘space’ (Robeyns, 2017, p. 51) of comparison. What people are effectively able to be and do, their relational agency and social participation, seemed to me ethically important questions for people with intellectual and developmental disabilities as a socially excluded group. Methodologically, capabilities are acknowledged to be difficult to operationalise, as doing so involves the presence, absence and viability of meaningful options, as well as judgements about which are the capabilities that matter in a particular case. Evaluating capabilities is therefore inferential and ‘informationally demanding’ (Robeyns, 2017, p. 50), yet it is also intentionally an adaptable framework, and concerned with practical and incremental improvements. The collaborative approach taken here respects the participatory ethic of the capabilities approach (Vizard & Burchardt, 2007).

In the next chapter I present the findings in two parts, as narrative portraits of participants and as a set of cross-cutting themes.

Chapter 6 Findings

The findings in this chapter are presented in two parts. Part 1 consists of narrative portraits of the primary participants, their work and family and professional support. Sub-sections on participation and learning reflect the way that these two elements were integral to the experience of ‘work’, as understood in social and cultural learning theory. Each narrative portrait finishes with a brief description of the contents of the participant’s film, to provide an outline of the footage reviewed in the video-stimulated interviews. In Part 2 I present the findings thematically.

Part 1: Narrative portraits

6.1 Anna

Anna, a cattery assistant, is in her late twenties. She lives with her teacher parents, two cats and a golden retriever in a commuter area in the southeast. She speaks quietly, almost under her breath, but is not shy. She hates being talked down to, and ‘can spot it a mile off’ (Judith, her mother). She is highly attuned to animals. At home she handles and talks to the animals continuously, and tracks animal/insect/bird activity when out, for example identifying a bird by its song. Anna readily shares her interests and knowledge and, when other topics are introduced, she is much less responsive; in this way, the cattery and staff there enable her to be sociable. She does not travel or go out independently. When she is not at her work, she is either with family or in a disability group.

Education and occupations

Anna attended a special school (students have ‘complex social communication needs or complex autism’) until age 19. She then attended a further education college in a nearby town, travelling by taxi service. The school had planned for her to start a course in animal welfare at college, but she was not accepted, supposedly on account of her lack of social skills (‘It was a huge blow after all the build-up’: Judith, mother). She attended the learning disability section, leaving with ‘just a sort of an experience of the outside world’ (Judith). She then attended a National Autistic Society day service for four years, but funding problems led to declining quality: ‘They never went out or did anything. And it was virtually like going back to school.’

At the time of filming, Anna is attending a day service that focuses on ‘life skills’ for young adults with intellectual and developmental disabilities. She is happy to go, but also happy to skip days if something else comes up. Judith thinks that she will outgrow the ‘kiddy’ provision: ‘it is a great place. But there's only so much bingo you can play. So much woodwork you could do…’). On employment, Judith says that Anna will not engage with it: ‘It’s a “road to nowhere”.’ She also blames school for instilling in Anna a fear of doing the wrong thing, which Judith sees as entrenched.

Anna’s work

Anna works at an animal rescue centre run by a national charity, helping to care for rescued feral and abused cats. She chose the role after observing volunteers in the cat enclosures on an open day. Judith did the brokering and taught Anna, with PA support, to get through the training programme, which Anna described as ‘very difficult’.

Anna’s work is socialising the cats, work that staff describe as important but for which they have little time. At the start of this study, Anna had been working about half a day a week over four years, depending on the number and needs of the cats. At the time of recruitment (before lockdown) she was attending less than she wanted to, due to problems in funding (the size of her personal budget allocation) and in finding congenial PA support.

The work environment

The animal rescue centre is in a greenbelt location, with fields around, and houses the animal pens, offices and a shop. Anna is driven there by her PA. The cat section comprises a shared staffroom with a communication board and sinks (see Figure 6.1). One room has a bank of washing machines, and another is for grooming tools and cat carriers. The main section is a corridor with the cat pens offset. Cats rest in raised sleeping areas behind glass, and can descend to ground level where there are toys, scratching posts and a chair. A closed staff-only section accommodates the more vulnerable animals. Pens are labelled with a name, character and care instructions, with a traffic-light system for handling (i.e., red = do not handle). Animals stay at the centre until adopted.

Figure 6-1 Video still: Anna at the staff communication board with Maureen.

There is a small core of paid staff and long-term volunteers. Work experience students and their supervisors come for placements, making it a busy environment. Pre-lockdown, the centre was open to the public on certain days of the week.

Covid-19

Volunteers at the centre were stood down for lockdown from March 2020 until March 2021. Anna stayed in touch through the website, which has videos of the resident cats, and through a member of staff who walks the family dog. Anna enjoyed having time with her parents. She received some provision from the day centre via Zoom.

Family and professional support

Judith teaches part time, to have time with Anna, and is a committed advocate for her. She acts as an unofficial autism ‘ambassador’, using her experience to shape her teaching practice (‘I never tell them they must look at me when I’m talking’) and to contribute to the National Autistic Society website, where she gives a strong message of accepting difference (‘Don't try to change autistic people’).

Anna’s day service is described as personalised, aiming to promote ‘independence as far as possible’ in the community. Most activities take place at the centre’s premises (craft, gardening), supplemented with visits with staff to community settings (e.g., pubs). To ensure continued funding the staff would like Anna to attend full time. Judith feels pressure to concede, but is reluctant to commit to so much ‘institutionalisation’ and to forego other activities. She has no expectation or wish for Anna to find paid work, describing it as something that Anna dreads (‘She’s terrified what that would entail – having, you know… just being stuck somewhere she doesn't know and not knowing what to do’).

Judith is weary and disillusioned with local authority support and has battled over Anna’s budget. She feels that the professionals who assess her do not have the expertise or empathy to understand her needs. In reviews of her care plan the assessors have suggested that she should attend the cattery by taxi without PA support, although Anna, her mother and the Centre staff all agree that she needs reassurance and support.

Anna’s PAs are supplied by a local agency. For the first two filming sessions she was accompanied by Lynn, who has taken on care work since her children left home. Lynn is responsive to Anna and companionable. They play an animal-spotting game in the car on the way to the centre. She shows interest in the cats, and she does not make suggestions or try to lead.

Prior to the study, a PA had been delivering Anna then spending the remaining time at the centre talking on her mobile phone. Other volunteers took up the slack, as one explained:

> Sue Elle, she used to get so cross about this because we're only volunteers, but we used to feel that it was so unfair to Anna. And so, one of us would go with her to make sure she was alright.… Even though she's more than capable of doing it herself. But she feels more comfortable when there's someone there with her. Yes. Just sort of as backup, really. She's pushed to know, you know, ‘Am I doing this right? Is this the right way?’

Judith complained, and parted ways with the agency. For this reason, and because she likes doing it, for one of the three filming sessions Judith took on the PA role at the centre. Commenting later, and still acting as PA, she struggled to balance Anna’s interests and her own doubts about the relational quality of support available:

> There will come a time when I look for a PA because I, although I love it, I feel I should withdraw so that she has the opportunity to work with someone else. But it’ll just be somebody worthwhile.… Somebody who just says, ‘Oh, you can go in by yourself’ and all that, is not invested in her, not valuing her as a person.

Anna’s supervisor (Claire) and a long-term volunteer (Maureen) took part in video-supported interviews. They showed warmth, commitment to her participation and an interest in extending her role. Anna avoids any engagement with the work experience people, and vice versa.

Film content

Filming took place on three occasions. Anna asked to be shown using the cat enclosure keys, which I think she sees as recognising her role within the centre.

Film session 1 (February 2020): At the rescue centre Anna signs in and collects keys. She checks the staff communication board for the ‘Talk to’ column, to select which cats to visit. She chooses the first cat to visit, enters and sits in the pen, waiting for the cat to come. It climbs onto her, kneads her lap and settles down. Anna talks to it, stroking and showing toys. She leaves and locks the pen, returns to the staff area for handwashing, and records her visit on the board.

Anna plays to me and/or the camera, showing the cats through the glass. In her whisper voice she gives an informed commentary on their needs and characters to me and to Lynn. As she has not passed the training Lynn is not allowed to enter pens but reads out the cat information and talks to staff. There are conspiratorial moments when they laugh together about the cat names. She takes a straightforward view of the arrangements — it is a ‘nice hobby’ (when they see it on film, Judith and the centre staff separately take offence at this characterisation).

Anna visits the cats. A large cat, Keanu, goes down the ramp to her directly she enters and gets on her lap, nuzzling and sniffing. Anna talks very quietly (she says she was saying, ‘It’s all right, it’s all right’). This cat is quite clingy and does not want Anna to leave.

The third cat is nervous. Anna watches and waits for it (I later labelled this clip ‘Self-controlled and responsive’). Later she visits a cat who does not emerge from its sleeping area – she waits and calls it, offers toys, but eventually accepts defeat. Lynn points out that it has just been chipped.

As we leave, Anna looks through the glass door at Keanu. He comes over, stands up at the door and meows. As she watches, he launches himself belly-flat onto the glass of the door where she is standing, and then slides down. It seems like a vivid illustration of her value to the cats.

There is conversation about cats. Anna tells me that someone reserved a cat but failed to pick it up. She has talked with staff by phone, so knows which cats have moved to new homes and which are off limits. She explains that some cats are ‘feisty’ and not to be visited. I comment on how thin one cat is; Anna answers, ‘It has an infection’.

Film session 2: The session proceeds similarly to the first visit, but there are more people, including a group of work experience pupils and their supervisor. In the staffroom Anna talks to Maureen, a long-term volunteer. Between cats she interacts with the supervisor, asking for access to kittens in the staff-only area, which she gets. As I know that she does not take on other volunteer duties, such as cleaning pens and bedding, I ask about the bank of washing machines. She says matter-of-factly, ‘I don’t know how to do that’, indicating her lack of interest.

Film session 3: For the final video session there is no PA, and Judith stands in. She can enter the pens because she took the training with Anna. Unlike Lynn, Judith tries to move Anna’s activities forward, for example by grooming a long-haired cat. She tries to influence what happens: ‘Why don’t you…?’ Anna complies with the grooming, but also wanders off to see a litter of kittens, ignoring Judith’s other suggestions.

Anna asks confidently for permission to visit more kittens (Figure 6.2). The supervisor gives advice, saying that the kittens are nervous and may not want to be handled. Anna sits patiently and entices first one, then all three, down the ramp. The boldest is happy to be handled.

Participation and learning overview

Anna learnt to follow routine hygiene procedures, and to consult and add to the shared communication board (Figure 6.1). Her mother described the discipline and the additional challenges that arise, such as when Anna had to decide whether to risk passing cat flu to her own pets:

> she has to remember the procedures to not forget them and do them correctly. Yes. And sort of follow, they're not rules, but correct procedures. Yeah. So, she learnt that and kept it up. And even things like not going to see the kittens who had cat flu, she's got to think hard and fast, whether she wants to do that. So, she's got a lot of decision-making. Yeah, she has. And she is really exhausted when she comes home.

She has built up extensive knowledge from experiences and conversations at the centre, and from the website and notices. She comments knowledgeably on cat illnesses and treatments and their after-effects, using specialist terms like ‘feral’ and ‘neutered’, and uses the staff jargon (cats who are adopted are said to be ‘going home’).

Anna identifies with regular co-workers, as people with whom she has a common interest, and this is reciprocated by staff, who value her skills. Co-workers describe her approach as ‘magical’:

> Every [pen] that she goes in, well, she'll sit there quite calmly and patiently, and they respond to her. And it's good for the cats, because some of them come from such appalling backgrounds. They find that this gentle human being isn't it going to hurt me… and it brings them out.

This approach contrasts with Anna’s handling of the cats at home, where she is demanding (for example, holding them against their will). I see her as having adapted to the behavioural expectations at work. She is aware of the two modes, explaining: ‘The difference is that they're not my cats... I'm used to my cats, and they’re used to me. At work you have to] let them kind of wait to get to know you.’

Figure 6-2 Video still: Anna asking for permission to visit kittens in the staff-only section

The social and communication side of being at work challenges Anna, but the intrinsic reward, such as the chance to interact with kittens, provides the motivation to be there and to interact with the staff. She knows that staff trust and value her. Communication has been built gradually, as described by Maureen (supervisor):

> She is still very, very quiet, but the first year or so she wouldn't talk to me.… I remember the first day that she spoke to me, I was like, you know – ‘Ooh, that's amazing!’

Anna is following a strong personal interest, practising and developing related skills and learning from others. She discusses with me her job in relation to human behaviour in the social world, talking about neglect and what happens when an owner dies (Figure 6.3). She manages the social situations that she finds difficult, such as navigating around the work experience students, and avoids outside work. Staff talk about her warmly and with respect, and are knowledgeable about her strengths and what she finds difficult. They want to invest in her and extend her participation: ‘You sort of feel it's her vocation, don't you? This is what she can do and what she is really good at.’

Figure 6-3 Video still: Anna taking a break during her video-supported interview

Having a PA is enabling Anna to work, but the development and learning were extended primarily by Anna’s drive and by her mother. Judith notes the difference in Anna’s position at the cattery compared to her day centre. The day centre aims to teach or shape its clients: as Judith explains, it is ‘fabulous, but they're sort of forming them all, to sort of improve their social skills’, while the cattery represents Anna’s own priorities: ‘But this is meaningful, this is what she really loves.’ Anna mentions often that staff trust her. Judith sees the shared values as key (‘They’re all obsessed with cats’) and that the staff ‘seem to be people who “get” her… who share that love of animals, see that she's one of them’.

6.2 Ciaran

Ciaran, who works in a community food shop, is in his mid-twenties, tall, energetic and sociable. His PA describes him as ‘a man who loves to help…. He's a very people person. Yeah, definitely.’ He lives with his mother, Tricia, and his sister in a medium-sized town. I meet him with his PA, Katie. He is friendly and co-operative. Katie describes him as helpful and keen to make himself useful. He does not see himself as a disabled person, according to his mother; according to his PA, he wants to be in the mainstream, ‘and part of that is working’.

He has excellent systemising skills[3] and is happy to use them. His mother describes how this worked when he was looking after an aisle in a sports shop:

> very clearly the job of every [shop name] worker is to keep that aisle clear and clean and tidy, and his job is no different. There was no differentiation.… So, he loved the fact that… the pride in doing a job well and also seeing himself as equally valued and no different.

Ciaran’s speech is fast and staccato. He uses phrases, such as saying ‘Oh dear’ when asked if he was sad that a co-worker left. He often speaks elliptically, so that his meaning is clear to people who know him well yet not to outsiders. I mention that Tricia said that he was good at folding clothes at the sports store. He answers, ‘That was hard one’, responding not to the folding but to the loss of the job. Katie often gives him response choices, ‘Do you think this one, this one or this one?’ She teases him as a means of correction, ‘We don’t take Charlie for a walk – we take Charlie’s dog! I’m going to tell her you said you were taking her for a walk!’

Education and occupations

Ciaran attended a mainstream comprehensive (‘Managed very well, thank you very much. Knew the boundaries and rules very well’: Tricia) and took two GCSEs, which were graded although he did not pass. The transition to further education was not successful. Tricia describes the end of school as like falling off a cliff edge. Ciaran spent a brief period at college. Tricia says that the college was teaching him to see himself as exempt from the rules that applied to others: ‘What he learned at college was if I behave inappropriately, he gets away with it... He's autistic, you're right. But he also knows the rules. Being autistic doesn't mean he can't learn rules.’ Instead, she found him unpaid work experience in business administration, and he attended adult education classes with the Workers Education Association, where he had support to structure his time (i.e., support to be in the right place at the right time). He has been on a waiting list for supported employment for several years, but this has not materialised.

Ciaran’s work

At the time of recruitment Ciaran had three part-time jobs in addition to the work that was filmed. Two of these were paid; all were PA supported:

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[3] I refer here to Baron-Cohen’s description of systematising skills as higher among autistic people (see Greenberg *et al.*, 2018), without intending to endorse the systematising/empathising theory of autism.

1. Sports store, national chain: Ciaran worked on a contract for eight hours per week in two four-hour shifts. The tasks were folding garments, keeping stock in size order and cleaning floors. He obtained the work through personal contacts, as a manager was a friend of a former PA.
2. Family Centre, for two hours, one day a week. This involved hoovering, clearing up after a toddler group and preparing chairs for the next group.
3. Charity shop, one day per week, tidying, ordering stock and sorting sizes. This was a voluntary job obtained through a personal contact of the PA, who knew that the charity had recently committed to an inclusive volunteering programme.

These jobs were lost during the Covid lockdowns, leaving only the community food co-operative where I had begun filming. Ciaran's mother had found and negotiated this placement. At the outset he had worked two shifts per week (half days), but fewer during lockdown when there was high demand for shifts from members. As a member of the co-operative, he works on equal terms with other members; that is, without pay but with shop discounts. Tasks are various: stocking shelves; cleaning the floors and dispensers; helping at the cash register; and sorting the recycling.

The work environment

The community co-op is located in the shopping area of the suburbs of a large town in the southeast of England. The shop sells fresh and dried food, baked goods and cleaning products, including low-cost basics. It is staffed by volunteers, following an online rota system. It has a strong co-operative and 'green' ethic. The shop is a community hub with a dedicated clientele and regular customers interested in ethical consumption.

Covid-19

Ciaran lost three of his four jobs around the first lockdown. Initially he was furloughed from the sports store, then made redundant. He resumed the charity shop work briefly, but was seen by his PA taking money from the cash register, and was removed from tasks involving cash.

During lockdown, Ciaran's sister had a mental health crisis. The distress and disruption of this and the loss of his jobs affected Ciaran profoundly. The difference in his confidence between the first filming visit (shortly before lockdown) and the last, early in 2022, is noticeable. The community shop stayed open and recognised a responsibility to give Ciaran work, '[they are] realising that it's a two-way street and actually people need to come to work as much as they are needed at work' (Tricia). Tricia saw the work as a lifeline for Ciaran at this time.

Family and professional support

Tricia is a powerful advocate for her two adopted children, who have diagnoses of autism and intellectual disability. She is a former civil servant and a member of the team supporting the White Paper 'Valuing People' (2001), and has extensive knowledge about personalisation and how the benefits system can be used to support her children. She is self-employed as a trainer and consultant, following her commitment to both inclusion and 'gloriously ordinary lives'.[4]

Tricia provides training for the PAs whom she employs. She explained the strong 'values' with which she leads: 'Like, you know, if [my daughter] comes out dressed in her socks tucked into her jeans looking like a dork, you wouldn't let your mate do that, would you? Go "Mate – your socks!?" Yeah.' Tricia sees work with PA support as offering the workplace a 'buy one, get one free' deal: Ciaran and his PA come as a package, with benefits on both sides, which she expects will help to persuade employers to take him on.

Trisha was well placed to use the resource is of personalisation knowledgably and creatively. During lockdown she had planned the future shape of support for them:

> My argument for the local authority is I need to have some experts. So, I need to have [expert job coach] around employments. I've got an autistic man, who is brilliant, who's advising us around autism issues, and I want to have somebody helping me with that around [my daughter's] educational stuff... then potentially we've got going a temporary bit around cooking, because the team needs some support around cooking and so we got someone who's a creative cook coming in to do some cooking stuff. So that's how I've used my budget.

Ciaran is supported at the food co-operative by his PA, Katie, who is also in her twenties. They function as a closely co-ordinated mini team, as if demonstrating the meaning of relational agency. Katie is attentive to the tasks and to Ciaran, but she does not take the lead. From the outside, it is not easy to see who is helping whom. At the till they are smoothly coordinated, working side by side (see Figure 6.4). Katie sometimes narrates, prompting and adding information: 'Right, so we'll weigh these, then they can go in the bag...' She fills in gaps for Ciaran ('Those are leeks, not celery'), in a peer-to-peer rather than teacherly style. They manage issues between them as they arise. The customers are not held up, and do not witness any lesson-giving.

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[4] This is a key phrase on her website.

Figure 6-4 Video still: Ciaran and Katie, having just resolved a glitch with the till

Katie also spends time outside of work acting as PA to Ciaran. They do crafts together, climbing and cooking dinner for themselves. She describes him as one of her favourite people in the world (‘No one can put a smile on my face like this man’). She sees an intimate, mutual understanding as the basis of her support: ‘Without speaking, I can tell when the till is getting too busy for him, right, and I need to step in a bit more, or, because he's got overwhelmed with the change [cash] and, once he's overwhelmed, he can't count to five.… He knows when he doesn't need me….’

The work that Katie undertakes is sometimes diplomatically tricky, such as the occasion when Ciaran took money from the charity shop cash register or when a trial of working unsupported went wrong. She works with Ciaran on job applications and interviews, acting as agent and negotiating on his behalf. The interview format does not play to his strengths: ‘Because he doesn't always use words to express everything he's capable of, they don’t see him as being as capable as he is.’ Seeking paid employment, they met resistance to the idea of Ciaran having support. Tricia’s idea of ‘buy one, get one free’ had worked for the voluntary positions, but employers interpreted it as evidence of incompetence. Her efforts to negotiate her role by framing it as ‘a translator’ were unsuccessful. She summarised the situation, post-pandemic: ‘We shouldn't be struggling. But sadly, we are. Yeah.’

Figure 6-5 Video still: Ciaran cleaning the dispensers

Film content

Due to pandemic-related lockdowns, I filmed at the food co-operative on only two occasions, before and after lockdowns, separated by 18 months. Ciaran was enthusiastic about being filmed. In the film planning meeting he had asked me to show him in the staffroom of the sport store, with his photograph on the staff noticeboard. At this time, he had only just started at the community food store and had no particular wish other than to be shown ‘working, being useful’.

Filming Day 1, March 2020, just before lockdowns

I meet Ciaran and Katie at the shop, where they have travelled by scooter. I film Ciaran and Katie first behind the counter at the cash register. The place is busy with short queues, and they work together fluently. He is active and engaged. Katie answers some customer questions that Ciaran has not understood, but also nudges him to ask customers if they would like any of the bakery items that need to be sold. I notice that one or two people address Katie in preference to him, but this does not seem to bother him.

When the queue disappears, Katie suggests that Ciaran move onto tidying tasks. He asks which area he should tidy, then gets on with it alone. He tidies meticulously, pulling packages to the front and straightening the sides, looking at the camera every now and then. Asked by a member of staff, he also moves a heavy pile of metal baskets across the shop.

Filming Day 2

The second film session takes place after lockdown, 18 months after the first session. The family crisis and problems with consent to film connected with coronavirus have caused extensive delays.

Ciaran is not at the till but is sweeping, cleaning (Figure 6.5) and taking out recycling, using a checklist of tasks (see Figure 6.6). Katie is not sharing the tasks, as before, but instead is prompting and acting in a ‘quality control’ capacity. She asks him whether he wants to work on his own or with help. He hesitates, but sweeps around the back of the shop on his own, carefully. He washes around the dispensers with Katie checking and prompting. At the end of the session, he takes his completed jobs list to the supervisor, who talks through the jobs and thanks him (see Figure 6.7).

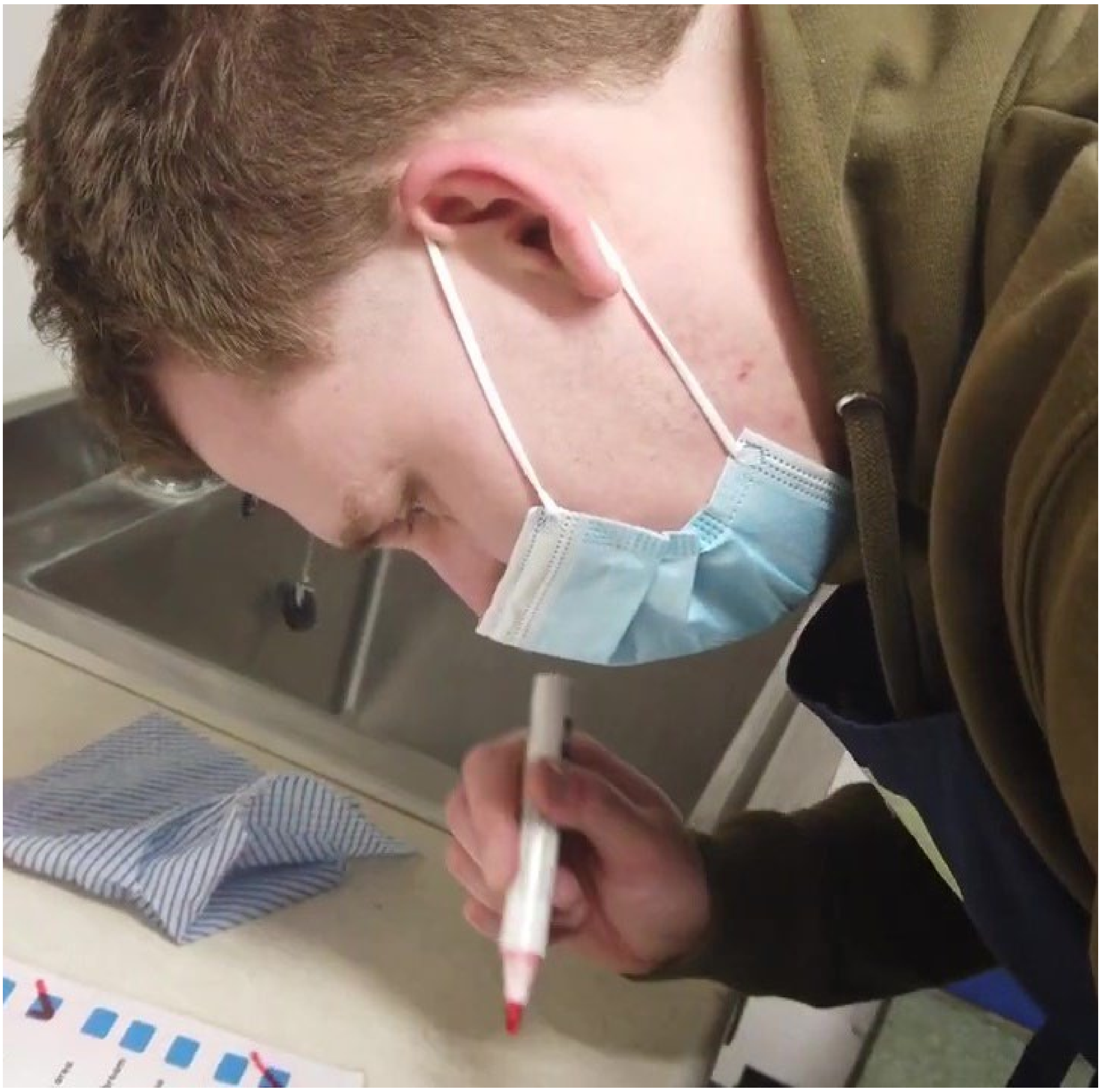

Figure 6-6 Video still: Ciaran checking off his list of tasks

Figure 6-7 Video still: Ciaran reporting back to Helga with his task list

Participation and learning overview

Ciaran’s work-related learning included learning to use the cash register, as filmed in session 1. He understood, according to Tricia, that operating a cash register is an important cultural role compared with others that he might be given:

> He’s dead proud of it […]. So, I think he's learned about being proud. He's also learned that it's a key skill, it's something that, you know, is important. There's something about doing something like that, so he's not just relegated to doing the jobs that ‘It's all right, you go and do that dear…’

The supervisor is keen to tell me that Ciaran’s work is useful and valued in the same way as that of others. The work relationship develops on that basis:

> He’s very much one of us and he doesn't get treated any differently. I personally value all our help, and I express that. From my point of view, it doesn't feel repetitive. I very much do mean it.

The supervisor describes the ‘give and take’ that occurs in the working relationship:

> We haven’t really changed things to accommodate him. It's a two-way sort of process, you could say it's a reactive process. When I notice something, I react. And I'm sure he does, too. So, we are accommodating all the time, and I'm sure he does accommodate us as well. The relationship changes all the time, it develops.

By the second film session Ciaran has lost his status at the cash register. The supervisor acknowledges and regrets the ‘demotion’. She is trying to accommodate his preferences, but the work situation takes precedence. She says:

> I know he would quite like to work on the till and… and that’s something he has done. But we've got a new EPOS system and it's, it's a little bit more difficult to fit in. And I do like to make sure that that he's got variety in what he does. Right. But there are things that… that are not so easy for him. And, well, one important bit is it's, uh, relating to customers, and that's a little — stops us from, from pushing that at the moment.

There is no linear ‘progress’ between filming session 1 and session 2, despite the length of time between them. In certain respects, Ciaran has lost ground, using more explicit props (the checklist) and doing lower-status tasks, yet he is happy to be there, he and Katie are companionable together and his work is valued.

6.3 Fiona

Fiona, a library assistant, is a woman in her late twenties whose immaculately plaited hair and precise style of speech reflect her fastidious character. She lives at home with her parents in the suburbs of a coastal city in the South East. Her older brother has left home. She presents as confident when we meet at her house: she gives a detailed account of her likes, dislikes and past experiences of work, including the problems that she has encountered. She thinks very systematically. She loves lists and has an excellent memory for information (as noted by her supervisor). In spite of her obvious skills and diligence she has a history of work placements that have broken down. Her sensitivity, her tendency to take offence and her blunt speaking – her ability to give offence – have made the placements difficult to sustain. Her parents referred several times to ‘rocket fuel’ driving her meltdowns. At one placement, they said, the people ‘didn't know how to deal with the problem. They were all, you know, they said if they spoke to her, rocket fuel was lit, and they didn't know how to bring her back down again’.

Fiona is keen to please her parents, her library supervisor and even me. She is interested in the research project (she has made a file with all the documents) and is very keen to be filmed. During lockdowns she texted regularly to say how much she was looking forward to it. Her parents say that they are hoping that seeing the film might help them to understand better what happens at work.

Education and occupations

Fiona attended a state special school for children with autism, intellectual disability and speech, language and communication needs. At 16 she went to a further education college for two years, taking courses at NVQ (National Vocational Qualification) Level 1 in Childcare, Social Care, and Health and Beauty. Through the local authority she received support from the employment team for about five years, in all, until they said that 'there was no more they could do for her, and they couldn't get her a job' (father). She had been working at a nursery, but she could not cope with the children, feeling that she was being bullied by them ('I find children quite difficult. Yeah. Because they wind people with disabilities up... that's the honest truth'). She had a two-year apprenticeship at the special school that she had attended but was not offered a job at the end of it: 'She was brilliant at the Makaton [signing], but she still couldn't deal with the youngsters' (mother).

Figure 6-8 Video still: Fiona checking shelves at the library

Fiona's work

Fiona works part time in a small library, reshelving and tidying the books (Figure 6.8). This work was set up by her parents at the suggestion of the employment team that library work might suit her. She is supported by a PA (Jon) from a local disability charity. Her parents believe that she is the only person being supported to work by this charity. She was already familiar with library systems when she started, and is able to classify efficiently and accurately. She finds the work absorbing and satisfying. Her PA identified her wish to contribute and to use her skills: ‘It does kind of meet her need for being resourceful and helpful, which I think, you know, she enjoys being someone that's providing help for people and doing something that she's capable of.’ He sees her as entering a ‘kind of state of flow’ while working, being positively immersed in the process. Asked how she feels when she is on her way to the library, Fiona says that she feels ‘excited’, and her parents report that she goes to bed early the night before, to be ready.

At the time of filming, she was doing two-hour shifts on a weekly basis. Her parents think that this is her maximum tolerance, in the current circumstances, but are ambivalent: ‘That's not enough, is it, per week? Well, she did start with three, but it was too much. The problem is that the library where she goes is not a big, busy library. And sometimes she would go in there and there would be a week's worth of books to put away, [sometimes] no books.’

Work environment

This branch library occupies a building dating to the 1970s, which Fiona can reach on foot in 10 minutes or less. There are small displays of local history objects and rooms set aside for community use. A group for autistic children meets there. The supervisor sits at the main desk, from where he can see the whole library.

Library use has been reduced by the pandemic, according to the supervisor, Barry. Barry says that she speaks to visitors sometimes, particularly to children, and he thinks that she finds them more approachable. Fiona asks them about their involvement in special events (Christmas plays, fireworks) and about Disney characters, one of her special interests. According to the PA these conversations can become difficult, as Fiona does not pick up on the signals to finish the conversation and can easily take offence.

Covid-19

All Fiona’s activities outside the home stopped during the Covid lockdowns (‘She’s had no contact since the start of the pandemic in March with anybody other than Mum and Dad’, they said, months later). She was anxious and preoccupied with the pandemic. Specifically, she was worried about catching the virus. Her film shows her working in the library in her coat, carrying her bag:

> AC: You don't want to leave it in the staffroom, is that right?
>
> Fiona: Right. In case people… because I'm worried about Covid getting on it.

During lockdown she had been at home, ‘drawing, reading books. Watch my favourite TV shows and films and going out for walks. And I tried my best to keep everybody safe.’

> AC*:* And did you miss going to the library?
>
> Fiona**:** Yes, I do. Totally, yes.

For Fiona, returning to work at the end of lockdown was an occasion that she had anticipated with excitement.

Family and professional support

Fiona’s mother, Nicola, is a teacher and her father, Phil, a retired police officer who has acted as parent lead for a local branch of the National Autistic Society. Fiona’s parents are frustrated about the number of unsuccessful work placements, through employment support provision, that she has had, none of which were paid or adequately supported. Before her library work, Fiona had been working at a charity shop on a placement set up by the local employment team, but this did not match her interests. Within weeks of her father’s retirement, she began to refuse to go, knowing that he would be at home. The employment team withdrew, leaving Fiona’s parents feeling abandoned: ‘It was, like, “We can't help you anymore. Over to you.” And there wasn't much – we’d run out of ideas. We've exhausted all these different…. There was nothing. We can't think of anything else.’

Fiona’s parents struggle to make sense of her success with her tasks, such as sorting the charity shop’s bookshelves in alphabetical order and cataloguing toys, against her social difficulties. To quote her father, ‘She asked [a woman] whether she was an alien because she was dressed in quite distinctive clothing. Another woman, another charity shop, she shouted across, ‘I know why you’re ratty, you've got PMT.’ They see her as close to work, yet not close: ‘She won't be able to do a whole job, but she might be able to do a part. Yes. Yes. But there isn't such a job out there.’

Fiona’s parents expressed frustration at the contrast between the expectation of employment embedded in the benefits system and the failures of placements in practice. Following a Work Capability assessment[5] Fiona was placed in the activation group, with a responsibility to seek work. Her parents took this decision to a tribunal, but lost: ‘And, well, if you could have seen her after the tribunal said she could earn money. She was over the moon. “Yippee I can get a job.” …

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[5] To determine eligibility for Employment Support Allowance, a benefit for people with a disability that affects how much they can work.

She went absolutely.... And we sat there, and we thought [about the panel], "What are you talking about, you know? Grow up." She can do things, there's no doubt about that. But when an employer looks at her, they look at what she can't do, not what she can do, and they're not looking at what jobs they can give her, they're looking at what she can't do within the jobs they've got'.

Figure 6-9 Video still: Fiona in the library, an environment where she is comfortable and can deploy her 'library brain'

Fiona rarely leaves the house, and her social contact is limited. Her work has a basic value, whereby 'This is something that is not at home. Yes. Not with mom and dad. And that's very important.'

Fiona's parents are highly frustrated at the loss of information and continuity now the social workers and local authority representatives have changed. Having PA support was positive, but the Pas were supplied by a local charity thus were available only for set contact hours, and this left no opportunity to share information: 'If we were able to brief a PA on how to deal with her…. I mean, we can teach them in half an hour what will take them the next five years to learn…' The parents are reluctant to employ a PA directly (i.e., not through an agency), citing the administrative burden of running a payroll. They felt that PAs had been too passive ('You've got to have them instigating stuff').

The PA supporting Fiona at the time of filming did indeed appear to play a passive role. He himself seemed unclear as to his function, suggesting at first that it was a matter of reassurance and of her expectations:

> I mean, I think she's unlikely to want any sort of change in her situation. Yeah. So, so I do think part of that is because she just would feel uncomfortable not having the reassurance of someone being there, like she always has. ’Cause that's how things always are for her. Like making that leap to doing it on her own, I think she would find that very difficult.

As the discussion proceeds, he concedes other reasons: ‘if she did have a difficult interaction, I could see how quite a small thing could end up escalating and she would never want to go back to the library.’ In Fiona’s case, PA support enabled her to attend work without fear, yet did not extend to developing her participation, whether at the library or elsewhere (Figure 6.9). Fiona showed her plans for a learning disability choir to her PA and to staff at the charity that supports her, looking for help to further the project, but they were uninterested in helping her to pursue the plans.

Figure 6-10 Video still: Fiona working: an understanding of classification systems that she was not fully able to deploy

Film content

I filmed Fiona at the library on two occasions. As there was little variation in her activities, I decided against making a third visit.

Film session 1:

I meet Fiona with her PA at the library. On entering she greets me but not the library supervisor who is in view. She washes her hands but keeps her coat and bag. She moves to the bookcases and tidies systematically, moving from shelf to shelf and from case to case (Figure 6.10). She focuses exclusively on what she is doing, not looking at the camera or away from her task. At one point she notices a mis-shelved book and moves it to its rightful location. The PA sits in the background at a library desk, appearing on film only at the beginning and end of the session. There are no interactions with others until she is finished. As a result, the film shows her working effectively and conscientiously, but it is repetitive.

At the end, Fiona wants to share with me the plan that she has made for the disability choir: ‘The Fiona H… Choralistic Society’. I have seen it before, but she has revised it. She reads from sheets of colour-coded handwriting, with listed options for venue, types of disability, types of musical support, types of snack, and so on. While this section of film is not directly related to work, it reflects her character, aspirations and skills quite vividly.

Film session 2: This session is very similar to the first. Fiona picks up where she had left last time and proceeds at quite a pace. As I had covered this content in the previous session, this time as she works, I ask questions about her aspirations and whether she would like to do work with more variety or challenge. On a previous visit we had discussed whether she might like to work in a university, organising a book or document collection. The topic made her nervous, and she later told me that she did not like the section of film containing this discussion. The library supervisor is careful to thank Fiona at the end of the session. She is pleased but does not engage further.

6.4 Greg

Figure 6-11 Greg posing by the village ‘Love where you live’ sign

Greg, a community litter-picker, was in his late twenties at the start of this study, living in a self-contained annex at his parents’ house near the centre of a rural village or small town in the South West. At our first meeting he shows me the community awards and commendations that he has received for his litter-picking work. He is pleased to show these acknowledgements, but is also preoccupied with his DJ equipment and DVD collection. He talks humorously about his weight, going to Weightwatchers and not liking cooking. He is amiable and chatty, and I can see that his community role gives him a profile and outlet for these skills.

Greg is familiar with the idea of being a role model. He shows me a video featuring him learning independent living skills. I think he likes the idea of extending this role through this study. He is not specific about what he wants filming, and just wants me to follow him as he works.

Greg’s community-minded approach has been shaped by his mother’s beliefs and practices. She has taught Greg to greet everyone he meets as he works. She contrasts this ‘community’ activity with ‘sheltered’ learning disability environments: ‘You could have had Greg with learning disabilities doing teas and coffees in the learning disability day service. Yeah. Or is it a mainstream voluntary setting which gives you that exposure that I keep talking about? But yeah, I'm not very keen on what I call sheltered work placements.’

Education and occupations

Greg attended a mainstream primary and secondary school. His mother was active in keeping staff and parents ‘on side’ through difficulties, including protests. He attends some community activities unsupported, including Weightwatchers, but does not like to leave the village environment where he is known and knows people. He has PA support for non-work activities, including cooking and cleaning.

The work

Greg is a regular (every day) litter-picker in his local village centre. Rachel thinks that he has followed her lead in choosing to do it, and that he wanted to experience the social rewards she was receiving, ‘I was litter-picking and people were saying, you know, ‘Thank you for that’, right? And [he thought] ‘I want some of that’.

Before lockdown, Greg had several voluntary roles, including an informal caring role and an official support job. He also walks other people’s dogs with his father. His main role is litter-picking in his local village. He follows set routes daily, walking several miles and filling bin bags of litter each day. Rachel has linked his activities to the Two-Minute Foundation (https://www.2minute.org/), a registered charity devoted to 'cleaning up the planet' through voluntary beach and street cleans (Figure 6.11). He wears a hi-vis jacket and T-shirt with the ‘Two-minute litter-pick' logos, and is recognised and often thanked as does his round. A couple of times a year he leads community litter-picks linked to the foundation, and sees them as a highlight of the year.

The work environment

The ‘village’ is a small rural town, with a population of less than 5,000 and a historic market square. Greg’s rounds take in the shopping streets, pubs, car parks, a play area with swings, the fire station and a large recreation ground (Figure 6.12). There are people circulating, and he greets everyone he sees. The work is demanding. He picks up large amounts of litter in his bag and is conscientious about small and difficult to pick items. He stops to chat with people whom he knows from Weightwatchers, bingo and chapel.

Figure 6-12 Video still: Greg taking a break upon finishing the playing fields

Covid-19

During lockdown in 2020 Greg lost his voluntary role at the blood donor service and his deejaying. After a short break his litter-picking resumed. As with Ciaran, the work seemed to act as a lifeline during this period, but over lockdown he had become socially isolated and lost motivation, not just for litter-picking but in general. He experienced mental health difficulties and saw health professionals specifically about motivation. Greg's brother, who is also autistic, had significant mental health difficulties during lockdown. At the final filming session and during the video review visit, Greg was noticeably lower in mood than he had been when I first met him.

Family and professional support

Greg's mother Rachel works in the field of learning disability, and is a powerful supporter and advocate for his interests. As the mother of two autistic young adults, she regards herself as an 'expert by experience', and is an active campaigner with a particular interest in self-directed support. She has worked in voluntary and paid capacities as a speaker for local and national disability organisations on the topic of working in partnership with families. One of her interests is to reduce the size of Greg's personal budget by using community resources that link him to local groups, such as Weightwatchers.

Rachel has structured and organised Greg's litter-picking. She advertises and supports the role with a community Facebook page and merchandise – T-shirts, pickers, and so on: 'The Facebook page has really kind of lifted his profile. Yes. He's very proud.' They had attracted another volunteer litter-picker this way and, Rachel says, he felt rewarded: 'You know, "I did that…', she saw us or me, and now she wants to [do it]"' (Rachel). She protects his role, too – she did not want community service pickers competing with him, and was concerned that people might interpret his activity as being a penalty. Rachel organises the community litter-pick days in which Greg plays a leading role, and of which he has said, 'Best day of my life, that is'. These are supported by local businesses, and the local pub offers free drinks to participants.

Greg began litter-picking in imitation of his mother, and often does it with her support. For part of one filming session, he was litter-picking alone with me after his mother had run through a checklist of prompts (she was also anxious about the traffic). He has had PAs from the local community, including his aunt. By the time of my final visit, Greg has 'fired' (Rachel's word) his aunt, because she 'nagged' him (his word): 'For four years. Always ear-bashing me, make sure you do this, make sure you do that… wear clean clothing.'

He discussed this issue during a filming session, objecting to her assumption that he needed help. The PA supporting Greg at the time of filming was Mary, previously a teaching assistant supporting people with intellectual and developmental disabilities. She struggled physically to keep up with him, and in her interview, she focused on his difficulties with motivation (to get up, to attend social events) and showed the signs of finding his low mood difficult to cope with. Mary supported Greg at this time by supplying prompts to initiate and plan the routes.

Greg had frequent interactions with people in the community but had no co-workers as such. The film shows him greeting other men with whom he identifies, such as firemen and refuse collectors, whom he sees as colleagues (Figure 6.13).

Figure 6-13 Video still: Greg greeting a skip lorry

Film content

I filmed Greg on three occasions: two mornings litter-picks and one afternoon session. I also filmed him dog-walking with his father, but he was less engaged with this activity, and I decided to focus on the litter-picking. Greg has been filmed in the past by his mother, and is pleased to cooperate and to be a role model.

Film Day 1: March 2020

Greg starts out unloading his equipment in a car park. He does a mock protest as his mother goes through a checklist of ‘Have you got?’ questions. He starts by going round the car park and back of a pub. He greets everyone he sees with at least a ‘Good morning’. He gets a warm response from most people. One person replies, then points out something for him to pick up. A shop owner comes out to thank him for retrieving something from her display that had blown away.

As we walk, he gives a running commentary on the kinds of litter he encounters and who has left it. He mentions the mess around a takeaway and the litter-dropping habits of schoolchildren. I think that he would make a great ambassador, so say that he could go into school and talk to them. He is enthusiastic, and is comfortable with the idea of being a leader in this area.

As he is telling me that someone should not have dropped the paper tissue that he is picking, a passer-by jokes, ‘Wasn’t me... promise!’ At another point, he runs into a lady he goes to bingo with. She is pleased to see him, and they chat humorously.

Filming day 2

The second occasion continues very much as the first. He continues to explain to me how it works: he does not do driveways (‘some people get aggressive’); he wears the high-vis jacket so that people know why he is there; the ‘sweepers’ (refuse collectors) are men he works with. Down a dark alley, he says 'I love this job, I really do...'.

Filming day 3

The final occasion is after lockdown. Mary is with him, walking and picking on the other side of the road, but she has a leg injury and gives up quite quickly, leaving him with me. It is not evident by observation that she is needed. He grumbles about the litter: ‘All this mess – they shouldn't drop it.' Nevertheless, he is conscientious, spotting a bit of packaging across the road: ‘I missed that bit.’ He is happy to clear around the fire station, as he considers the firemen to be co-workers. He waves his litter-picker and greets the driver of a lorry with a skip, whom he interprets as another colleague. There are humorous moments. In the car park, he finds a pair of high-heeled shoes, and mentions that he often finds ‘ladies’ things’. He sings a song – ‘Hot cross buns’, as he’s been talking to a man eating a scone. When he has been particularly conscientious in digging litter out of a hedge he starts to dance and laugh, because there is also a £20 note. He gives it to me to look after then carries right on working, with a further running narrative about his finds.

Participation and learning overview

Greg has been litter-picking in the community for years, and has accumulated extensive knowledge about the habits of the various demographic groups in different locations. He has built up an expert practice and sees himself as serving an important function. He is not a mechanical tidier, but connects his activities to questions of community and social responsibility, qualities that also show in his greetings. His presence is a visible reminder to the community of his contribution. When he was caught eating cakes without making a payment in the honesty box, I was able to point out to his mother that this was a small detail, in the shop owner's knowledge of him, as he litter-picks regularly past the shop.

Rachel speaks about the difference between the kind of social learning that took place at school and college and what happens out in the community: 'You can go to college, and you can learn through role play interactions and things like that. But until you're out there actually living these interactions…' (there is no impact). She speaks of the various levels of adjustment to the needs of people with intellectual and developmental disabilities in the community compared to at school. At school, Rachel says, allowances were routinely made, with the attitude, 'Oh, you can't cope with that. Therefore, we've got to stop doing it'. In the community, she says, 'that isn't going to happen':

> So, when he first came out into the community, he struggled, because although he had a meltdown because of the way that the library door was moving, all that noise of people in the different shops, in the library, they weren't necessarily going to adjust for him.... Then he'd go out again. Nothing. They're not adjusting for me. And so, his tolerance gradually got better and better and better.

Greg has learnt to modify his behaviour in other ways, and Rachel sees this as a reciprocal process:

> Dropping litter used to infuriate him. He couldn't get his head around. 'Why do people persistently, after we've been round, drop the litter again?' So, he'd want to put notices up and tell people off, and things like that. And he will tell people that are walking past… if I was a turtle, I would have gone into my shell. When he very vocally tells other people that this is not acceptable behaviour and gives them an absolute right lecture.... Majority take it in a really great, good way. And I don't know, maybe in their own way, the community themselves learn from him. Yeah. So, but also, he has to learn from, or he learns in a slow way because of the repetition, if you like, about the different members of the public, that what is acceptable to speak out about and what is, we might think it, but we don't say, though yeah, maybe we should.

Greg does not collaborate with others directly. He identifies with other key male workers, particularly firemen and refuse collectors, seeing himself as serving in the same sort of capacity, and this relationship is significant to him. As a truck passes, he tells me:

> That's my work mates – that's who I'm doing it for, for them. Keep it in the film because that's important, that is.

Greg has acquired extensive knowledge about who uses the public spaces that he clears, and for what. Paying attention to these things, he has begun to think about questions of individual and collective responsibility. He explains that it is important for him to clear the firemen’s area (‘They’re busy fighting fires and that’), but questions why other people drop litter (‘I’m not their slave, am I?’). He thinks of himself raising awareness about various issues that touch on his activities, such as the council’s hedge-cutting and bin-emptying responsibilities. Rachel says: ‘So if he finds these little drug capsule things, he'll pick it up. And anyone that's around: “Look, teenagers are doing...” Right. And he kind of reports back at the end, and he'll say to me about it.’ Once or twice, they have photographed his finds:

> We report it to the council, as did quite a few other members of the public... dog-walkers, whatever, and we are worried about them treading on needles and things like that.

Developing a community framework for the litter-picking and raising Gregg’s profile in the community were undertaken by Rachel, and by comparison the PA role is relatively small. Significantly, it does enable the practice to be sustained on a daily basis without Rachel's full-time commitment.

6.5 James

James, a groundsman and litter-picker, is in his early twenties and lives with his parents on a housing estate in a Derbyshire town close to Sheffield. His mother, Noreen, is a teacher and former SENCO (Special Educational Need Coordinator). James is the youngest and only adopted member of the family of five. His elder brother is also autistic. He is friendly and sociable, greeting people with a smile and a thumbs up.

James has high support needs for personal care as well support. He does not have speech and uses a photographic system of communication devised by Noreen. When he is going somewhere, she shows him a photograph of the destination and purpose (café, hot drink). Teachers and social care staff sometimes offer him choices using photographs, for example to select food, but Noreen does not believe that he is able to choose purposefully. His face is expressive, and he is communicative in his behaviour. During filming, as I talked to his PA, who stood in the middle, he inserted himself between the two of us, apparently to be better included. At the end of the day, when we returned to the office base, he found and returned to me a black bag that I had left in a corner. The fact that he had noticed it and recognised that I needed it suggest that he is more aware and intentional than is immediately obvious.

The family are active walkers in the local countryside and have a strong community service ethic.

Education and occupations

James first attended a mainstream primary school and had positive experiences there, Noreen believes: ‘Classes… were just used to James, and they never batted an eyelid. They supported him. His success became theirs, “James did this today” and yes, [I thought] because he was part of the community.’ At secondary level he went to a specialist autism school, where Noreen felt he lost ground, and at 16 to a local further education college: ‘They basically childminded him for a year. And he did nothing, nothing at all.’ James was also given two days at a day service, but to her that represented the worst of social care provision, as she told them: ‘So I just said, you're wasting your money, and I don't like wasting money. I know it's not my money – wait a while, it is taxpayer money – but I mean, he's not going to sit there and just vegetate for a day.’

James started at a local independent specialist college in 2021, following a lengthy battle with the local authority, including appeals. The college takes young people ‘with complex behaviour and learning difficulties including autism’, and is supported by an education charity that has developed a practical land- and craft-based curriculum that Noreen rates very highly.

The work

James is an official volunteer for a national charity, working at an outdoor centre on an estate in a National Park. He works in maintenance, doing things like sweeping leaves, collecting brushwood and litter-picking. The PA (Andrew) and volunteer supervisor negotiate the tasks. At the start they used a visual schedule of tasks, but James adapted quickly and began to work without it. James and Andrew begin with tasks around the centre, before litter-picking walks on the paths. James is happy to work and walk long distances in all weathers (Figure 6.13).

Figure 6-14 Video still: James and Andrew on a litter-pick walk, shortly after his return to work post-lockdown

The charity has a policy of inclusive volunteering, but there are limits to this rhetoric, as the volunteer co-ordinator explained:

> It scares people on my end. You know, in the hierarchy, even if they say they're not and even if they say they want to. They imagine it will be harder than it is, they imagine that there's all kinds of safeguarding issues for them. Yeah. You know, so it's it is a tough nut to crack.

She thinks that James is probably the most disabled volunteer in the charity's workforce nationally, and she was initially concerned:

> You know, the first time I met James and [his PA], I won't lie to you, I was nervous – because when James is in full nervous mode, yes, he's got a lot going on, you know, and I was just like, 'How is this going to work?' Yeah. And I just had to fly by the seat of my pants and hope for the best, really, you know.

The work environment

The centre consists of a cluster of buildings containing offices and flats, a small kitchen garden and large car park, all within a National Park. There is a newly built café and facilities for visitors, including a learning area. It is the hub of a network of walking paths in an area of moorland, woodland and farmland in the National Park (Figure 6.14). The small core of permanent staff are the rangers who maintain the site environment and the voluntary staff who work in the kitchen garden and as guides.

Covid-19

James' work stopped at the first lockdown. He was reported to miss it, bringing his uniform to communicate to his mother his wish to go to work. There was a marked difference in James' confidence between the first film session, when he had returned after a long absence, and the second session, when he had readjusted.

Figure 6-15 Video still: James sweeping the courtyard

Family and professional support

James' mother, Noreen, has used her knowledge of education and the special educational needs and disabilities system to promote James' interests as she sees them. She has been on the brink of appeal to the local authority for not following SEND procedures 'half a dozen times'. Noreen offers a trenchant critique of social care provision and its priorities. She recognises excellent individuals within the system, but is scathing about the type of activities offered, the costs and priorities: 'It's all, let's chill, let's have a pizza, let's sit on our backsides and watch a movie… and so they're charging four hundred and something pounds for the weekend for the kids to sit there watching telly and eating pizza, whatever.' She mentions aimless shopping trips and time-filling activities: 'When I see these people trailing around the shops with a PA, I want to cry... [James] he'd smile… but he'd get nothing out of it.' She goes on to contrast this with what she seeks for

James through work: ‘I hate wasting time doing things that are meaningless. Yeah. And I think for young adults with learning disabilities, a lot of the things they do are meaningless… and so, for him it had to have a purpose.’

Andrew, the PA, is an experienced youth worker. Unusually, he has a degree in occupational therapy, completed mid-career. Although he is employed through a not-for-profit agency (‘and we’ve had some dire ones from them’), Noreen had selected and waited for him to become available. Andrew set up James’ work placement in line what he understood to be James’ preferences. The partnership between Noreen, Andrew and an adventurous volunteer co-ordinator make it an unusually strong placement. The supervisor credits James’ support:

> The reason it works is Andrew and Noreen, and that's the crux of it. It's not us. Yeah, it's not us… and what they give to James, that, I think, is sorely lacking for people with disabilities in general, is consistency.… So, Noreen, right from the get-go, said, ‘Can we arrange things around this guy? Andrew?’ Yet the supervisor perceived herself to be taking risks by the standards of the national organisation. Importantly, the relationship and the work suited Andrew himself, a local who knows and loves the landscape of the National Park. I suggested this to the volunteer co-ordinator. She agreed, ‘And he's come to love, I think he's come to love what him and James do together.’ (See Figure 6.16)

Figure 6-16 Video still, James and Andrew: ‘From what I feel, we have a good relationship, James and I’

Film content

Film session 1

The first filming visit follows James' long absence from work due to Covid-19 lockdowns. On site, new procedures are in place, equipment has been rearranged and personnel have changed. James and Andrew collect equipment from various cupboards on the property. Walkers are milling around the picnic tables and queuing for the toilets. James and Andrew sweep up outside the café, front and back, wipe down signs and wash and refill dog bowls. James holds his broom and sweeps, but is not always focused. Andrew prompts and calls his attention back.

After a break the pair set off on the footpaths with a litter-picker and rubbish sack. James wins a disagreement about which way to go, resisting Andrew's preference and pointing his way with his litter-picker. He picks up litter, responding to prompts from Andrew. It takes concentration to manage his hand–eye co-ordination, and he is pleased when he succeeds. He holds Andrew's hand, more often than not, and smiles often. He greets a family group of walkers with his thumb and a smile, and they stop to wave and return his thumbs up. This is repeated later as he meets the same group returning. At a certain point of the path James sits down to rest, his signal to return to base for lunch. After lunch they walk three miles or so with the litter-picker, sometimes through wind and light rain. It is here where James relocates himself from the outside edge of the three of us, into the centre.

At the end of filming we return to base, to the offices, where James retrieves my bag from a corner and hands it to me.

Film session 2

Session 2 takes place the day after I show James the first set of video clips. On this visit he is markedly more confident and focused on his work, taking the initiative more and sweeping with energy and focus. He and Andrew wash and refill dog bowls and empty and reline bins before their litter-picking walk. For part of the footpath James walks behind rather than hand in hand with Andrew. He is also communicative with me, posing and asking (by gesture) to be photographed in various locations. The footage of Andrew and James together in the Peak District landscape has an idyllic quality. They love the views, trees and sheep, and are absorbed in the work. James smiles and hums as he walks.

Participation and learning overview

Reports from other participants about James' learning are rich and diverse, such as on his mobility and confidence, communication and interaction and the changing attitudes among staff. James had adapted to the routine and the environment, quickly moving beyond the picture schedule that he started with:

> So, it's building up that knowledge of what we're going to be doing next, where we're going to be doing it and what we need to do it. (Andrew)

James had learnt to spot human litter in the environment and to manage the hand–eye coordination involved in using a litter-picker. Noreen sees a positive transfer between learning at work and at college, which she says is rare for James:

> Yeah, there is a transference of learning there and that's coming through from being at work, it's amazing. Although he had to be shown lots of things, he's done a lot of things automatically, like the sweeping… in the past it's always been a case of, I do that in that environment, therefore I don't do it somewhere else.

Both Noreen and Andrew talk about James learning from the positive reception given by visitors, who thank or compliment him. Noreen, with her focus on making a contribution, understood him to be learning about values:

> He doesn't have his own conception of the difference between purposeful and not purposeful, or meaningful and not meaningful, but it's the reaction back from other people that helps James, because he doesn't have that ability for himself.… In a sense, his pride, that's where his pride in and sense of achievement will come… because of the acknowledgment.

Andrew has a similar perspective:

> 'Cause people are always giving him compliments and contacting him, even if he's not really taking on what they're saying, it's like a positive contact that came as a result of that [working], and I think he can make that connection. I think he realises that because of what he's doing, that's then eliciting this positive.

Reviewing James' video, the volunteer supervisor also responded to communications between James and visitors, saying, 'The thing about your film that almost made me cry was seeing him interact with our visitors. Absolutely. Seeing him giving them the thumbs up'. Commenting on the difference between the two video sessions, she was prompted to consider whether they might be 'promoted' to Ranger status:

> Watching James… I actually think I'm going to meet with a few members of the team to see if we could try them out [as rangers]. Because I was really impressed with his, with his fine motor skills and also with his, you know, like really getting the bags just straight

> into the bin. And I thought, man, I would faff around with that. And he was just like, smooth, right in there. And yeah, so that got me thinking about, I wonder what else James could do? And is it time to give him a little bit of a push?

Part 2: The cross-cutting themes

In Part 2 of this chapter, I consider the themes that emerge from the data set as a whole in response to the research questions. These are arranged to address the two areas of the research questions, first work arrangements und personalisation and second, learning and capabilities. The first research questions were:

a. Why and how did young people with intellectual and developmental disabilities come to work in public settings?

b. How far did personalisation promote or support this choice?

I then turn to the second part of the research questions, regarding participatory learning and capabilities. These questions were:

c. What kinds of participatory learning do participants identify?

d. How far did the work and the learning involved enhance the capabilities of the young people?

The aspects of working and learning that emerge are interwoven and interdependent. I hope that the separate sections build up an integrated picture.

Research question 1: Work arrangements

Part 1 of the research questions concerned motivation, access and the role of policy. There were five key themes in the material addressing these questions; i. a critique of services; ii. purpose and meaning; iii. access and participation; iv. PA support makes work viable; v. structure and agency. A smaller amount of material was coded as intrinsic motivation.

The largest amount of material addressing this question was coded as critique of services, suggesting how encounters with provision and policy underpinned motivation to make work arrangements outside the existing framework for people with intellectual and developmental disabilities. The response to personalisation policy was summed up in one parent’s comment: ‘take the money and run’.

The critique of services: ‘take the money and run’

This was a broad and diverse set of comments and stories covering employment services, group-based day services and typical PA supported activities, as well as benefits and assessments. The material was often highly emotionally coloured. There were differences in individual focus, but the common thread was frustration and desire to establish a way of life more purposeful and better integrated with ordinary places and roles than could be found through the expected pathways.

This theme concerned employment and employment services. I have presented Fiona’s long and difficult engagement with the supported employment services, which ended with her parents’ sense of being abandoned (‘it was like “We can't help you anymore.”’ (p. 105). Anna's mother would not contemplate further engagement with employment services for Anna, as it would ‘just be sort of the road to nowhere’ (p. 88). Their experience of Connexions, the government employment information and support service, had been both oppressive and frustrating:

It was pathetic. Yeah, absolutely pathetic. You know, all this sort of promises of support and help, and it was just meaningless, just total drivel. I did more than they did. I mean, I found out everything for Anna. Everything.

Ciaran and his PA, Katie, continued to seek voluntary work and employment, but they did so using their personal connections without reference to employment services. Ciaran’s mother, a person well placed to navigate the system successfully, felt, as others did, that ‘the system’ was actively obstructive. Responding to a question about Ciaran’s work history, she commented: ‘Nothing that I've ever got for either of my kids has been because of the system, OK, so, I spend more energy fighting the system than I do it helping me.’

The heading for this section is taken from a response by Greg’s mother. She spoke of the inadequacy of preparation for transition to adult services. I asked, ‘They can either point you towards, you know, day-care type provisions, or they can point you towards supported employment. But what else can they offer?’ Her response was: ‘Take the money and run’, a phrase that captured the intensity of families’ desire to escape from service provision (whether for employment or care) and go their own ways. She questioned the cost of day services and supported employment schemes ‘where they are stuck for God knows how long’: ‘You're talking £60 an hour going into these things. Give me the cash for that, because I can do a damn sight better.’

James’s mother’s view was similarly sweeping. James was given three days at a day centre service which she reduced to one day: ‘One day was too much for me and my stress levels, I couldn't cope with it, so I just said, you're wasting your money… he's not going to sit there and just vegetate for a day'. In response to the question, 'How can you be helped?', she responded: 'I think the whole system needs to be readdressed. The whole day-care service…. It's a moneymaking exercise for private companies, it needs to be scrapped.'

The critique covered group-based activities and the type typically supported by PAs. Judith described Anna's day provision as juvenile ('a bit kiddy'). She hoped that Anna could do more cattery work, because the day centre's capacity to vary and develop the provision was limited: it would be 'coming to the end of its useful life at some point'. Ciaran had been 'fed up' with his brief experience of day care provision offering 'training in the form of horticultural therapy'. Several parent participants questioned the practice of offering PA support for 'going for walks or going to the shops' (Fiona's father). Library work was the highlight of her week: the rest of her PA-supported time was taken up 'wandering round the shops in George Street' (her words).

Parents' voices dominated this critique, but PAs shared the sense that the rationale for PA support was often limited. Speaking of his own role, Andrew, James' PA, reflected:

> We have some clients where we basically... probably shouldn't say, but it's just like babysitting – we go along and they just do what they do anyway, but… their parents don't have to be there. If I'm doing that, I'm feeling we're not really achieving anything.

Noreen used the same 'babysitting' analogy to describe services offered to James.

Participants' critique of the service status quo was multifaceted, but the scale and emotional charge of the theme indicate that it acts as a major driver of the work arrangements that people strive to make. Pathways are set up in a spirit of dissent: they constitute bottom-up routes away from 'social care' and stand in implicit challenge to the expectations of both social care and society. Setting up a work arrangement means escaping the provided framework – the 'road to nowhere' of supported employment, the bingo, jigsaws and 'pizza and chill' of day provision and the wandering around shopping centres supported by a personal budget.

The critique of services theme had three positive counterparts: the qualities sought or found in successful participation in work. These were purpose and meaning; participation and access; structure and agency.

Purpose and meaning: 'accomplishing something at the end of the day'

This theme reflected participants' sense that the primary participant sought to perform a function or service. It was clearly reflected for Fiona in similar accounts given by her work supervisor and her PA. The supervisor reflected that working meant she could achieve something using the abilities she has; it served her ‘need for being resourceful and helpful … she enjoys being someone that's providing help for people and doing something that she's capable of … that she’s accomplished something at the end of the day’. According to her PA, ‘what she sees at the library, [is that] she's accomplished something. ... and having done it, you know, done something worthwhile and something good. Definitely.’ James’ mother saw him as learning from the responses of others to his work. She thought he was learning to understand something about meaning and purpose in this way, to distinguish activity perceived as ‘meaningful’, where ‘he gets that reward back’. This was a reason for involving him in the work: ‘He wouldn't get that if we didn't persist in taking him and getting him to do those activities’. By working, she thought, ‘he gets that benefit from, you know, of having had that, you know, that positive feedback and purpose to his life. And I think everybody needs purpose …’

Access – ‘getting into society’

These themes concern locating and accessing a social role. Fiona’s father articulated the most basic function of work arrangements: ‘Anything that gets her out of the house and integrating with people other than mum and dad, that's got to be good.’ He intuitively linked this function with other ‘goods’, the ideas of learning and social reciprocity. He continued:

> It gets her out of the house. Yeah. Gets her into society. Gets her meeting people... seeing what goes on in the world.… It's something they want doing and that gives her value. Yes, I think that’s a big part of it.

As there were few existing pathways to follow, achieving a social role involved breaking new ground. Parents or PAs had to introduce the idea of working with PA support to the gatekeepers or, in Greg’s case, themselves build the public framework around the activities he undertook. The critical process of getting through the door in the first place remained difficult. James’ supervisor gave an account of meeting James and Andrew, referring to her own apprehension – ‘I won’t lie to you, I was nervous’ – and her organisation’s hesitancy. The charity has an explicit commitment to ‘inclusion and diversity’[6] in its volunteer base, yet:

> There will be the problem that it scares people on my end. You know, in the hierarchy – even if they say they're not, and they even if they say they want to – they imagine it will

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[6] ‘We are working to create a culture that values difference, includes everyone and recognises the strength that comes from diversity.’

> be harder than it is, they imagine that there's all kinds of safeguarding issues for them. It’s a tough nut to crack.

Her comment on her own role, ‘I just had to fly by the seat of my pants and hope for the best’, was true of most participants at the outset, as they faced a culture of cognitive ableism and few precedents for working with PA support.

The arrangements that people made were therefore idiosyncratic, involving personal contacts and locally available openings such as Ciaran’s food co-operative. There were limitations in the choice and variety of work that could be accessed. However, by virtue of not being sheltered the work involved challenge, to some degree, even when in itself it was not demanding. Access was ‘tough’ (James’ supervisor), but looking outside the parameters of contracted employment widened the range of the possible, making an appropriate fit more achievable. Anna’s role, for example, could not be a paid role, because ‘so many volunteers want to do it‘.

Viability and support – ‘As a unit he and the PA are depended on’

This theme reflects how participants saw the viability of work as dependent on the presence of personal support. A sub-theme concerned specific needs for support. Two further subthemes concerned the balance of priorities for work and ‘care’; and the presence and absence of organisational/institutional support for work arrangements.

There was a consensus that the arrangements had worked because of the pairing of the young person and the PA; they were viable in work contexts as a partnership. At Ciaran’s co-operative this was subtly put, in the context of appreciating Ciaran’s contribution to the workplace and his relative autonomy there:

> I say I’m a supervisor. Really, we do very much depend on his help. And the helpers being there with him…. And I suppose it does help Ciaran to be sort of independent from… I mean, we don’t have to supervise all the time.

James’ mother described him and Andrew as serving a function jointly: ‘As a unit he and the PA are depended on… and they desperately needed people [at the estate].’ His supervisor accepted the PA as an equal-status partner and part of the volunteer workforce: ‘I said [to him], “I recognise that you are being paid to do this for James. So that’s your paid context. But I’d like you to think of yourself and consider yourself one of our volunteers”’.

Referring to Fiona’s temperament, Fiona’s father put it more baldly: ‘Barry down the library, he thinks she's the best thing since sliced bread. He absolutely thinks she's wonderful, but he wouldn't take her on without her own support worker being there.’

There was a consensus that the workplaces themselves could not and should not take that role. They did not have skills or resources, and doing so would mar the terms of participation. With their own support, as part of a partnership, at the workplace the young people could avoid dependency. Ciaran’s supervisor saw the advantage for him in having his own support. As Judith, Anna’s mother, put it: ‘She's working as a volunteer. And as you're working there, you are, you're not there to be supported. Yeah. You’re there to support them.’

Structure and agency: ‘given something to do, he comes into his own’

The structure and agency theme concerns how work provided a structure that acted as a support framework. Workplaces provided procedures, standards and expectations, that were perceived as giving people motivation and a framework in which to invest effort. Specifically, it gave people a way to ‘get into society’ and provided a structure for activity, interaction and relationships. For all the young people, the time spent at work was the only time, or the most extended time, that they were active in public settings on their own account; that is, not as a part of the family or a disability group. This amounted to a significant gain, expressed by parents and on behalf of young people, but some co-workers also became aware of function. James’ supervisor described a story told to her by Noreen, which the supervisor saw as ‘one of the most humbling things that anyone's ever shared, you know, from volunteering’. Noreen had visited James at work, where she had experienced James knowing people and being known independently of her for the first time: ‘Lots of the volunteers and staff said hi to James, because they recognized him, and he gave the thumbs up. And she said that was the first time - like even at school and stuff she hadn't had that experience - of them going somewhere and people engaging with James, and in a relationship with him in his own right that wasn't linked to her’.

Anna’s mother understood that a fundamental form of agency was enabled by Anna’s access to work: the freedom for her to pursue her own interests and plans which care arrangements often curtailed. I asked her what she thought it meant to Anna to return to work after lockdown, and she replied:

> I think in a world where she’s so sort of looked after and guarded, really where we can't feel safe that she's crossing the road... in that sort of environment, I think it's freedom. Mm hmm. Respect, freedom.

Participants linked the activity of work with agency, contrasting it with what they represented as default, passive modes of occupation: watching television, eating, ‘sitting on my bum’ (Ciaran). The Covid lockdowns highlighted this basic function of work. Rachel, speaking at the time that Greg was struggling, said of him:

> He needs to have a purposeful, meaningful day, or at least a morning or an afternoon. Otherwise, he would spend it in front of the TV and start getting up later and later and later. Being in front of the TV, eating, being in front of the TV, eating, [computer] games, bed….

Working and the work routine gave a means to free him from this pattern. She considered the framework that she nurtured both for and with Greg – the PA support, the Facebook page promotion and outreach activities – and saw this framework as supporting Greg’s autonomy: ‘Structure and purpose, meaningful activity – once he's got them, he's fine if left to his own devices.’

Two PAs, Andrew and Katie, make similar arguments for the capacity of work structure to support agency. Andrew described how, at home, James tends to sit and listen to music, ‘which is where he feels confident and calm’, yet ‘when he's given something to do, he really comes into his own and starts getting more active’. Katie compared her role as PA within and outside the structure of work. She described how starting a new job was demanding for them both but after that period, supporting him at work ‘is probably the easiest part of our PA support’. She and James’ PA described how the environment, routines, expectations and other people provided strong support for themselves and the people they supported.

Moreover, the structure of work supports interactions and relationships, the third subtheme. Anna’s co-worker gave a short speech about this in the context of her charity:

> You get all these different volunteers who come in. Everybody, even if under normal conditions, you would never actually know each other or speak to one another or be friends, you have all got something in common, and therefore you have conversations with people – as with her (Anna) – that you might not have a conversation with otherwise. There's always something of joint interest. Even if it's absolute horror because of how badly [a cat’s] been treated, to an absolute delight when kittens have been born and they're starting to play. Yeah, or something's been ill and it's now getting better.

For autistic people the structure may have added importance. Ciaran’s mother, Tricia, talked about how ‘the team’ had ‘failed’ (her word) to help Ciaran establish friendships outside of work:

> There's a guy, at [the food co-op], he and Ciaran get on and we've managed to get them – and I've had to push a little bit – they've been out for a walk together on their own. So, Ciaran really struggles to…. Ciaran is naturally introvert, so if you say, ‘Would you like to see John from the shop?’ ‘Yes. Yes. John from the shop’ – but he would not take the

> initiative. It's always going to be difficult for him. He does tend to get his head down and yeah, do his job.

I asked whether this was indeed a failure, suggesting that the relationships that are embedded in work might be less problematic and good enough. She agreed that in the structured environment of work the relationships worked. Ciaran looked forward to going to work to see the people, and this form of socialising did not present problems for him.

Fiona's PA, Jon, felt that her official role in the library modified the awkwardness of some of her interactions with customers, who were sometimes puzzled by her distinctive voice and topics of conversation: 'I think people are more understanding and it makes sense, that someone whose voice or, or, accent doesn't sound exactly the same as most people…. I think if people can put them into a volunteer category, then they don't need to expect anything different from them.'

Parents sought structure and 'meaningful' activity ('I think for young adults with learning disabilities, a lot of the things they do are meaningless': Noreen) – that was a consensus aim. But there was ambivalence about imposing parents' own values or understandings of what matters. For them, supporting working for pay did not seem to involve any such ambivalence, supporting work for less concrete reasons was harder to defend. Noreen referred to her understanding that James was learning about values by experiencing social reward at work:

> He gets that reward back from doing the meaningful activities... he wouldn't get that positive feedback, you know [without work] so it's a great benefit to him because everybody likes, you know, the feeling of self-esteem.

Noreen struggled with how her role might be perceived: 'It almost seems like you're kind of trying to control his life, but you're not really. You are just giving him the opportunities to experience.'

Rachel (Greg's mother) referred specifically to the personalisation framework of choice and control being in the hands of the care recipient, touching on the central problem of what choice and control may mean for people who are excluded from shared social and cultural life:

> You've got to have choice in your choice and control, yeah, but that doesn't mean you can choose to not do anything *all the time*. I mean, there are times when [Greg] can choose not to do anything. That's fine. But that can't be every day.

These themes do not cover some of the basic observations about intrinsic motivation and taking pleasure in the tasks themselves. The fitting of work with primary participants' motivations and interests had been part of the selection criteria, and was not explored at length in discussion. There were nevertheless comments suggesting how 'fit' worked in each case.

Anna said her aim was ‘to help cats’; Ciaran wanted to be face-to-face with customers; Fiona commented on using her ‘library brain’ (Figure 6.8); and James was understood to love being on the estate with Andrew and to miss it when it was not possible. Co-workers were conscious of these motivations too. Fiona’s supervisor discussed how ‘she was really excited to be back after lockdown, and how: ‘She might be quite quiet, but she always says ‘I really enjoyed working here. Thank you for having me’ every time she leaves….’

The best evidence for work satisfying the need to perform competently and be seen to do so is perhaps in the video footage itself. This shows participants choosing to engage effort and, as co-workers discussed, being focused, enthusiastic and conscientious. The bulk of debate and explanation centred on a critique of the available pathways: the time and effort involved in making and sustaining work arrangements (and misgivings about how this might be perceived); and questions of structure and agency. The relationships, skills and opportunities of the primary participants were at the forefront of most participants’ thinking, both co-workers and supervisors. Work with PA support presented challenges, yet it enabled a range of choices and opportunities that were not otherwise attainable.

Research questions 2: Participatory learning and capabilities

The material addressing participatory learning and capabilities includes learning identified by participants, aspects of learning that are implicit in accounts of other matters, and wider dimensions of learning and participation that relate to capabilities. Five key themes were identified i. support enabling agency; legitimacy; ii. effort and recognition; iii. affiliation and social bonds; iv mutual adaptation (see Appendix D). These themes are closely related and mutually reinforcing. I consider first legitimacy; effort and recognition and affiliation and how these themes relate to each other. I then look at the last two themes under separate headings.

Legitimacy, effort and recognition, affiliation

The theme of legitimacy pervaded participants’ discussion, as they highlighted that the work was being done within the world inhabited by the majority, and that young people were authentic contributors in that context, responding to workplace needs. It concerns the significance of an accepted role in shared social and cultural practices. Participants other than Greg worked limited weekly hours and in this sense was peripheral in that, as described by Lave and Wenger (1991, p. 14), they took part ‘to a limited degree and with limited responsibility for the ultimate product as a whole’. However, the status of primary participant as legitimate contributors was an important theme in the discourse of participants of each type. Participants highlighted young people’s acceptance as contributing members of national and local organisations, focusing on markers of legitimacy such as passage through training (Anna) or a trial period (James and Ciaran), signing in, having access to staff areas, tools and systems – the till, the library classification system, the cat pens. Certain attributes of work had symbolic importance, such as Anna's keys and James' red sweatshirt. As Greg was effectively a self-appointed worker, his status was marked by his membership of the 'two-minute litter-pick' organisation (see Figure 6.11). The Facebook page about his work and the high-profile community litter-pick ('the best day of my life, that is') were underscored and as signs of legitimate status.

There was similarly a focus on the allocation of responsibilities, that is, on taking on tasks the successful completion of which mattered to others in the workplace. Such tasks signalled how young people contributed to shared goals. Ciaran's supervisor outlined the basic reciprocity involved in his work arrangements: 'All these jobs are, we are not creating them for him. They are valuable for us in the shops. So, it's a two-way exchange…' Following procedures and carrying out tasks acted as embodied forms of collaboration. James' PA pointed out that they 'address quite a lot of the jobs that needed doing, one way or the other, not necessarily the way everyone else would do it, but with the same end results'. The idea of legitimacy was stressed by co-workers too, as in the library supervisor's assurance that 'you can tell when Fiona's been to the library, once she's finished you can actually tell what she's done'. Anna's co-worker defended her role as 'Definitely it's important. This is a desperately important. Yeah, no, because the staff is so busy here'. Fiona sees herself as performing a service for library users and, like the other participants, is pleased for that role to be captured on video ('I'm so glad you're filming me here'). As volunteers and as part-timers, young people might be construed as 'peripheral' participants, but in practice participants saw their activities as making a difference and contributing to shared goals.

Having such access and taking on such tasks allowed primary participants to develop work specific knowledge and skills, and this was a subtheme of legitimacy. Anna's mother talked about her accumulating expertise, recalling a staff member saying '"Anna knows more about the cats than I do". Yes. [She knows] All their names and details exactly. And what state they were brought in and [whether they are] reserved or not'. Fiona's supervisor stressed that she knew exactly where to put different kinds of books, 'you know which ones are numerical order, which ones are in alphabetical order, where children books go, wherever the teenage reading, or you know, younger children's [books]'.

In addition to learning work-specific knowledge and skills, participants understood having legitimate work to give access to wider social and cultural learning. Ciaran's mother talked about his encounters with implicit social rules. She saw him as learning to be 'mindful' about 'people's mugs and about washing up and about the loo and things like that'. She saw this as critical since 'the rules of life don't make much sense to Ciaran' and since, mistakes in such areas can 'make you crash and burn more than any explicit rule will do' and 'You could probably get away with giving the wrong change to somebody more than you can get away with messing up a coffee break and using someone's mug.' In rejecting sheltered forms of work, ('serving teas in disability services'), Greg's mother argued for 'that exposure that I keep talking about' for its potential in terms of social learning. The video footage and discussion of it prompted different stakeholders to highlight ways in which it was part of and contributed to the 'real' majority world. Legitimate work was hard won and highly valued as admission to the real (majority) world, which then provided a context for developing skills and knowledge, and making a contribution using those skills. Legitimate participation might even contribute to public learning or understanding. One expression of this latent idea came from James' supervisor, who commented, 'I hope somebody is asking themselves, "Why aren't there more James?"'

Effort and recognition

This theme brought together separate emergent codes concerning the investment if effort and positive evaluations of work. Performing legitimate tasks opened up reciprocal processes between primary participants and co-workers. Much of participants' video records them putting effort into work – James putting physical effort into sweeping, or Greg loading and unloading bags of picked litter. This factor was recognised by other participants. Some video labels reflecting my perception of instances of care and effort were coded as in this way: 'Patience and restraint' (Anna with the anxious cats); 'Conscientiousness' (Fiona); and, for the moment that Greg found a £20 note in the hedge, 'Find money – carry straight on'. Correspondingly, other participants acknowledged young people's work. Fiona's focus at the library shelves elicited the response from her supervisor, 'there's nothing casual in the way she does it'. Co-workers and supervisors reflected at length on the quality of the work being done. For example, Anna's co-workers responded to footage of her working with a particular kitten,

> Yes, she's really built up a bond, and that really helped him come out of himself. So, you know she just, I think she reads the cats quite well... she knows which ones she can and which one she can't pick up, and they pick up on that … you can just see his body language with her. I think they pick up on her gentle nature, her quietness.

Such recognition provided important validation to other participants that the work arrangements were valued. Judith commented, 'No, they appreciate her, not just her cat interest, but what she does too.'

This significance of the effort-recognition connection was summarised by Ciaran's mother, 'he's learnt the wonderful feeling of doing something well and people praising you. Yeah, being appreciative. So that actually if you do a good job ... it's good for you because people tell you you're doing a good job – “I did a good job, and doesn’t that feel great?”.

A large proportion of the interviews with co-workers and supervisors linked the themes of legitimacy, effort and recognition, as they saw young people as making a difference, as in this comment by Barry: ‘If she didn’t come, you’d notice. I mean, she’s not here this week, right? And it’s not as tidy as it normally is. Period. Because Fiona isn’t here doing it.’ He comments that when he visits other libraries, he can observe how his branch looks better organised. Responding to the concentration evident in her video, he recognises her investment: ‘I mean, she wasn't playing to the camera, if you like. She is always like that.’

Fiona’s supervisor connects her status in the library to her performance of tasks, seeing the arrangement as a matter of reciprocal respect. She too is given accepted status:

> because she's such a … she's very focused with her job when she comes here. She does it and you know she's always on time, and I think she treats it as a job so, as such, I treat her as a member of staff.

These reflections were often striking for their accumulated insight into young people’s characters, their strengths and challenges, and for the emotional warmth implicit in them. Anna’s co-worker described the impact of Anna’s first verbal interactions with her, as reported, but also about what she had learnt about Anna’s modes of communication and interaction:

> sometimes she'll be looking at the [staff communication] board and you can suggest something... but she's already decided. She takes it all in and she listens of course. I know that she doesn't always say anything back, but she will be listening… she doesn't really question me much. It would be whoever's in with her. But she obviously takes in everything that we say about [the cats’] stories.

She described one of Anna’s characteristic hand gestures, and what she understood by it. Anna might not join in conversation, she said but she understood what Anna expressed, ‘she will always physically show you how she feels. I saw her face, yeah, her body language, in her eyes, her smile’.

In some instances, recognition by co-workers came with reference to the understanding of a wider public, as co-workers seemed to argue on behalf of primary participants, for greater recognition. Barry at the library welcomed the opportunity to talk about Fiona:

> It’s nice to talk to somebody about her, because she – I think sometimes she's a bit of an unsung hero kind of thing. She just comes in does her job quietly and goes away. It's about time people realized what she is doing.

Participants understood being admitted, having a valued function and being recognised as significant gains for young people. Judith described how these elements were linked in Anna’s work, and implicitly, how this contrasted with other experiences, ‘I think giving her that sort of value by the staff there is so good for her that it doesn't matter that … she's not interacting, and they're obsessed with cats. .... they trusted her to take that training on and to know what to do. They never sort of condescend to her.’

Affiliation and social bonds

The third in the trio of linked themes concerns affiliation and social bonds, where participants show or describe elements of social closeness developing between primary participants and those they encounter through work. Affiliation, identified as a core capability in Nussbaum’s scheme, is described by her as ‘Being able to associate with others, living with them and acting for them. Showing concern for people in general and interacting with others. Having sympathy and compassion, acting to help people’ (2006, pp. 76–78). I initially had other names for this theme, but Nussbaum’s definition of affiliation was a better fit, as it covers ordinary co-participation (‘association’ and interaction) and mutual recognition, which were already thematically salient, as well as ‘acting to help people’ which featured as a motivation for choosing to work.

A sense of social bonds and social insight developing on both sides through co-participation ran through the video supported discussion. Some examples have appeared: the library supervisor calling for Fiona and her work to be recognised (‘It's about time people realized what she is doing’). As legitimate participants serving valued functions, young people come to be seen as ‘insiders’ and ‘one of us’. Anna’s co-workers acknowledge differences between kinds of workers (paid or unpaid, longer or shorter hours), but make the claim that Anna is important to the enterprise; she is

> definitely part of the team. Everyone plays their part and there are different roles within this team, but yeah definitely… what Anna does is a kind of work, yeah. It's important, it is desperately important.

Anna’s co-worker recalled how her relationship with Anna had developed over years, from her first conversational exchanges (‘the first time she spoke to me... It was amazing') to her pleasure that Anna now told her about her life, and her understanding of Anna’s communications in gesture and facial expression (‘I see it in her face, her eyes’). She had empathised when Anna had an absentee PA (‘we used to feel that it was so unfair’) and had tried to supply some of the reassurance she saw Anna as missing.

The experience of lockdown brought out the significance of some of these connections. When Ciaran was made redundant from his paid work and his other voluntary work dried up (‘he lost everything’), Tricia, his mother, felt that the people at the co-operative grasped his situation and gave him shifts despite the strong competition at that time. She interpreted it thus:

> At the shop they are seeing the bigger picture, recognising that, well, first of all, they need to keep open, but also, secondly, realising that it's a two-way street and actually people need to come to work as much as they are needed at work. So, they're really good at that.

Without using speech, James communicated a sense of belonging to the workplace, and consequently of missing it in lockdown. His mother referred to the ‘kind of speed with which he goes out the door, you know’ on workdays, and the symbolic importance to him of his volunteer uniform. During lockdowns he continued to walk in the National Park with family, but this was not the same: ‘When he can't go, and he knows he should be going, he'll go and get his top from the drawer …, his polo shirt, and bring it to say, you know, I should be wearing this today, I should be going [there]’. Noreen recounted this story to the volunteer supervisor, who thought further about James as a member of the group:

> Nobody just volunteers, but James is a volunteer, you know, so is, you know, just part of the team. And of course, all, a lot of people have had a difficult time with not being able to volunteer.... And so, you know, it just goes to show the commonalities there.

Though his arrival had unnerved her (‘I won't lie to you. I was nervous’), she had come to see the ‘commonalities’ between him and other members of the team, which brought him into a general category, not connected with his disability: ‘You know, he was feeling a real human feeling that that many of our volunteers felt.’

Mutual adaptation: ‘then they started coming with ideas’

The mutual adaptation theme describes changes in knowledge, behaviour and understanding by co-workers and others that occurred as a consequence working with primary participants, and corresponding changes in young people. Highlighting the importance of the theme, participants also described the effects of failures of mutual adaptation, for example in accounts of Fiona’s and Ciaran’s unsuccessful work experiences. Here, I focus on the examples based in the filmed work placement. Ciaran’s PA, Katie, discussed an example focused on language, in which Ciaran and his supervisor modified their behaviour to make their communication more successful. The supervisor, Helga, speaks strongly accented English, and Ciaran’s use of language is highly condensed and grammatically idiosyncratic. He is used to not being understood and often relies on Katie as an intermediary. However, Katie discussed how,

> he can pick up on who is going to take the time to understand him and who isn’t. She [Helga] has taken a long time but has really made an effort. Now he gives her the full attention. If she's talking, he will stop cleaning the shelf and listen, whereas before he would continue with the shelf, not realise what she was saying, and look to me for help.

James’ PA, Andrew, gave a detailed account of adaptation by staff at the estate, based in collaboration. Initially, Andrew had had to take the initiative to communicate with staff, but this changed,

> At first, I went to them if I needed any co-operation or collaboration. But then they started coming with ideas, because we were looking for more tasks to do. At first some of the ideas were, like, 'We'll try it, but don't hold out hope', but now it’s, like, 'Oh you've really thought about that and taken into account what James does.

Their supervisor at the estate gave her perspective on the same process, starting with the initial reluctance of staff to get involved. No-one wanted to take the responsibility to be volunteer manager for James and Andrew, she said. Then someone agreed, ‘and then other people got involved, so they got to know James… they did more around getting stuff ready for them, talking about tasks’. As a result:

> James and Andrew got more confident and came to us, ‘Have you ever noticed your picnic tables are quite bad?’ I'm like, ‘Man, they are bad!’ and they're, like, ‘We can do that’. And they're like our go-to people, now. When the moles came, we knew they were great at that. You'd leave in the morning, and you'd come back and right where people are going to be eating and stuff, molehills going up. So that was quite funny. So, they like waged a war against leaves and moles.

This supervisor continued, describing incremental change whereby the participation of James and Andrew became normalised as they and other staff focused on work-related problem solving. She reflected on the learning process:

> It's been more of a drip, rather than big ‘Aha!’ moments. I think it's one of those things, you know, when you're scared to do something. I used to be really terrified of driving on the motorway. And then once I did it, I was like, ‘What was I worried about?’ And I think it can be like that when you work, maybe, with, alongside someone with a disability,

> you're like, so worried. And then maybe a year later, you're like, 'Oh, well, what was I worried for? And why was I worried?'

As suggested in the exploration of work arrangements, support roles, especially the PA role, were critical in enabling these processes.

Support enabling agency: freedom and security

In relation to work arrangements, it was a consensus finding that they were viable and sustainable on account of PA support. This theme brought out the relational element involved in pursuing work. Thinking about Anna's role, Anna's mother refers to this as a first barrier: 'we come up against the question of who's going to go with'. Material addressing the research questions on learning and capabilities explores the ways that support operated to make work possible and successful. Since the choice to work depended on support, agency was entwined with PA support. First it served immediate practical functions (to get there, to know what to do/how to do it) as suggested by Anna's mother. However, it was also understood as relational. PAs gave vital social and communication support (Katie as 'translator', Andrew as intermediary). They gave psychological support (in relation to Fiona's anxiety, Greg's flagging motivation). Having a PA meant having an ally, 'someone who's got his back' (Tricia), mitigating the anxiety felt by participants in certain situations, often unpredictably, and by others on their behalf. PAs provided 'reassurance' (helping people to cope with 'daunting' situations. Taking on tasks that were otherwise out of reach, such as handling customers and the cash register, meant having dedicated and personal support. Katie described how she handled situations like the one filmed, where customers spoke to her in preference to Ciaran:

> So, 90% of situations, for example, if we're at the doctors, and they try to speak to me, I redirect them to Ciaran. And if we're climbing [at the climbing wall] and they try to speak to me, I redirect them to Ciaran. If it's a two-second interaction with a customer and it's either rude or I can tell that he would just be pressurised, he's not bothered by it, and I don't really redirect them. Yeah. And if it is a customer that is either asking a difficult question or is coming across stressed, impatient, all it's going to do is make him look to me anyway, yeah, so I just deal with it.

Her description gives a clear account of how support can underpin successful work arrangements. In the case described, this involves reconnecting speakers to Ciaran and deflecting the kinds of encounters that might undermine his ability to work.

Some parents and PAs understood PA support as essentially relational, and dependent on compatibility, shared interests and mutual liking. Tricia spoke about this in abstract terms: 'So, the most important thing, the starting point, for anybody supporting any other human being should be that you get each other at a fundamental level. You enjoy each other's company. And if you don't. Yeah, then it's awful.' Anna referred to a failure of this kind, talking about a PA who had not lasted: 'She wasn't interested. Yeah. Maybe she's more a dog person.' Andrew considered whether his role could be done by someone within the organisation: 'I don't think it's something that the staff there could take on just as an extra job. Plus, an important part with James is that relationship. From all reports and from what I feel, we've got a very good relationship, James and I.' he went on to point to the practical consequences of the quality of the relationship: 'And I think that helps facilitate him being more engaged in the work and that.'

Judith reflected on the decision-making involved in finding the kind of relationship that might support her daughter's capabilities. Her experience with unchosen and uninterested PAs had undermined her faith in the ability of an agency to supply what she sought. When she returned to PA support, she said she would be foregrounding the value of the relationship:

> It'll just be somebody worthwhile. Mm hmm. Not somebody… that is not invested in her. Yes. Not valuing her as a person… I don't want somebody to just take her just to give me a bit of time off.

Ideal relationships were described as personal and peer-like. Judith recalled a previous PA, 'He'd tease her and get away with it... You have to be very careful if you tease, because she'll turn round on you and sort of get really upset, but he could do it.'

For Katie, the relationship with Ciaran was centrally important, for her and for other PAs in Ciaran's team:

> I love the relationship he has with me. I think it's really good, it's really healthy and I think it is important that there is friendship when people are paid to be in your life, otherwise what the hell's the point of us being there, you know, if you don't enjoy our presence?

Katie saw her knowledge of Ciaran as informing her moment-to-moment judgements about when and how to support, as in the case of her decisions about when to mend and when to deflect interactions with Ciaran.

The themes relating to learning and capabilities are rich in accounts of participatory' learning, in which the legitimacy of the enterprise and of the contribution to it mattered. The pairing of primary participant and PA produced successful working conditions. In which young people were able to succeed in tasks without bringing additional staff responsibilities, and to enter into reciprocal relationships and experience social situations that were otherwise not accessible. In video-supported discussion, participants gave brief accounts of work-specific learning – of gaining specialised knowledge and skills over time – which were often tied to more complex commentary on reciprocal learning in collaboration. As primary participants and PAs navigated work-related and social demands in partnership, co-workers recognised them as valued participants. Social bonds developed through these reciprocal connections. Changes in behaviour were described as occurring to enable more effective working relationships.

Chapter 7 Discussion

This chapter discusses this study's contribution to understanding the capabilities of young people with intellectual and developmental disabilities in circumstances where they work in a public setting with PA support. As the social and policy context is key to what young people can achieve in terms of their capabilities, I first revisit key points in the context of care, work and policy that are relevant to the findings. I then bring together the narrative portraits of participants and the findings for work arrangements to make comparison between cases. The second section explores the findings for participatory learning and social participation. I then reflect on the role of film in the study. The chapter closes with a consideration of capabilities.

7.1 The people and their arrangements for work

Consistently minimal levels of employment indicate the lack of a capability for employment for people with intellectual and developmental disabilities, regardless of theoretical rights (Burchardt, Evans & Holder, 2015). This fact entails the loss of basic opportunities to participate in social and cultural life, so that many people with intellectual and developmental disabilities are confined to domestic and disability settings. Yet the shared space of the public sphere is likely to be where the potential for integration or 'social inclusion' lies (Susen, 2009, p. 44). If learning is understood to be an integral and inseparable aspect of social practice, as it is in social and cultural theories of learning (e.g., Rogoff, 2003), the exclusion of people with intellectual and developmental disabilities from mainstream social practices will compound their disadvantage. If learning is construed as a process by which humans identify, affiliate and adapt to participate in their cultural group effectively – it is a process requiring of co-participation. People learn skills and knowledge and he generic structure of their cultural worlds' (Tomasello, 2016, p. 643) by participating. This view gives a significant place to work, since it involves shared intentionality and culturally sanctioned goals ('valued productive activities': Rogoff *et al.*, 2017, p. 884). Work is rich in opportunities for observational, instructed and collaborative learning, and collaborative work in particular is understood to be important for cultural learning and transmission (Tomasello, 2016). For people with intellectual and developmental disabilities, access to work in a public setting provides the opportunity both to learn and develop the skills and knowledge necessary for the work and to take an active role in a publicly recognised endeavour.

Social, cultural and work-specific learning was linked to the work situation. James for example, developed manual dexterity and hand–eye coordination as he learned to a litter-picker, and he encountered social values around litter and litter-picking. The theory of mutual constitution suggests the possibility of shifts in the perceptions and expectations held by co-workers about people with intellectual and developmental disabilities. Here, participants identified reciprocal learning processes taking part, as participants and co-workers adapted to each other. Participation in work provided opportunities for these young people to exercise their agency in important ways, as co-participants, able to represent themselves to others as co-workers and as unique people.

I have explored the role of personal assistance in work arrangements as an opportunity arising under personalisation. As conceived in disabled people's movements, personal assistance is not an individualising force (it 'complicates and even undermines the reduction of the human being to a self-sufficient, detached, rationally calculating subject', (Mladenov, 2012, p. 14). Rather it can enable social participation and can be understood, as I have argued, as activating disabled people's agency (Davy, 2019, p. 146). The proposal explored in this study is to interpret and assess personal assistance in terms of relational agency and, as a form of guided participation that supports learning.

The work of the young people in this study took place in the context of UK personalisation policy. Two aspects of personalisation were linked in the findings - the liberating potential in funding for personal assistance and the poverty of aspiration in social care. The overall direction of economic policy to maximise employment appeared in the lives of participants in the form of Work Capability Assessments, supported employment advisors and the dominant employment framework. Young people and families were caught between these unattainable expectations and the limited beings and doings offered by social care. In this sense their arrangements arose from failures in policy and practice to imagine substantive alternatives to employment as a way of life.

Finding a way to work: Dissatisfaction and improvisation

The narrative portraits of work in Chapter 6 show a diverse group of young people with intellectual and developmental disabilities, living in rural, urban and suburban settings, with educational backgrounds in both mainstream and special schools. All work in public settings selected, as far as reasonably possible, to fit their strengths and interests, and are unpaid. Their histories include disappointing encounters with supported employment services and unsuccessful temporary work placements. One had some experience of PA-supported work that was paid. Views of pay differed. Parents viewed employment as out of reach - either undesirable or unachievable. Some were frustrated by its inaccessibility, some not. Two (Fiona and Ciaran) had pursued employment and 'work experience' placements, but unsuccessfully: 'They look at what she can't do, not what she can do' (Fiona's father). For two (Anna and James), employment was seen as untenable, even 'terrifying' (Judith, Anna's mother).

The position for Greg and his mother, Rachel, was most conflicted. Rachel regretted the lack of connection between the effort that Greg put in and the money that he received in benefits. She expressed guilt that Greg was not employed, (‘Hands up, I have not put much effort into the employment side and – we’re recording this, aren’t we? OK – but yeah, hand on heart, I have probably done more around the volunteering’) though she doubted his ability to cope with a work schedule or to sustain the focus needed for employment. Ciaran and Katie continued to seek work, paid and unpaid work, encountering problems with language-based interviewing and employers’ resistance to the concept of a PA supported employee. Among co-workers, the prospect of pay was taken to be distant, however much they recognised the value of the voluntary contribution. The young people themselves were not preoccupied with the topic of pay.

The findings indicate families’ profound dissatisfaction with the life envisioned for young people in social care and their resistance to it. Anna and her mother were avoiding a life of full-time day care. Ciaran expressed his boredom with his therapeutic horticultural day care, he did not perceive himself as disabled and wanted ‘to be a part of everything society is’ (Katie). Fiona and her parents engaged with employment services over a long period, until they were told that there was nothing further to offer: ‘It was like, “We can’t help you anymore. Over to you”’ (Phil, Fiona’s father). Greg and his mother had made their own work pursuing a public profile and community recognition in lieu of pay. James’ mother fiercely resisted what she saw as expensive, ‘meaningless’ activities and ‘babysitting’ services that were offered to him.

On the basis of these experiences, the families took on the personal-level responsibilities offered by personalisation. Setting up novel arrangements was a significant task, carried out independently of the social care framework and, in some cases, against resistance, such as the pressure for Anna to secure her funding by going into full-time day care, and pressure for her to work without support). Faced with the elusive target of employment and impoverished aspirations in social care, families set up their own arrangements on various scales and with various degrees of perceived success.

A legitimate place ‘in society’, structure and supports agency

Against this background, the study finds that PA-supported work in public settings is achievable and is compatible with an ethic of care. This is notable since personalisation as a policy has been viewed as tantamount to an abandonment of care (Barnes, 2019). Working in this way enables individuals with vulnerabilities to pursue their own purposes, making agency and care complementary rather than opposing ends. Participants highlighted the significance of access and participation in the wider social world - ‘not being hidden away’ (Judith) and not doing ‘sheltered’ work (Rachel). The legitimacy of their positions as active contributors in the work settings was highlighted, because it seemed to mark and signify forms of competence and inclusion in the work situation. Performing tasks for others (Greg's 'I do it for them'), being 'trusted' (Anna), 'depended on' (Ciaran and James), or 'someone that's providing help' (Fiona) were highly valued. Taking responsible roles such as these were sometimes taken to have wider social implications by demonstrating the potential for social participation by other people with intellectual and developmental disabilities. The aim to learn, 'to see what goes on in the world' (Phil), or to get to know 'the rules … about how things work' (Tricia) was also implicit in discussions of motivation. An emotional drive underpinned work arrangements as participants rejected the low expectations they found, and set out to do better ('Give me the cash … because I can do a damn sight better', Rachel). Though strongest among parents, this theme included contributions from PAs and young people, both explicit (as in Andrew's references to the 'babysitting' aspect of social care) and implicit, as in Fiona's desire to use her 'library brain' to do something she perceived as useful and worthwhile.

Given the effort required and difficulties experienced in gaining access to fitting legitimate roles, the factors that made it viable and successful featured strongly in discussion. Having personal support was the single most significant factor, such that parents took on this role at times to make the work possible (Tricia, Rachel, Judith). However, it is important to note that recruitment criteria included the specification that young people should be pursuing their own motivations in work, as far as possible. A large factor in the success of placements was the mutual structuring of setting and tasks to suit individual preferences and primary participants' motivation in their work.

Finding viable and fitting roles and tasks

The work filmed for this study was characterised by a strong degree of fit between the interests and abilities of the worker and the type of work and work setting – the quiet and ordered local library, the cat-focused rescue centre and Ciaran's sociable cooperative. The fit of the work to the person was achieved through collaborative decision-making between the young people, the parents and, in two cases, the PAs (for James and Ciaran).

This process resembled what Rogoff refers to as 'mutual structuring of participation' (2003, p. 287), a basic component of guided participation. Rogoff describes it as the joint selection and structuring of the kind of participation that learners have access to, including the help that is made available. The aim of mutually structuring participation, in the terms of Rogoff (2003) is to ease the newcomer's engagement in the shared endeavour. In the case of finding work for participants in this study, this involved interweaving several factors: their motivations and preferences; an understanding of the tasks and work situations where they could succeed; a manageable level of challenge; and knowledge of what was locally available and accessible.

To a large extent, people gained access to their role by taking on unpaid work. It was ‘a tough nut to crack’ (James’ supervisor), even for people bringing their own support, and it was negotiated carefully. All participants worked in not-for-profit environments, and that were in various ways congenial to them. Anna worked with other volunteers in a role that was not likely to be funded given the number of willing volunteers; Ciaran’s cooperative operated on a voluntary basis; and Greg’s role was self-generated, without barriers to entry. The portraits show that arrangements were finely tuned, based on intimate knowledge of personal characteristics and local availability. In the case of Fiona, the library setting provided an outlet for her systematising skills and responded to her preference for an ordered, quiet environment. Though she was underchallenged in her tasks, her anxiety might have ruled out a larger and busier library. The level of fit achieved for primary participants would be difficult to replicate other than through such collaborative, bottom-up processes.

It was the fitting of the person to the task and environment that enabled the participants to be competent and motivated at work, on which basis they could contribute to shared goals and receive recognition for doing so. In this sense, putting budgets in the hands of knowledgeable and motivated families can enable a meaningful level of customisation, a key aim of personalisation policy.

Converting personalised funding into capabilities

The findings reveal a range of novel arrangements made outside of the official social care parameters, in implicit challenge to the expectations of both social care and society. The critique of existing services, pathways and expectations - the perceived and experienced impossibility of employment and inadequacy of employment support; the limited horizons of day care and of typical PA-supported activities – compelled the investment of effort outside this framework. Personal level funding provided a resource to support it. In capabilities terms, participating families were able to convert the resource of such funding into meaningful activities and roles. The narrative portraits demonstrate the viability and value of these beings and doings, to individuals, to their families and to people in the workplaces.

As shown in these portraits, each primary participant had a commitment to their working role that was independent of receiving pay, and was sustained over a number of years (a minimum of three years). This in itself is in strong contrast to the short-term internships and work experience placements offered to some people with intellectual and developmental disabilities who want to work, which are terminated by employers and providers without tangible outcome (e.g., Romualdez, Yirrell & Remington, 2020; see also Stevens & Harris, 2013).

Primary participants and others portrayed work in substantially positive terms. Work was something looked forward to as a highlight of the week, and something missed during lockdown. Participants saw work in each case as corresponding to young people's personal interests and as responding to needs (to be useful, to exercise skills, to be recognised and valued). Co-workers and supervisors perceived primary participants to be 'keen', 'focused', conscientious and, importantly, valuable. To look forward to the thematic findings, the 'effort and recognition' and affiliation themes linked positive appraisals of participation and the appreciation of the primary participants as unique people. The responses of co-workers and supervisors, and sometimes the public, enabled the primary participants to understand that they could be 'valued' and 'trusted' by people outside the circles of family and disability, and to encounter positive reflections of themselves in these appraisals (attributed to Anna, Fiona, Ciaran and James). The enthusiasm of young people to be filmed and for their film to be shown publicly reflects their positive perception of themselves as workers. In these ways, the impact of work is disproportionate to the amount of time that most spend working. Anna embraced her identity as 'cat whisperer', despite spending a greater number of hours at her day service. The work Ciaran and Greg were able to do in lockdowns was said to act as 'a lifeline' (their parents) for them. I infer that the importance of work found in this study relates at least in part to the known and experienced risks of under-occupation and social marginality. This question is discussed further in the next section of this chapter.

A key finding across narrative portraits is the shared view of work arrangements as significantly valuable. It comes with some caveats, as discussed below.

Personal support: relational agency and the limitations of choice and control

In social care terms, the participants had widely varying levels and types of support need. Strong evidence in the study that participants' work was successful and sustained came alongside a clear consensus that it was PA support that made it viable. This was ascribed to participant characteristics (their need for informed and personalised support) and workplace characteristics (time and workload pressures on staff). The structuring of participation – the careful fitting of work to personal characteristics – included the mutual structuring of the support.

PA support met a variety of needs for these young people. There were large differences between individuals in the role of the PA, from the least involved to the hands-on, physical and communication support received by Ciaran and James. Fiona neither looked at nor spoke to her PA throughout her filmed shifts, yet she, her parents, her PA and Barry, the supervisor, accepted that her ability to work depended on having support in place. She phrased his support as 'supervising', while her parents and the PA himself saw it in terms of mitigating anxiety and stepping in for ‘awkward social situations’ to avoid the distress that might result. Other PAs (Katie and Andrew) liaised closely with their partners s that tasks were completed successfully. A large part of their role concerned learning - modelling tasks, filling gaps in knowledge, supporting and ‘repairing’ interactions and giving hands-on guidance. A particular advantage of their support was its responsiveness - adjusting support dynamically in the light of individual characteristics and the changing demands of the moment. Hence James chose to hold Andrew’s hand for the duration of the first filming session (early after lockdown), but walked alongside him in the later session. PA Katie described how she monitored the demands on Ciaran in the light of her understanding of him, managing incidents as they occurred.

Participants in differing relations to young people considered the possibility for them to work ‘independently’ to be either undesirable and/or unworkable, other than for short periods. This perception had been confirmed in some cases by adverse experiences of short-term placements without support (Fiona, Ciaran and Greg). The co-workers for two (Anna and Fiona) discussed their experience of circumstances when adequate support was not available. In the workplace, people did not see in-house staff support as a viable prospect – it was rejected on the grounds of resource and workload pressures, the lack of expertise among staff and the understanding that this could recast the relationship between worker and workplace in undesirable ways. For Helga there was more dignity in Ciaran being regarded by staff as ‘sort of independent’ of management; while Anna’s mother had a clear-cut view of roles: ‘You're not there to be supported. Yeah. You’re there to support them really. And they've got their job to do.’ Generally speaking, Helga’s assessment of Ciaran: ‘We do very much depend on his help. And the helpers being there with him….’ accurately represents the co-worker perspective.

PAs themselves understood their support to be a key factor in the arrangement’s success. They saw their role as personalised and relational, not as an interchangeable commodity. As Andrew said of James’ work performance and motivation, ‘an important part with James is that relationship’. The relational role of each PA was perceived as tied to close understanding of the supported person’s existing knowledge, communication style, habits and modes of thinking.

Language and communication was a key area where PAs were instrumental in supporting the agency of primary participants ‘helping the individual to negotiate the world around them and intervening in the social world to make it more accommodating’ (Davy, 2019, p. 109). Katie acted as ‘translator’; often she redirected speakers to Ciaran, but not always: ‘If it’s a two-second interaction with a customer and it's either rude or I can tell that he would just be pressurised… I just deal with it’. In this way, based on her knowledge and experience of Ciaran, she simultaneously managed his capacity to understand language and to handle pressure. Even in cases where the young people managed their tasks with little hands-on assistance (Greg and

Fiona), the arrangements were co-constructed to provide the support that participants perceived and experienced to be optimal: generalised guidance and ‘reassurance’; accessible problem-solving support for the inevitable challenges. At a minimum, young people were perceived to need a personal ally in the workplace, ‘someone who’s got his back’ (Tricia).

In summary the was a strong consensus finding that PA support made the work viable and sustainable is informative. The sustained nature of the work arrangements can serve as a basic indicator that arrangements were successful, in contrast to participants’ adverse experiences in previous arrangements without PA support. It highlights how support for work might be conceived not as a temporary measure while task competence is learnt (as conceived in most job coaching arrangements), but as enabling ongoing learning and development within work. In learning disability policy and provision, thinking around learning for work is mainly concerned with ‘task acquisition’ and conforming to behavioural norms, so that learning is not conceived as a reciprocal process involving others in the workplace.

In this study, detailed accounts of enabling participation relate to the side-by-side guidance given to James and Ciaran. Other PAs had less active roles. Those PAs whose support was more distal, or perhaps more passive (as suggested by Fiona’s and Anna’s parents), gave less extensive accounts of both learning and of how support operated. Fiona’s PA described vividly how Fiona’s interactions could go wrong, yet he saw this tendency in deficit-focused terms. The varying levels and kinds of PA support relate in part to characteristics of the supported person, but might also relate to s uncertainty about the purposes of the role in a work context. The role is unfamiliar to in the workplace and often to PAs themselves. Of the PAs in this study, only Katie and Andrew had received relevant training. The culture of social care, its attention to vulnerability and its social and leisure focus (Watts *et al.*, 2014) may constrain. The ‘babysitting’ conception of some support work, a term used pejoratively by Andrew and Noreen, may have played a role in some shortfalls of PA support. Participants’ responses to patronising views of the of the work (‘it’s a nice hobby’) and to controlling behaviour (Greg’s ‘ear bashing’) recall Mackenzie’s claim that supporting agency where there is vulnerability is critical ‘to avoid opening the door to objectionably paternalistic and coercive forms of intervention’ (2014, p. 33). Partnerships between PAs and young people appeared to participants to be intrinsically valuable in their own right, in terms of everyday companionability and as significant relationships involving liking and common values. This was strongly true of Ciaran and Katie and James and Andrew. In these cases, PAs provided, as well as supported, significant relationships. Such qualities were sought by other participants. For PAs with experience of other forms of care, this capacity is a distinguishing feature of PA support, and makes it preferable to other forms of care work (Woolham, 2019). Woolham (2019) links this characteristic with risks on both sides, when the professional status of a paid care role is ambivalent (see also Robinson *et al.*, 2020). This risk can be detected in this study in young people's preference for stable support relationships. However, a wider implicit message involves how such support is conceived. If personal assistance is to operate in the terms of relational agency and as a means for disabled people to reclaim an autonomous position in the public sphere (e.g. Mladenov, 2012), it may need to be understood by practitioners and within provider organisations as having this potential. The consumer orientation of personal budgets and the focus on domestic and leisure occupations in social care do not currently contribute towards such an understanding. In this study, Greg rejected his aunt's services as PA because of her didactic approach. Two other PAs (Anna's and Fiona's) saw their partners' work in patronising terms as 'a nice hobby'. Anna's mother's search for 'somebody worthwhile' rather than somebody who is 'not invested in her, not valuing her as a person' can be seen in these terms.

The difficulty of finding the right kind of PA partner raises the important question of how much 'choice and control' can be achieved under personalisation. For disabled people generally, as originally conceived in the independent living movement in Europe, the ability to choose a PA is the most important factor in enabling choice and control (Mladenov, 2020). These findings indicate the practical limitations to the ability of people with intellectual and developmental disabilities and their families to 'choose' or 'control' support, as well as the skills involved in negotiating and managing it. The idea of an individual, autonomous, disabled employer does not generally reflect how the support arrangements operate for people with intellectual and developmental disabilities (see Williams & Porter, 2017). Brennan *et al.* (2016) propose the concept of 'supported personal assistance' to distinguish between user-led personal assistance and assistance requiring the support of others, particularly parents. Such a distinction is arguably incompatible with a relational view of autonomy, and creates a false dichotomy between 'user-led' and 'not user led'. the notion of choice and control in the hands of the user, whether supported or not, fails to capture the complexity of the factors involved in employing PA support, especially the role of the agencies and third-sector organisations that supply PAs and the basic dependence of choice on the availability of a supply (Scourfield, 2005, anticipates the current lack of candidates). In two cases in the current study (Anna and Fiona), the PA had been provided by an agency and a third-sector organisation with little or no choice or communication between the employing and employed parties. James' PA, also, was employed through an agency, but his mother had succeeded in negotiating to obtain the specific person she wanted. Greg was supported by a 'micro-provider' (an individual with several clients), but as this was a rural setting there was little choice locally available. Fiona's parents regretted their inability to establish channels of communication with the PA ('We could tell them in half an hour what it would take them five years to learn'), but were understandably reluctant to take on the responsibility and labour involved in employing directly, which might have made such communication possible.

Katie was employed directly, but Ciaran and his mother had the advantage of a professional framework for employment, through his mother's company. In these findings, therefore, choice and control by individuals and parents was highly constrained, and joint working between paid PA support, unpaid family support and the workplace, once in place, had added value, bracing work arrangements. Responsibility for keeping making arrangements successful could be shared across the parties, with each party having recourse to more than one source of support. This raises the question of the 'employer' contribution.

The limits of 'responsibilisation' - securing organisational co-operation

The findings show differences in the strength of collaboration with the workplace, as well as with the PAs. Supervisor and co-worker participants gave responsive accounts of the primary participant, but they did not offer equal organisational support. The national organisation that hosted James and Andrew had an explicit commitment to inclusive volunteering, however imperfect, and the supervisor involved was prepared to take risks ('fly by the seat of my pants'). She had the authority to consider promoting James and Andrew to ranger status on the grounds that they were becoming more widely appreciated and competent (more central) participants on the estate.

In other cases, three-way collaboration was less secure. Greg had no supervisor or co-workers as such and appeared to feel the lack of this kind of contact. Instead, his mother, Rachel, acted at times as co-worker/supervisor. The role taken by Mary, Greg's official PA, was small in comparison, so the arrangement rested disproportionately on his mother's efforts. At the library, Fiona's supervisor Barry was keen to extend Fiona's responsibilities, but unable to do so as the role of a volunteer is strictly regulated by the local authority. In these cases, possibilities for learning and development were restricted, and responsibility for accessing the potential benefits of accessing work in the public sphere remained largely outside the public sphere, in the hands of individuals and their families.

The teams with strong PA and organisational contributions had significant advantages in providing access to opportunities and organisational resources to support the arrangement. Indeed, the level of organisational backup significantly determined how far ongoing learning was possible. Hence James, whose support needs were higher than other primary participants, was about to take on a diverse and responsible job with Andrew. Fiona, however, could use her existing skills only to a limited extent, while Greg's work continued independently of the local authority that employed the people with whom he aspired to work, and which also provided his personal budget. The lack of organisational backing for arrangements made access 'tough' and limited what it was possible for people to do. For parents, securing organisational co-operation and appropriate PA support presented substantial difficulties, so that the ideal collaborative team was hard to secure. Nevertheless, there were substantial gains for young people.

7.2 Learning and capabilities: Changing the terms of social participation

Working constituted a significant change in the terms of social participation for primary participants. First, they were able to take active roles in the public sphere. Involvement in a chosen form of work, and the evidence of effort, recognition and affiliation indicate fundamental changes in what they were able to do and be. In terms of agency, they gained an ordinary ability to enact being ‘part of the team’ and to represent themselves as people and as viable co-workers. Themes of effort and recognition, mutual adaptation and affiliation indicate how learning was distributed across co-participants, as co-workers engaged with the primary participants and adapted to working with them.

The findings provide evidence of this kind of learning embedded in the social practice of participants’ work, and suggests that participatory learning theory offers a valuable framework for understanding the learning that occurs when people who are socially marginalised seek a place and a role in a public setting. In particular, there is evidence that learning is distributed among co-participants and that it engages processes by which people identify and affiliate with others in the group. The concepts of legitimacy and peripherality also seem particularly useful in the context of these participants and findings. I discuss these aspects of the findings for learning and wider capabilities in the following sections.

Legitimate doings

The learning arose in the context of legitimate participation in authentic activity, this aspect of social and cultural legitimacy was salient: there was value for participants and families in being an accepted part of shared endeavours ‘in society’ (Phil, Fiona’s father). The findings align with the claim that ‘Acceptance by and interaction with acknowledged adept practitioners make learning legitimate and of value from the point of view of the apprentice’ (Lave & Wenger, 1991, p. 111). Shared places of work, access to tools and systems, interaction and collaboration with staff are understood as forms of inclusion, while following procedures and carrying out tasks are understood to be embodied forms of collaboration with established, ‘legitimate’ practitioners. The primary participants were physically engaged in their tasks. Their engagement was sustained by the ‘fit’ of the workplace (most evidently for Anna and Fiona), by the interest and support of the PA and by the structural expectations of their work environment. The learning identified supports the participatory view that learning arises in such situations as an ‘integral and inseparable aspect of social practice' (Lave & Wenger, 1991, p. 31), often below the level of attention. The logic of participatory learning was intuitively grasped by many participants through their valuing of 'getting out into society' (Phil, Fiona's father), entering into reciprocal relations ('as a unit they are depended on', as Noreen had it) and receiving recognition ('It's something they want doing and that gives her value': Phil). I interpret the social and work structures erected by Rachel around Greg's activities – the logos, organisational affiliation and community litter-pick day that she organised – as efforts to secure the structural support and reciprocal relations of legitimate work. The policy significance of this point is that the legitimate access on which participation and learning depended was difficult to achieve, and securing and sustaining it was the family's initiative and responsibility.

Participants of each type understood work arrangements to be exceptional to some degree, running counter to social expectations about people with intellectual and developmental disabilities and relations between them and people in ordinary jobs. The key participants expanded their social networks, not hugely, but in significant ways, as in the report of Noreen's first experience of her son knowing people in his own right, independently of her through his work. The significance of 'legitimacy' is evident in the highlighting of keys, uniforms, Greg's sandwich board and other signifiers of accepted status, of having access to places and functional roles. From the participants' point of view, the social legitimacy of the role was taken to provide an external validation, which in turn secured ongoing engagement. Greg, who lacked co-workers, found a motivation for his work in his identification with the key workers he encountered: 'I do it for them.' These findings suggest that for these participants being part of a 'legitimate' enterprise, where their activities mattered to others and were recognised, consolidated engagement and motivation. This phenomenon of effort and performance being related to the perception of others' investment in a cooperative activity is noted by Lave and Wenger (1991) and in recent psychological research (Chennells & Michael, 2018, p. 1). Here it is prominent as a theme as a notable contrast with other experiences of low expectations and exclusion.

People learnt effectively from being active in their public setting - according to those who knew him best, James was learning from positive public response that his activities might be socially valued. In Greg's phrase, litter-picking (what he does) 'makes people happy', in a phrase he repeated when people thanked him. Having a socially shared goal – to maintain and shop or estate, or keep a village community clean, meant that young people's performance was held up to evaluation, and mattered to others. Participants' understanding of this is implicit in Anna's mother's description of the effort that Anna put into learning work practices: 'to remember the procedures, to not forget them and do them correctly… she learnt that and kept it up.'

The primary participants were physically and affectively engaged, preparing carefully (going to bed early), putting in effort (‘she’s not putting that on for the camera, she’s always like that’: Barry) and consequently ‘exhausted’ (Anna’s mother) at the end. They worked with ‘focus’, ‘patience’ and ‘enthusiasm’, according to co-workers. The theme of effort and recognition relates to the interdependence involved in working towards a shared goal, which, as cared-for people, they did not often experience. Given the apparently peripheral nature of some participation, effort and recognition are strikingly represented in the findings.

The theme underscores how the changing role of the participant or partnership was mutually defined with others in the situation (Rogoff, 2003); that is, their effort made a difference to others. This is clear in James’ supervisor’s account of how he and Andrew became allies (‘our go-to people’) in the battle against leaves and moles at the picnic tables. Even with her limited hours of work, Fiona’s work contribution and her character had made an impression on her supervisor (‘she's a very focused woman… a bit of an unsung hero, kind of thing’) so that, in his perception, his library had benefited and was in better order than others, and Fiona deserved wider recognition (‘It's about time people realised what she is doing.’)

Together these themes constitute a cycle of participation and reciprocal learning that, in James’ case, was moving towards more central participation and further learning as a ranger. Without organisational support, Fiona’s supervisor could offer only interpersonal recognition, and her opportunities were not extended.

Legitimacy, learning and value

Most participants in this study were able to identify significant learning by the young person, despite the unobservable and elusive nature of learning. They first identified work-specific knowledge and skills, such as understanding cat illnesses, how to identify human litter, dexterity with a litter-picker or how to use a cash register. I infer from the findings that the primary participants learnt how their personal skills and interests could serve a functional purpose and be valued in a public setting, perhaps in a specialist setting (like Anna and Fiona). They attached importance to the evaluations of others in the workplace. Anna was ‘always saying’ how much she was trusted at work; she gained the confidence to ask for special privileges, such as access to staff-only kittens. Fiona was proud that Barry rated her work highly.

Learning and exercising functional skills that were useful in the chosen environment acted as an important counterweight to the presumption of incapacity and redundancy spelled out by the limited range of options and horizons found in social care. Ciaran’s mother described how, through learning to use the cash register, Ciaran had come to understand that it was a valued skill and that using it had implications (‘he learned that kind of pride in doing a job well and also seeing himself as equally valued’: Tricia). Judith described the regard that Anna earned in work at the cattery, by contrast with the ambivalent message implicit in Anna’s day care: ‘They're sort of forming them all, to sort of improve their social skills’.

Learning through embodied and situated encounters with values and practices is prevalent in the study’s findings. Andrew’s account of James’ learning not to take offence when people ignore his greetings (‘It would've been nice if they said “Hello”, but they haven’t, and we'll carry on’) is a striking example of useful social learning understood to have caused a change in behaviour (‘James used to have difficulty coping with that - he'd try to follow them to get that response. But now he seems to accept it more’: Andrew). James was also thought to have learnt something about his work appearing to be meaningful to others (‘He realises that because of what he's doing, that's then eliciting this positive’: Andrew), which his mother saw as having a long-term implication for him: ‘In a sense, that's where his pride in and sense of achievement will come… because of the acknowledgment’: Noreen).

Greg’s ability to interpret people and places through his litter-picking is a further example of social learning, for example his capacity to ‘read’ a residential street (‘Obviously people down here cares a lot’) or his understanding of objects concealed in a shrubbery (‘Really winds me up [when] people hide things. Like they’re guilty’). Other social learning ascribed to Greg was seen as advantageous for his future work and social functioning. Interaction with members of the public involved learning about social norms: ‘he learns, in a slow way, because of the repetition, about the different members of the public, what it is acceptable to speak out about and what we might think but we don't say.’ This exchange involved learning by others, as Rachel reflected that, when Greg lectures people about litter-dropping, ‘Majority take it in a really great, good way. And I don't know, maybe in their own way, the community themselves learn from him’.

These examples suggest the stream of learning that is embedded in participation and work, mediated by PAs and by others in the situation. Billett (2008) describes a relational interdependence between the contributions of personal and social agency in learning at work. He sees the participation aspect as providing access to work requirements and as structuring learning opportunities, while personal factors such as individuals’ ‘capacities, subjectivities and agency’ (p. 39) shape how they interpret and engage with their experiences. I interpret the positive learning findings here as highlighting the value of access to work for people with intellectual and developmental disabilities, for the opportunities it can provide for the development of such a relational interdependence between social and personal agency. Through supported participation and learning, these primary participants seemed to be navigating social structures that enabled them to take part in ‘interpretive sense-making’ (Yeoman, 2014) of the world around them.

These findings offer an alternative to the instrumental and didactic conceptions of learning exemplified in supported employment and social skills training (Beyer & Robinson, 2009; Nord *et al.*, 2013), where compliance is strongly featured. Significantly, the learners here are able to act as agents in their social environments. To my knowledge, these learning findings are the first in research on participatory learning at work by people with intellectual and developmental disabilities.

Personal support and the goods of work

PAs supported learning while simultaneously ensuring that young people achieved work targets. This was especially the case for the two PAs (Katie and Andrew) who worked closely alongside the primary participant whom they supported. They gave detailed accounts of how they operated to facilitate work and learning through such practices as 'translating' communications (Katie's term), correcting misunderstandings ('these are leeks, not celery'), modelling behaviours (how to replace the bin bags) and performing a quality control function. For co-workers, these PAs also modelled positive relationships with the supported person and demonstrated forms of communication, for example using simplified language, which also enabled tasks to be completed successfully. These were the sorts of practices that made work and learning manageable for primary participants and for co-workers and underpinned the consensus that successful arrangements depended on PA support. Katie and Andrew's detailed accounts of learning and adaptation by others in the workplace indicated their close attention to this mediating aspect of their work. Andrew's description increasingly well-judged suggestions by staff at the estate show his close tracking of co-workers' perspectives, as does Katie's description of the mutual adaptation in communication between Ciaran and Helga (p. 133). Supporting reciprocal learning and positive relationships were interwoven aspects of making work successful that can be understood as significant contributions to the agency of the primary participants.

In the capabilities literature, learning is primarily discussed in terms of formal education, which is understood as a key capability for its ability to generate further capabilities. The approach ascribes an intrinsic and instrumental value to education in promoting well-being and agency (Saito, 2003; Terzi, 2005; Reindal, 2009). To achieve this value, education should foster autonomy, the capacity to make informed choices (Saito, 2003, p. 28). Outside the capabilities approach, learning is supposed to have the capacity to 'translate' into agency (Biesta *et al.*, 2008). Yet the capacity of both education and learning to translate into agency is dependent on the learning being positive, which cannot be assumed (Biesta, 2008; Unterhalter, 2003). Unterhalter (2003), for example, questions the assumption that education can be unproblematically equated with capability expansion, pointing to the potential for negative learning embedded in unequal social relations in schools. Here, the mothers of Anna and Ciaran gave instances of negative learning that occurred in school (see pp. 99 and 107). Work participation, too, has negative learning potential. People with intellectual and developmental disabilities have often experienced rejection and social isolation in work (e.g., Hall, 2004; Hall & McGarrol, 2012; Merrells, Buchanan & Waters, 2019; Ramsey, 2020), learning at first-hand how they are perceived by others in such contexts. Without PA support, primary participants in this study might have learnt 'that things are too difficult or that they cannot cope' (Biesta *et al.*, 2008, p. 20). They and their co-workers might have experienced collaboration as too demanding, as James' supervisor feared. Fiona's PA conceived of the possibility of negative learning for her if she were alone at work, recognising that an aversive episode could end her work at the library, and that this possibility justified his attendance. In acting to support mutual understanding and successful work, mediation by PAs appears to have been effective in preventing this kind of learning on either side. The findings for recognition and affiliation in this study contrast with previous research documenting difficult experiences in work (e.g., Hall, 2004; Hall & McGarrol, 2012; Merrells, Buchanan & Waters, 2019; Ramsey, 2020). Social problems and social isolation at work in particular have been widely reported (Jahoda *et al.*, 2008; Beyer & Robinson, 2009; Hall & McGarrol, 2012; Ramsey, 2020). Participants referred to diverse support functions underpinning positive learning and work outcomes, which were differently distributed between PAs and families in each case, and which promoted the capabilities of the young people. These findings can be understood in terms of theoretical accounts of relational agency (e.g. Mackenzie, 2014; Davy, 2019). They add examples and qualitative detail to the conceptualisation of relational autonomy for people with intellectual and developmental disabilities.

To my knowledge, these learning findings are the first in research on participatory learning by people with intellectual and developmental disabilities.

Capabilities and the goods of work

'Meaningful' is a term used by Yeoman (2014) and Weidel (2018), in their arguments for work with this quality to be understood as a fundamental human need, the lack of which constitutes an important capability deprivation. Meaning and purpose in work are elusive concepts, but the study's findings show families and young people investing effort to counter the 'meaningless' activities understood to be offered within social care parameters. The term 'meaningless' recurs in the critique of services theme (e.g., 'I think for young adults with learning disabilities, a lot of the things they do are meaningless': Noreen). The findings suggest that the primary participants occupied roles that were meaningful to them~~.~~ The recognition of co-workers and supervisors, and the warmth it conveyed, suggest that they too saw the contribution to work as 'meaningful'.

Yeoman sees such work as constituting a fundamental life opportunity, for experiencing meaning and for the development of capabilities. Following feminist arguments, she proposes that the possibility to find meaningful occupation is enhanced when work is not equated with employment but ‘includes the diversity of unpaid work which sustains and reproduces our common life’ (Yeoman, 2014, p. 238). Weidel (2018) argues that a capability to work is necessary to ‘shape our connection with the world’ and to develop ‘sociability with others’. Moreover, these are capacities, he argues, that develop through use, ‘insofar as we are able to connect with others and work together’ (p. 74). For these reasons, a capability for meaningful labour should be a core capability, he claims, rather than a ‘right to seek employment without discrimination’ since such a right offers nothing in capabilities terms to people ‘who seek but cannot find any employment’ (p. 76). I interpret the findings for participants in this study as validating these ideas of specific capabilities gains attached to work understood to be meaningful, rather than to all forms of employment. Primary participants attained the kinds of capabilities described by Yeoman and Weidel, linked to learning, making sense of the world and legitimate social participation.

It is a key finding that work acted in these people’s lives not as an occupation on a par with leisure and consumption activities, but as an opportunity offering distinctive potential in terms of capability expansion. In Sen’s terms a capability is precisely an ‘opportunity made feasible’ (Robeyns, 2011). For primary participants, having PA and family support, and bypassing the constraints of employment, made such opportunities attainable. Active social participation, positive reciprocal learning and affiliation can be conceived as significant capabilities gains, independently of the scale of participation.

Nonetheless, these capabilities had an ambivalent relationship with personalisation.

Personalisation: capabilities for some people

These significant achievements by the primary participants demanded ongoing parental investment in addition to the PA support that was funded by personalisation. The setbacks of Covid-19 highlighted the capability-enhancing aspects of supported work (the ‘freedom and respect’ that it offers, in contrast to inactivity and confinement) but also the scale of the parental effort needed to keep it going in challenging circumstances.

While parents could use the resources of personal budgets to employ PAs, and PA support made work viable and sustainable, the arrangements were otherwise based on a rejection of the values and practices found in social care. The considerable role taken by parents is in line with previous findings about family support in work by adults with intellectual and developmental disability (e.g., Petner-Arrey, Howell-Moneta & Lysaght, 2016; Romualdez, Yirrell & Remington, 2020).

However, the magnitude of the support that is found in this study differs, in that parents had set up novel arrangements and found and supervised PA support for them, as well as providing the psychological and practical support that have been identified in previous research.

The option to take part in work enabled by PA support constitutes an important capability gain made possible by personalisation. The study's findings here are paradoxical: for primary participants and their carers, PA-supported work could end the key constraint that limited opportunities for social co-participation, the restriction to disability and domestic settings. PA support enabled care and support to take place in the public sphere, alongside ordinary processes of learning and participation. It also enabled the responsibility for care to extend beyond the family and disability-specific organisations. This is seen as an important freedom for disabled people and families, advocated by feminists and disability activists (e.g., Fineman, 2013; Shakespeare *et al.*, 2017). Yet personalisation also implicitly provides an added role for family carers, described as 'an extended caring and advocacy role as the welfare state retreats' (Giri *et al.*, 2021, p. 1), and which is well documented (e.g., Brennan *et al.*, 2016; Malli *et al.*, 2018). Establishing new practices outside the parameters of social care and social norms presented a substantial task for the parents in the study, sometimes shared with PAs, who were themselves precariously supported for this role. Even where the PA role was larger and the responsibility was thus more widely shared, securing and overseeing support remained parents' responsibility. The comprehensive critique of services theme saw parents dismayed and frustrated by the unshared nature of responsibility that they found in social care settings: 'It was like, "We can't help you anymore. Over to you"': Fiona's parents). Participants perceived control over money to be the sole empowering aspect of personalisation. Rachel's phrase, 'take the money and run', summarises effectively what the participating parents thought and did. In this sense, the arrangements for work involved the chance of long-term capabilities gains for the young people and for family carers, alongside the immediate reality of substantial responsibilities and constraints of unknown duration and scale.

Reciprocal relationships, affiliation and social inclusion

Chapter 3 discussed the four kinds of 'goods of work other than money' identified by Gheaus and Herzog (2016): attaining competence or proficiency, making social contributions, experiencing community and gaining social recognition (p. 51). To differing extents these are reflected in the study's findings for the young people. Through their work they developed of competence or proficiency to varying degrees as suggested in the findings for participatory learning. It is strongly exemplified in the specialist work-related knowledge acquired by Anna and Greg, and is also recognisable in Ciaran's resilience and versatility as a worker. For James to become one of our 'go-to people' (supervisor) indicates a shared competence (i.e., with Andrew) that was outstanding, for him. Fiona, however, was using rather than developing her skills. The other 'goods of work' emphasise the dimensions of social cooperation interwoven in work. As a whole, as argued in Chapter 3, these goods align with some views of what constitutes social inclusion (p. 51. I focus here on reciprocity as a dimension of work relationships, the 'experience of community', and the theme of affiliation, for their bearing on social inclusion.

Positive attitudes towards the supported person as an individual were a striking feature of the findings, and as stated, stand in contrast to reports elsewhere in the employment literature. Co-workers expressed such attitudes directly and implicitly, and they were referenced by other participants. Patronising and discriminatory attitudes towards people with intellectual and developmental disabilities and primary participants specifically are referenced within the 'critique of services' theme and as possible attributes of PAs be avoided. Given the negative reports for social acceptance reported elsewhere, it is likely that the mediating role of PAs was instrumental in this outcome. Other research suggests that the quality of interpersonal interactions with people with intellectual and developmental disabilities is strongly related to positive attitudes toward them (Keith, Bennetto & Rogge, 2015). These findings provide evidence that PA support might be an important factor in maintaining such quality. Over time, working with PA support work appears to offer a degree of social inclusion, at least insofar as it enables active participation by people with intellectual and developmental disabilities outside domestic and disability-specific networks.

In these findings, the theme of mutual adaptation shows learning and changes in behaviour occurring in response to work participation by young people. The idea that individual, interpersonal and cultural-organisational processes are dynamic and mutually constituting is an underlying premise of participatory learning theory (Rogoff, 2003). It is understood as the means by which people can achieve agency: by taking an active role in a 'mainstream' shared practice people are able to exert influence in the community involved. In small but meaningful ways, other people in the workplace adapted to accommodate the primary participants in this study, modifying how they communicated or shared tasks and coming to greater understanding of their positions and outlooks. James' supervisor described the learning that took place for her and other co-workers as a cumulative process: 'I just think it's been like a drip, drip… rather than big "Aha" moments'

The theme of adaptation includes references to primary participants as part of their work communities, with responsibilities on both sides. Tricia understood the community shop as recognising that 'it's a two-way street and actually people need to come to work as much as they are needed at work.' James' supervisors came to understand him as 'just part of the team', and responding to events as others did ('he was feeling a real human feeling that many of our volunteers felt'). These are ordinary feelings between people who have something in common, but in representing the sentiments and actions of people in workplaces towards people with intellectual and developmental disabilities they are unusual and, indeed, may represent what people had been seeking in moving outside social care. I interpret the findings for recognition and affiliation as indicating that the participants had attained at least a micro-level of social inclusion within the setting in which they were active.

7.3 Film, speech and embodiment

The video-making part of the methods for this study was planned primarily to provide engaging and supportive stimuli for interview and the opportunity for me, as researcher, to observe the circumstances of people's work and how they engaged with it. As the research progressed the video record gained importance for its function as a representation of competent and valued participation in its own right. Collectively, the videos show primary participants immersed in their work, investing effort and being productive.

In the video review sessions, the primary participants made useful points and comments, but their verbal contribution was relatively small. (The exception was James, who has no speech, but engaged in watching intently and gave his thumbs-up sign many times – to the video, to the activities shown or to himself and Andrew (see Figures 5.1, 5.2)). They saw the video as the substance of their contribution to the project. They were pleased to be filmed, pleased with the resulting film and keen for it to be shown in public. The problems of access and past histories of difficulty that featured in the parent discussions are not observable in video, although some limitations and challenges can be inferred. Greg's film, for example, shows him commenting on what he is doing and why. Reviewing the video, he had little to add ('Well, you can see that…'). He did say that his video might show other people like him that they, too, could have a working role. In general, primary participants tended to see the video as explaining and showing the business of their work and learning in its own right.

In the course of analysis, I concluded that the video represented the beings and doings of primary participants more completely than was possible by quotation from their transcripts. One outcome is the limited number of direct quotations of primary participants, as their comments tend to need elaboration and contextualisation and, given the language difficulties, would be liable to conceal rather than to reveal the participant's competence. This conclusion suggests that for people with intellectual and developmental disabilities, film footage of their work might have a useful function in advocating for their participation in work and employment circumstances (e.g., in place of interviewing), as it has in representing autistic children in transition planning processes (Wood-Downie *et al.*, 2021).

The role of video in this study as a means to communicate competent embodied activity therefore highlights important issues for research methods and for education for people with intellectual and developmental disabilities. First, it highlights how learning in embodied activity in participation gives opportunities for people with intellectual and developmental disabilities to experience competence as learners, lessening the burden of verbal mediation that dominates in education settings. Second, it provides an added dimension to the appraisal of interview methods in research with people with intellectual and developmental disabilities: the difficulty of representing the competence of people with intellectual and developmental disabilities by verbal means.

7.4 Capabilities outside employment

A capabilities approach provides a framework to examine how the prevailing context of economic production (i.e., the dominance of competitive employment) and social interaction (or lack of it) impacts on the ability of individuals of all types to pursue the ends that they value. The difference between capabilities and a rights-based perspective is represented in the difference between the rhetoric of real jobs and the achievability of any job by people with intellectual and developmental disabilities. The rhetoric of 'real jobs', where the terms and conditions are the same for everyone, 'including pay…, employee benefits, safe working conditions and opportunities for career advancement' (BASE, n.p.), is far from 'real' achievable beings and doings. The study's findings here indicate that some forms of work participation can be achieved even while 'real jobs' are not achievable, and that work participation can enhance the capabilities of the people concerned.

A capabilities approach provides a means to assess the capacity of personalisation policy to promote meaningful choice and agency in the lives of the people to whom it is applied. It highlights the range of possible ways of life from which a person can choose, so resisting the imposition of a normalising ethos. In this study, I took the capabilities of social participation and participatory learning as the capabilities of interest, and understood agency and relational agency to be skills or cognitive abilities to be developed through the support of people, institutions and, in particular, PAs. Sen (1999) argues for five priorities in assessing capabilities: real freedoms; conversion factors; the significance of variability in individual preferences; a balance of material and non-material factors in wellbeing; and the equitable distribution of opportunities. I consider each of these in relation to participants and themes.

The findings of the study indicate that people who have little capacity to compete in a globalised jobs market can extend their capabilities and agency through participation in work, provided that they have adequate relational support. The processes of cooperation and reciprocal learning that are involved in participation are significant to social inclusion. The option to take a preferred role in a public sphere that is being realised by these participants can be interpreted as a significant change in their capabilities: it represents access to elements of 'mainstream' society in terms of places, activities, roles and relationships.

The study's findings show this access to have been valuable in delivering opportunities for social and cultural learning, including for reciprocity in learning, access to shared public places and tools, and affiliations with others. The relational support provided by a PA promotes the capability of the participant concerned, even if it only minimally allows them to undertake an activity or pursue an interest that would otherwise not be possible. In this sense the capability to participate serves a foundational purpose in what people can do or be.

It is a core premise of the capabilities interest in diversity that individuals differ greatly in their ability to convert the same resources into a capability, and a capabilities approach is concerned with equality in the distribution of opportunities across society (Robeyns, 2017). In capabilities terms, the primary participants and families were able to convert the resource of personal-level funding into a capability for work by employing a PA. In doing so they were responding to some of the aims of personalisation: to move from undifferentiated group day care to more personally tailored activities in the community. However, the personal conversion factor of being disabled played out differently, depending on the kinds of work and support for work that people were able to secure.

Effective organisational support was difficult to achieve, and there were differences between the PAs in terms of their capacity or intent to support the agency of the young person. The study's findings show these families, with a substantial investment of time, effort and resources, achieving significant capabilities. Funding for PA support was a significant factor, but the capability generated by these families was not achievable through personalisation policy alone: individual differences in family support indicate that, under personalisation, the capability to work is not available to every person with intellectual and developmental disabilities. This finding is in line with research suggesting that the promise of choice that is assumed in personalisation is likely to be conditional on other factors, and that the 'responsibilisation' of individuals and families undermines the equality of opportunity (Malli *et al.*, 2018; Dursin *et al.*, 2021). Here, the theme of critique of services constitutes evidence that personalisation policy and its embodiment in practice act, in many respects, as a significant constraint on young people's capabilities.

Important social conversion factors are also at play: a society in which public policies and social norms hold employment to be the valid form of social participation constrains other possibilities. This factor added significantly to the difficulty of access to organisations that was experienced by the participants: the proposal for young people to work, unpaid, with PA support was outside the organisations' experience and expectations. Some parents themselves struggled with the implications of the work being unpaid, and some workplaces, including the library, had restrictions on what work could be done without pay.

Personalisation continues to promote independence and the reduction of dependence as an aspiration for people with intellectual and developmental disabilities, using the language of independence 'in a way that fundamentally distorts the origins and potential of the term' as a means towards an enabling society (Roulstone, 2015). This focus has produced increased isolation (Malli *et al.*, 2018) and erected attitudinal barriers to the possibilities for relational agency. There is evidence that complex interdependencies underpin the practices of people with intellectual and developmental disabilities and enable valued opportunities for (e.g., Power *et al.*, 2021).

With respect to the balance of material and non-material factors in wellbeing, capabilities scholars have been prominent in noting how the shift in global social policy towards promoting people's labour market participation is coercive and constrains people's capabilities (Dean *et al.*, 2005; Laruffa, 2020; Van Berkel, 2021). Laruffa (2020, p. 1) notes its reductionism: it 'reduces people's capability to their capacity to participate in the economy.' He argues for social policy to increase, rather than to reduce, the number and variety of valuable options open to individuals, including unpaid care work and political participation. His argument has particular force when applied to the position of people with intellectual and developmental disabilities in the labour market. I see the findings of this study as supporting the value of work outside employment as a means to develop the capabilities of people who have been disenfranchised by an employment-focused paradigm.

The final point on Sen's list of factors for assessing capabilities is the distribution of opportunities across society. First, when a particular group has no route to social participation, opportunity is profoundly unequally distributed. To be able to navigate values and meanings in their societies, people require access to the social structures that allow them to develop the relevant capabilities (Sen, 1999). Personalisation policy, as I have suggested, provides resources that can be converted into capabilities only insofar as families are able to mobilise the interpersonal, social and institutional scaffolding to support the person's participation.

Chapter 8 Conclusions

Introduction

This study has explored work participation and learning by young people with intellectual and developmental disabilities in the context of personalisation policy in social care, which made possible the employment of personal assistance. I have considered the participation and learning from the point of view of participants' capabilities, or what they are effectively able to do and to be. Re-examining questions of inequality, in Sen's view, requires evaluating and assessing social arrangements in the relevant social and cultural setting. I have aimed to address research questions on the motivation and practicalities of work arrangements under personalisation, and to explore how far participation and learning have extended the capabilities of a small group of individuals who are at risk of social marginalisation.

I considered in depth the cases of five young people with intellectual and developmental disabilities who were engaged in work suited to their preferences and abilities, with PA support, in various public settings. I used a bespoke research design, taking a collaborative approach involving the perspectives of the young people, the family members supporting them, the PA working with them, and the co-workers and supervisors involved. The collaboration involved recording video footage of primary participants in action at work.

I filmed each primary participant performing their tasks in their work setting on several occasions in a process that was interrupted and extended by the lockdowns of Covid-19. I reviewed and labelled the video footage, making it available to the group of participants involved in each young person's work. I then met with each participant separately to review the video, using it as a stimulus and support for reflective dialogue on their experiences and perspectives. We discussed why and how the arrangement was made, from the perspectives of the various stakeholders and the impact of the work on both the individual and the workplace. We zoomed in to recorded incidents, such as interactions and tasks, and zoomed out to consider the broader questions of impact and significance. I video-recorded participants' spontaneous responses to viewed episodes and asked about access, roles, learning, interactions and relationships.

The process of analysis took place throughout collaboration and transcription. In the final stage I coded and analysed transcripts of video footage and video-supported discussions to produce case-by-case narrative portraits and findings in the form of cross-cutting themes. These narrative portraits emphasised the diversity of personal characteristics, circumstances and work preferences, and differences in the kinds and levels of PA and organisational support for the arrangements. Some people worked rather limited hours, not necessarily by choice, yet the work had taken on a defining importance in their lives. Despite the diversity within the group, a characteristic strongly shared among all primary participants was the robust and informed family support combined with the will to achieve forms of social and occupational inclusion.

The fieldwork and analysis addressed, first, the motivations for making the work arrangements: how far personalisation had promoted or supported the choice to work with PA support. The findings showed three driving forces underlying the relationally shared wish to do work: the critique of services theme; the desire for social participation; and a wish for structures of legitimate work to support purposeful activity.

Participants and others spoke about the legitimacy of the work: the primary participants embraced evidence of their ‘legitimate’ status, and the co-workers and supervisors recognised their own gains. This theme brought together ideas of belonging in the work situation and being an accepted part of it. Effort and recognition marked the reciprocity involved in work participation, while mutual adaptation and affiliation captured aspects of accumulating and deploying mutual knowledge, and of developing social closeness. Participants highlighted these small-scale reciprocal processes as significant to young people and also to other participants through shifting the balance of evidence away from a dependent and devalued identity.

These findings make a strong case for participatory learning as a mode of learning that has advantages for people with intellectual and developmental disabilities. The learning findings suggest the potential in approaching inclusion and agency as dynamic, reciprocal, learning processes, as implied in the theorising of relational autonomy (e.g., Mackenzie, 2014) and participatory learning (Lave, 1991; Tomasello, 2016). Participants described episodes of social and cultural learning that they understood to have occurred, giving examples of developing and new skills and knowledge, and some striking examples of modification in people’s understandings of ‘how the world works’, in one parent’s phrase. The learning described fits well within theoretical descriptions of social and cultural learning as being about learning to participate effectively in shared goals from the structure of the environment and from the people within it. The five key participants came to know, and were known by, an additional circle of people, and were recognised by them as legitimate co-participants. These achievements may appear unremarkable, but the effort to establish novel arrangements outside of social care parameters suggests how strongly families and young people sought these ordinary forms of inclusion. It was evident that access to participation in public social settings had extended the capabilities of the primary participants in important ways, giving them access to social and learning situations and, importantly, opportunities to develop and demonstrate competence as co-participants.

The findings show diverse patterns of support need being met by PAs, and partnerships with PAs, to be jointly valued. PA support made it possible for participants to pursue work arrangements, tasks and relationships that would not have been achievable ‘independently’. Since the work arrangements depended on both PA support and the efforts of young people and their families, funding for personal assistance has enhanced the capabilities of only those people who are able to mobilise other resources.

The sections below report the key conclusions of the study under six headings:

- Valued work in public settings can be attained through bottom-up arrangements
- PA-supported work is sustainable and compatible with an ethic of care
- Bottom-up arrangements can provide interpersonal support for capabilities and agency, but organisational and social support is limited
- Personalisation provides a resource but no infrastructure to support people to work
- Participation and learning can bring relations of reciprocity, recognition and affiliation
- The capability to participate in the social world is a substantive and fertile opportunity linked to agency and learning.

For each case I consider the study’s contribution to the literature on intellectual and developmental disabilities.

Valued work in public settings can be attained through bottom-up arrangements

Fitting, legitimate work is not easy to achieve for people with intellectual and developmental disabilities, but it can be a valued and sustainable means to social participation. Work arising from jointly structured, bottom-up arrangements can be personalised to a high degree of specificity. In the study’s findings, parents, young people and PAs had jointly arrived at the arrangement to suit individuals’ personal characteristics, recognising their strengths and interests and providing for the impact of difference through flexible, one-to-one support. When organisational support, as opposed to interpersonal support in the workplace, and purposeful PA engagement were in place, collaboration between the parties had the most potential to extend capabilities and to distribute responsibility beyond domestic and disability-specific settings.

Bottom-up collaborative processes can achieve a creative fit of the person to the work at a level of specificity that is not conceivable for supported employment as currently conceived. As well as finding an appropriate niche for an individual, working from the bottom up enables the overall advantages and disadvantages of a possible arrangement to be taken into account, including choosing what counts as a worthwhile setting for unpaid work.

The study provides a first report on the PA-supported work that is undertaken by people with intellectual and developmental disabilities. It identifies the significant gains attached to successful participation: access to active 'legitimate' roles in the public sphere; embedded opportunities for social and cultural learning and for recognition and affiliation. The findings provide a counterpart to the literature on supported employment, highlighting both the basic problems of access to and availability of supported employment (e.g., see Department of Work and Pensions, 2019; Scottish Government, 2021), alongside limited conceptions of learning and social support (e.g., Roulstone, Harrington & Hwang, 2014). The strong family support found in this study aligns with many accounts of its importance in the literature (Petner-Arrey, Howell-Moneta & Lysaght, 2016; Chan *et al.*, 2018; Giesbers *et al.*, 2020), but the specific role detailed here is novel, and shows parents acting to support the autonomy of young people. The analysis extends and adds detail to findings connecting productivity and social inclusion (Lysaght *et al.*, 2017).

PA-supported work is sustainable and compatible with an ethic of care

Having PA support extends the range of what people are free to pursue. With PA support, people who cannot choose to take part in work as a solo activity can work, giving them access to public spaces, tools and activities, and so enabling further capabilities for social and cultural learning, self-representation and affiliation. PAs can provide flexible, relational support for participation and learning, making tasks just out of reach viable and adapting to manage opportunity and vulnerability. The partnership between a PA and the supported person is valued, and supports positive relations in the workplace.

The study indicates that PA support can itself extend the capabilities of people with intellectual and developmental disabilities, and in this sense the findings challenge the discourse of independence in policy and practice. As a first research report on PA support for work, findings indicate the value of relational agency as a theoretical basis for understanding PA support. They lend qualitative support to the contention that personal assistance, as a form of relational support, can enable relational autonomy and extend capabilities (Mladenov, 2012; Mackenzie, 2014). Indeed, they illustrate vividly how prioritising independent performance can constrain people to a limited range of environments and activities. This has important implications for personalisation policy and the recruitment and orientation of PAs.

Bottom-up arrangements can provide interpersonal support for capabilities, but organisational and social support is limited

In a capabilities framework, a person's options 'depend greatly on relations with others' and 'on what the state and other institutions do' (Drèze & Sen, 2002, p. 6). The arrangements described in this study were set up outside of the social care framework, in a spirit of dissent and in implicit challenge to the expectations of social care and society. The interpersonal element of support was strong but social and institutional elements were weak or absent. Access to work in public settings – the first requirement of participatory learning – is impeded by social and institutional factors, including the difficulty of negotiating access as a person with intellectual and developmental disabilities using personal assistance. The findings support arguments in capabilities and feminist literature for work to be understood more broadly than as paid employment, to include 'the diversity of unpaid work which sustains and reproduces our common life' (Yeoman, 2014, p. 238). Social norms around employment (both for work to be configured as employment and for solo performance) and the culture in social care ran counter to arrangements for work. These two frameworks narrowed the conceptual and social space available for the alternative approaches pursued by the study's participants. Bottom-up arrangements extended participants' capabilities but the absence of social, institutional and policy support limited in some cases how far this was possible.

Personalisation provides a resource for PA support but not an infrastructure for participation

Personalisation provided the basic mechanism for PA-supported work, yet in other respects gave no support for work arrangements in the study's cases. Knowledgeable and motivated parents communicated directly and implicitly the effort and costs that had been involved in their making their arrangements. Hence these findings confirm the mismatch between personalisation's 'reponsibilisation' of individuals and what, without institutional and societal support, individuals are able to achieve (Roulstone & Morgan, 2009; Power *et al.*, 2021).

From a capabilities perspective, personalisation enables people to convert the resource of a personal-level funding into a capability to work only where strong family support is available. In this sense these findings align with other evidence that personalisation does not support equal opportunities for people with intellectual and developmental disabilities, because the realisation of choice and control is reliant on further support, and on social and institutional factors that personalisation policy fails fully to recognise.

Participation and learning can bring relations of reciprocity, recognition and affiliation

The study's finding is that there are strong links between work participation and opportunities for basic social and cultural learning. Strong collaborative relationships between young people, PAs and people in the workplace reinforce motivation and underpin reciprocal learning. The film and the discussions around it highlighted how learning in these settings held a meaning as a socially and culturally sanctioned activity. Participants' 'apprenticeships', however peripheral, provided individualised and realistic learning settings (Lave, 1991) with the mandate of the cultural group and its institutions (Tomasello, 2016).

The processes of working in a well-fitting role can engage participants in powerful processes of experiential learning that are personally meaningful, shared with others and grounded in social co-participation. As participants contribute to shared goals in concrete and embodied ways, they achieve the status of co-participants and group members. Embodied forms of learning have important benefits for the learning competence of people with intellectual and developmental disabilities, replacing the constraints of formal learning practices with achievable actions. This is evident in the video footage, where each person performs functional tasks that have value in the workplace. The relational and self-directed aspects of participatory learning respect the adult status and agency of people with intellectual and developmental. The examples of changes, both in how the primary participants made sense of and acted on the world and of how the people in the workplace adapted to them as people and co-participants, provide evidence of significant learning taking place. The learning findings fit many of the patterns described in the literature for social and cultural learning (Lave & Wenger, 1991; Rogoff, 2003; Tomasello, 2016). Participatory learning theory is distinguished by its theorisation of the purposes of learning; that is, more effective or ‘central’ participation in community practices or learning ‘to collaborate, with appropriate demeanor and responsibility… to be responsible contributors belonging in the community’ (Rogoff, 2011, p. 413).

Learning embedded in social participation deserves further exploration as an active process of social inclusion for people with intellectual and developmental disabilities. The findings stand out in the context of the extensive literature on under-occupation and social exclusion for people with intellectual and developmental disabilities (e.g., Ashley, Fossey & Bigby, 2019; Charnley *et al.*, 2019; Merrells, Buchanan & Waters, 2019).

Capability to participate in the social world is a substantive and fertile opportunity linked to agency and learning

In the intellectual disability context of social exclusion and a lack of employment, the capability to participate in shared community endeavours is a substantive capability. This capability is arguably wider than the (absent) capability to be employed, marking the difference between social participation and social marginalisation. People unable to access employment were able to participate in the underlying process/activity of work, and to do so on terms more nearly controlled by them (i.e., through the bottom-up processes described above). Through the reciprocal processes engaged by work primary participants were able to modify a key dimension of a disabled identity by taking on roles as helpers rather than as helped people. This suggests that a basic capability for agency, a critical requirement for people not participating in employment (Claassen, 2015) can be met through supported work.

8.1 Contribution

This study challenges the social norms that delegitimise work outside employment and the conception of autonomy as solo performance ('independence'). These norms are embraced in policy, and they impede access to participation and reciprocal learning in the public sphere.

Referring to the capabilities approach and the recognition of diversity, I argue for language, policy and practice to acknowledge the impact of differences between people. My aim has been to recognise the possibility of disability identity, and identity beyond disability. Arrangements for supported work manage this dual identity; that is, people with intellectual and developmental disabilities have joined with others in public settings and achieved recognition as people and as co-workers. Equally, PA partnerships recognise and meet the need for support. The findings therefore contribute to the debate on collective versus individualist provision (Roulstone & Morgan, 2009; Power *et al.*, 2020).

The findings overall show strong, positive possibilities for people with intellectual and developmental disabilities to work as a means to extend their capabilities and agency as social participants. The participatory view of learning as a two-way process of induction to culture and society is particularly valuable to consider learning in the context of intellectual and developmental disabilities.

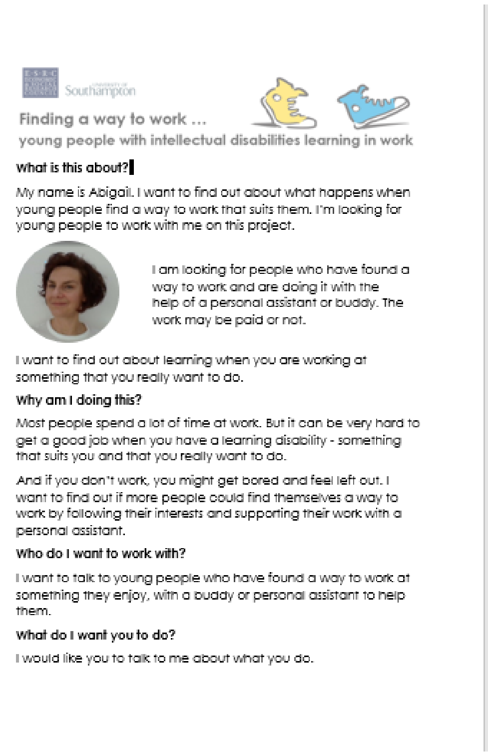
The findings raise questions about the equality of opportunity under the current social arrangements for people with intellectual and developmental disabilities. The achievements documented relate to a distinctive group of families with the skills and agency to realise ordinary aspirations. However, the critique of services that impelled them is likely to be much more widely shared, and this study suggests ways in which the status quo reduces the freedoms of people with intellectual disability to be active participants in their social contexts.

There were novel aspects to the topic of this study. Learning in informal ways by people with intellectual and developmental disabilities is a neglected topic (Nind, 2016). This study constitutes a first research report on sociocultural learning and participation in work by this population. It is one of few studies on support to bridge the gap between personal capacity and environmental demands (Garrels & Sigstad, 2021). It adds to the research literature on learning at work by exploring participatory and work-based learning for a new population. Little is known about the use of personal budgets to support work participation, described as a significant research gap

(Watts *et al.*, 2014). The study also contributes to a new literature on employment for adults on the autism spectrum (e.g., Hedley *et al.*, 2017) by focusing on those with intellectual disability.

Finally, I return to the question of equality and capabilities. The capability to participate in socially valued endeavours, attained by the primary participants in this study, is intrinsically valuable and linked to important further capabilities: to learn how to participate more centrally; to enter into reciprocal relations with others; and to have an agentic social role rather than a dependent one. The strong theme of recognition by co-workers provides grounds for optimism.

Appendix A Information and consent forms



Finding a way to work …

young people with intellectual disabilities learning in work

What is this about?

My name is Abigail. I want to find out about what happens when young people find a way to work that suits them. I'm looking for young people to work with me on this project.

I am looking for people who have found a way to work and are doing it with the help of a personal assistant or buddy. The work may be paid or not.

I want to find out about learning when you are working at something that you really want to do.

Why am I doing this?

Most people spend a lot of time at work. But it can be very hard to get a good job when you have a learning disability - something that suits you and that you really want to do.

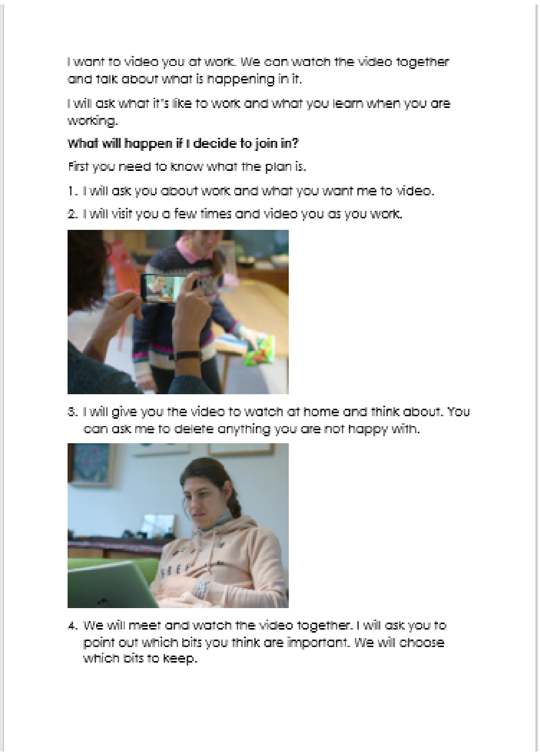
And if you don't work, you might get bored and feel left out. I want to find out if more people could find themselves a way to work by following their interests and supporting their work with a personal assistant.

Who do I want to work with?

I want to talk to young people who have found a way to work at something they enjoy, with a buddy or personal assistant to help them.

What do I want you to do?

I would like you to talk to me about what you do.



I want to video you at work. We can watch the video together and talk about what is happening in it.

I will ask what it's like to work and what you learn when you are working.

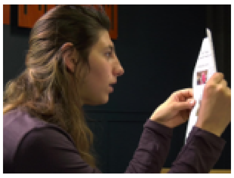
What will happen if I decide to join in?

First you need to know what the plan is.

1. I will ask you about work and what you want me to video.
2. I will visit you a few times and video you as you work.
3. I will give you the video to watch at home and think about. You can ask me to delete anything you are not happy with.
4. We will meet and watch the video together. I will ask you to point out which bits you think are important. We will choose which bits to keep.

5. We will meet to watch and talk about the video clips. I will need to understand what's happening. I might ask something like 'What did you think when that happened?'
6. I will video the meeting, so that I can see the bit of video we are talking about.

7. I will show the chosen video clips to your PA or buddy and ask them what they think about your work and what you learn.
8. I will show the video clips to someone else at your workplace and ask them what they think about your work and what you learn.
9. I will think about what everyone said. I will write a short report putting together everyone's ideas.



10. I will show you what I wrote and ask what you to tell me what you think about it.
11. I will then write a long report and a new short one for you to keep.

What will happen when the research is finished?

People will be interested to know what we found out about working and learning in this way.

I may talk at meetings and write papers about the project. When I talk about your work, I will not use your real name. If you agree, I may show video of you at work.

The film I have taken will be kept safely at the University of Southampton for 10 years after the end of the project.

Are there any risks involved?

I do not think that taking part in this research will be unsafe for you in any way. You can stop taking part at any time if you wish.

If you are worried about something to do with this research, please tell me. I will do my best to answer your questions.

If you are still unhappy, you can ask someone you trust to contact the University (University of Southampton Research Integrity and Governance Manager, 023 8059 5058, rgoinfo@soton.ac.uk).

Thank you for reading this!

Southampton UNIVERSITY OF

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Finding a way to work …

Study Title: Finding a way to ~~work:~~ young people with intellectual disabilities and learning in a work environment

Researcher: Abigail Croydon

Information sheet for employers

This study considers the learning potential of supported inclusion in work environments. If you host a young person with a learning/intellectual disability at your workplace, I would like to ask you to consent for them to be videoed while working.

This information sheet explains why this research is being done and what it will involve. Please take time to read the following information carefully.

What is this study about?

Young people with learning disabilities rarely find appropriate employment after school and college. Young people are at risk of being under-occupied and socially marginalised. They may have few opportunities to participate in the kind of life experiences shared by most adults – of going to work, learning from others and contributing to shared goals. They may be side-lined from adult life in ways that prevent them learning and developing as adults.

Hosting a young person and their Personal Assistant in your workplace may be significant for their learning and development.

Young people with learning disabilities may opt for a 'personal budget' to help them make their own choices about the kind of support they need. A personal budget makes it possible to employ a Personal Assistant who can support work aspirations as well as their care, leisure and social needs.

This study aims to investigate the experiences of a small number of young people who have chosen an area of work that suits them and are employing a Personal Assistant to support their participation – paid or unpaid – in the work environment. It will explore how these arrangements work, asking how far young people are promoting their own interests by taking this route.

By consenting for video to be made in your workplace you would be contributing to a better understanding of how young people gain from participating in work.

The research is being conducted as part of a doctoral study at the University of Southampton and is funded by the Economic and Social Research Council.

What is the point of the study?

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E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Finding a way to work …

The study will consider working somewhere you choose, with a Personal Assistant, as an option that is open to young people when competitive employment is inaccessible and in the current funding climate, I want to contribute to knowledge about learning beyond formal education for young people with learning disabilities, and to debate about policy and provision for young adults.

I aim to find out how far this form of supported participation in work deserves to be more widely adopted.

Who participates in the study

I want to collaborate with young people who are working somewhere they are motivated to ~~contribute.,~~ I am keen to find cases where young people are following their interests and strengths to work where people with learning disabilities are not usually found.

What do I want young people to do?

Young people will be filmed in the workplace. They will watch the video and think and talk about their work. The aim is to investigate this kind of participation from the point of view of young people themselves and how far it serves their purposes in life.

I will need the consent of staff at the workplace for filming to take place. I would also like to interview one co-worker for their perspective on the arrangement.

Filming in the workplace

It is essential to the design of this research that young people are videoed while working. The video will be used primarily by participants and the researcher within the research process. It may also be used to support presentations about the study.

My focus is on the young person. The video may involve others in interactions with the young person, but they are not being evaluated in any way. Any identifying features such as names or places will not be made public. If a co-worker wishes, I can obscure faces by pixilation. People featured in video clips will be asked to approve video of themselves for use in the project. Footage will not be used without consent.

Talking to a manager or co-worker

It would be extremely helpful to speak with someone who works with the young person. Ideally, they would also look at the video clips that have been selected and comment on the events recorded. This will take up to one hour of their time.

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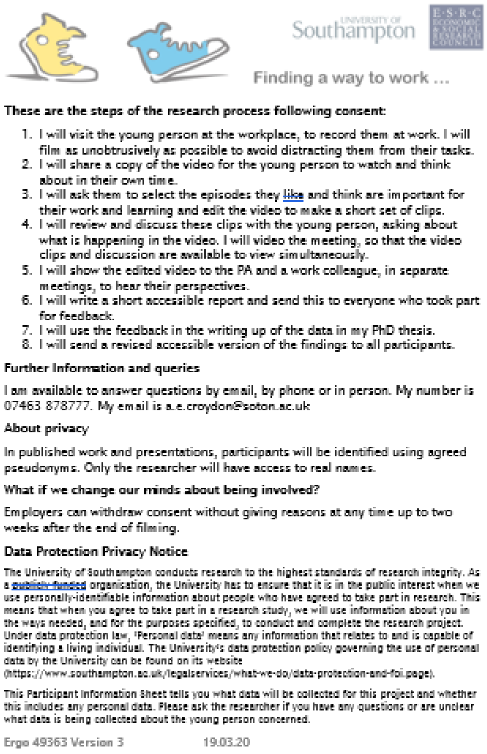

Finding a way to work …

These are the steps of the research process following consent:

1. I will visit the young person at the workplace, to record them at work. I will film as unobtrusively as possible to avoid distracting them from their tasks.
2. I will share a copy of the video for the young person to watch and think about in their own time.
3. I will ask them to select the episodes they like and think are important for their work and learning and edit the video to make a short set of clips.
4. I will review and discuss these clips with the young person, asking about what is happening in the video. I will video the meeting, so that the video clips and discussion are available to view simultaneously.
5. I will show the edited video to the PA and a work colleague, in separate meetings, to hear their perspectives.
6. I will write a short accessible report and send this to everyone who took part for feedback.
7. I will use the feedback in the writing up of the data in my PhD thesis.
8. I will send a revised accessible version of the findings to all participants.

Further Information and queries

I am available to answer questions by email, by phone or in person. My number is 07463 878777. My email is a.e.croydon@soton.ac.uk

About privacy

In published work and presentations, participants will be identified using agreed pseudonyms. Only the researcher will have access to real names.

What if we change our minds about being involved?

Employers can withdraw consent without giving reasons at any time up to two weeks after the end of filming.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the researcher if you have any questions or are unclear what data is being collected about the young person concerned.

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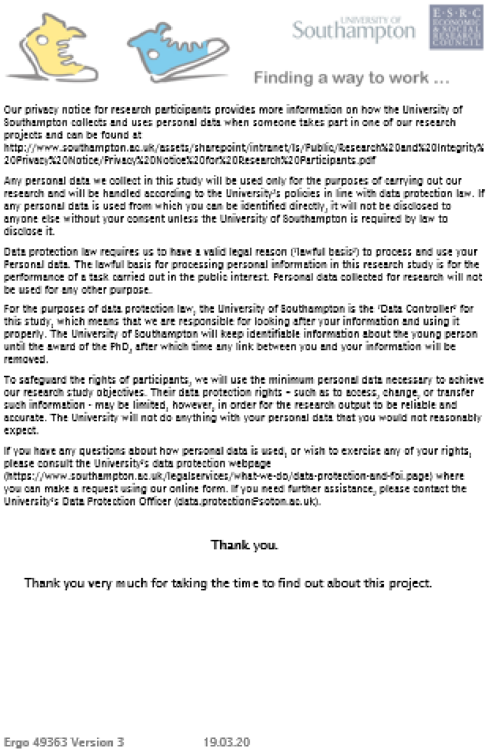

Finding a way to work …

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses personal data when someone takes part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about the young person until the award of the PhD, after which time any link between you and your information will be removed.

To safeguard the rights of participants, we will use the minimum personal data necessary to achieve our research study objectives. Their data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Thank you very much for taking the time to find out about this project.

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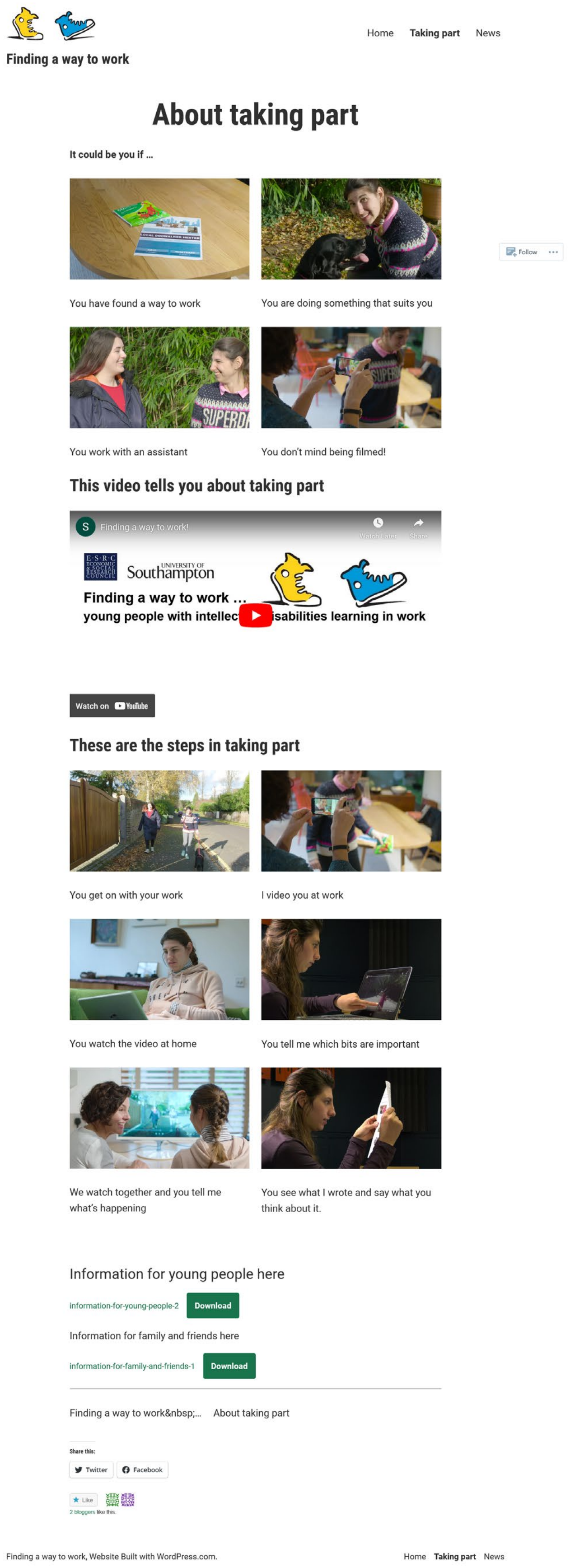
Appendix B Screenshot: Information website and film



Finding a way to work

About taking part

It could be you if …

You have found a way to work

You are doing something that suits you

You work with an assistant

You don't mind being filmed!

This video tells you about taking part

Finding a way to work!

Finding a way to work …
young people with intellec… isabilities learning in work

These are the steps in taking part

You get on with your work

I video you at work

You watch the video at home

You tell me which bits are important

We watch together and you tell me what's happening

You see what I wrote and say what you think about it.

Information for young people here

information-for-young-people-2

Information for family and friends here

information-for-family-and-friends-1

Finding a way to work …   About taking part

2 bloggers like this.

Finding a way to work, Website Built with WordPress.com.

Appendix C Member check newsletter

‘Finding a way to work’

The right work - ‘it’s a tough nut to crack’

People with learning disabilities and those around them have to work hard to get work and to keep it going. Some young people in this study had already experienced difficulties and rejections in trying to get paid work. For others it was a ‘road to nowhere’ from the outset. The kinds of work arrangements described here – unpaid, and individually supported - are rare. Finding worthwhile work – even without pay – is tough. Potential ‘employers’ are not always welcoming – whatever their policies say. Finding and keeping the right kind of support is also an ongoing challenge. But by working young people can challenge the social marginalization of people with intellectual and developmental disabilities. These stories show what can be achieved and some of the challenges to achieving.

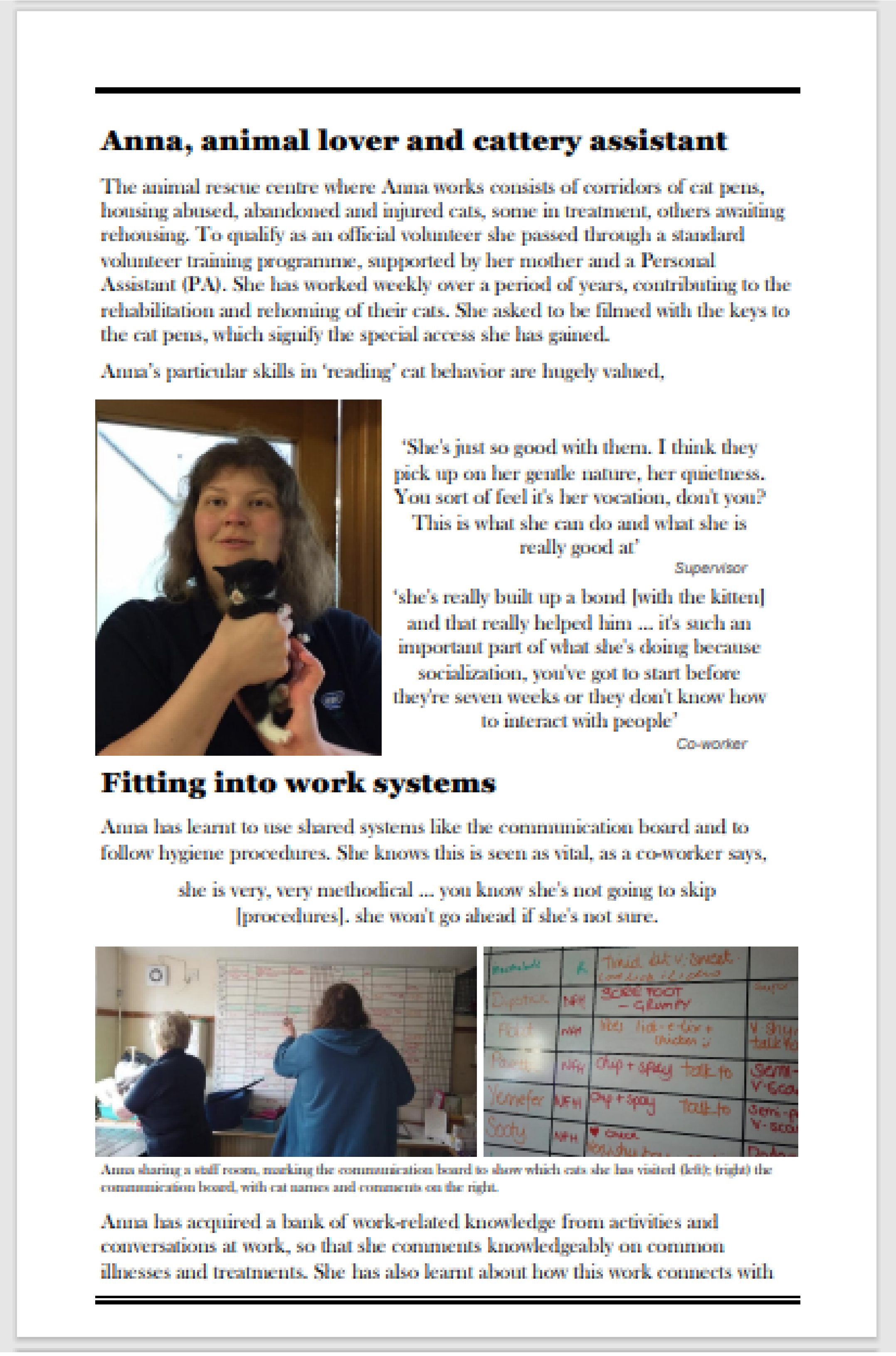
Ciaran and his PA Katie working at the food cooperative - the right kind of work, in the right place, with the right support.

But it’s worth it …

James and his PA Andrew on a litter-picking walk in the Peak District.

The stories here show what young people can achieve with highly motivated support

By taking part in public spaces and contribute to shared goals and projects, young people can find roles for themselves and gain work-related skills and knowledge. This kind of situational experience can shape what they learn and how they think. But it can also enable others to learn firsthand about what they can do and how they can fit into the societies where they live.



Anna, animal lover and cattery assistant

The animal rescue centre where Anna works consists of corridors of cat pens, housing abused, abandoned and injured cats, some in treatment, others awaiting rehousing. To qualify as an official volunteer she passed through a standard volunteer training programme, supported by her mother and a Personal Assistant (PA). She has worked weekly over a period of years, contributing to the rehabilitation and rehoming of their cats. She asked to be filmed with the keys to the cat pens, which signify the special access she has gained.

Anna's particular skills in 'reading' cat behavior are hugely valued,

'She's just so good with them. I think they pick up on her gentle nature, her quietness. You sort of feel it's her vocation, don't you? This is what she can do and what she is really good at'

Supervisor

'she's really built up a bond [with the kitten] and that really helped him ... it's such an important part of what she's doing because socialization, you've got to start before they're seven weeks or they don't know how to interact with people'

Co-worker

Fitting into work systems

Anna has learnt to use shared systems like the communication board and to follow hygiene procedures. She knows this is seen as vital, as a co-worker says,

> she is very, very methodical ... you know she's not going to skip [procedures]. she won't go ahead if she's not sure.

Anna sharing a staff room, marking the communication board to show which cats she has visited (left); (right) the communication board, with cat names and comments on the right.

Anna has acquired a bank of work-related knowledge from activities and conversations at work, so that she comments knowledgeably on common illnesses and treatments. She has also learnt about how this work connects with

human behavior, talking to me about animal neglect, what happens when owners die and the fallout when a planned rehoming falls through.

Although she has owned and known cats throughout her life, Anna has learnt a distinct professional approach appropriate to work. She follows the prescribed procedures, but also handles the cats in a differently way, suppressing her preferences – for example to pick up or touch - to watch and wait, letting the cat lead. She is aware of this,

The difference is that they're not my cats … I'm used to my cats and they're used to me. [At work you have to] let them kind of wait to get to know you.

Anna

The social and communication side of being at work is challenging for Anna, but the intrinsic reward of the work – contact with the cats - motivates her. She also has a sense of sharing values with staff and being trusted that makes communication easier. Things have changed since Anna started,

'she is still very, very quiet, but the first year or so she wouldn't talk to me. It was amazing and I remember the first day that she spoke to me. [now] I'm always delighted when she tells me about the kitten that she's just been in with …'

Anna asking for permission to visit kittens in the staff only section.

Anna's mother sees shared purpose as key to how the arrangement works and what makes the work worthwhile, above other activities.

> 'this is very meaningful, this has got real value. I know at [day centre] it's fabulous. But they're sort of forming them all, to sort of improve their social skills. But this is what she really loves. And I think giving her that sort of value by the staff there is so good for her'

'They seem to be people who get her … who share that love of animals, see that she's one of them.'

Ciaran, team player, food cooperative

Ciaran works in a local not-for-profit co-operative that is busy, full of loose foods and cleaning products, fruit, vegetables and packets. The shop does not look or feel like a supermarket, but a neighbourhood shop where staff and customers talk and customers are often regulars. Ciaran sees himself as a regular guy - not as a separate category of disabled person. In this cooperative set-up, he has the same status as other staff - all are unpaid members.

Working with a PA - 'buy one get one free'

Ciaran works with his PA Katie. Ciaran's mother says, it's a BOGOF deal for employers – they come as a package, with benefits for him and the employers. At the till, the two of them are smoothly co-ordinated, working side by side, as colleagues. Having two together behind the counter seems natural here, though it might not at a supermarket. Katie sometimes narrates: 'Right, so we'll weigh these, then they can go in the bag ...' She fills in gaps for Ciaran ('those are leeks not celery'), in a peer-to-peer rather than teacherly style. They manage issues as they arise – customers are not held up and don't witness lesson-giving.

Ciaran uses his systematising skills to make order on the shelves. He has learned appropriate phrases to use when he doesn't understand or know how to help a customer. He has learnt to use the till, and by doing so learnt how such skills are valued, and how having that role means something,

> he's dead proud of it [using the till]. So I think he's learned about being proud. He's also learned that it's a key skill, it's something that, you know, is important. There's something about doing something like that, so he's not just relegated to doing the jobs that 'it's all right, you go and do that dear...'
>
> *Ciaran's Mother*

In later filming Ciaran is not at the till but sweeping, cleaning and taking out recycling, using a checklist of tasks. Katie is not sharing the tasks as before but prompting and acting in a 'quality control' capacity.

Ciaran checking jobs off his list (left) and sharing the finished with his supervisor at the end of the shift (right)

Fitting people together

Ciaran's supervisor describes the practical realities and mutual benefit of working with Ciaran and his PA,

> I say I'm a supervisor. Really, we do very much depend on his help. And the helpers being there with him. Because we've got other jobs that we need to attend to, and of course we need to attend to customers. So we just provide the work. And I suppose it does help Ciaran to be sort of independent. I mean, we don't have to supervise all the time.

The work that Ciaran does, like the work of other participants, is not tokenistic but functional and valued. The work relationships develop on that basis.

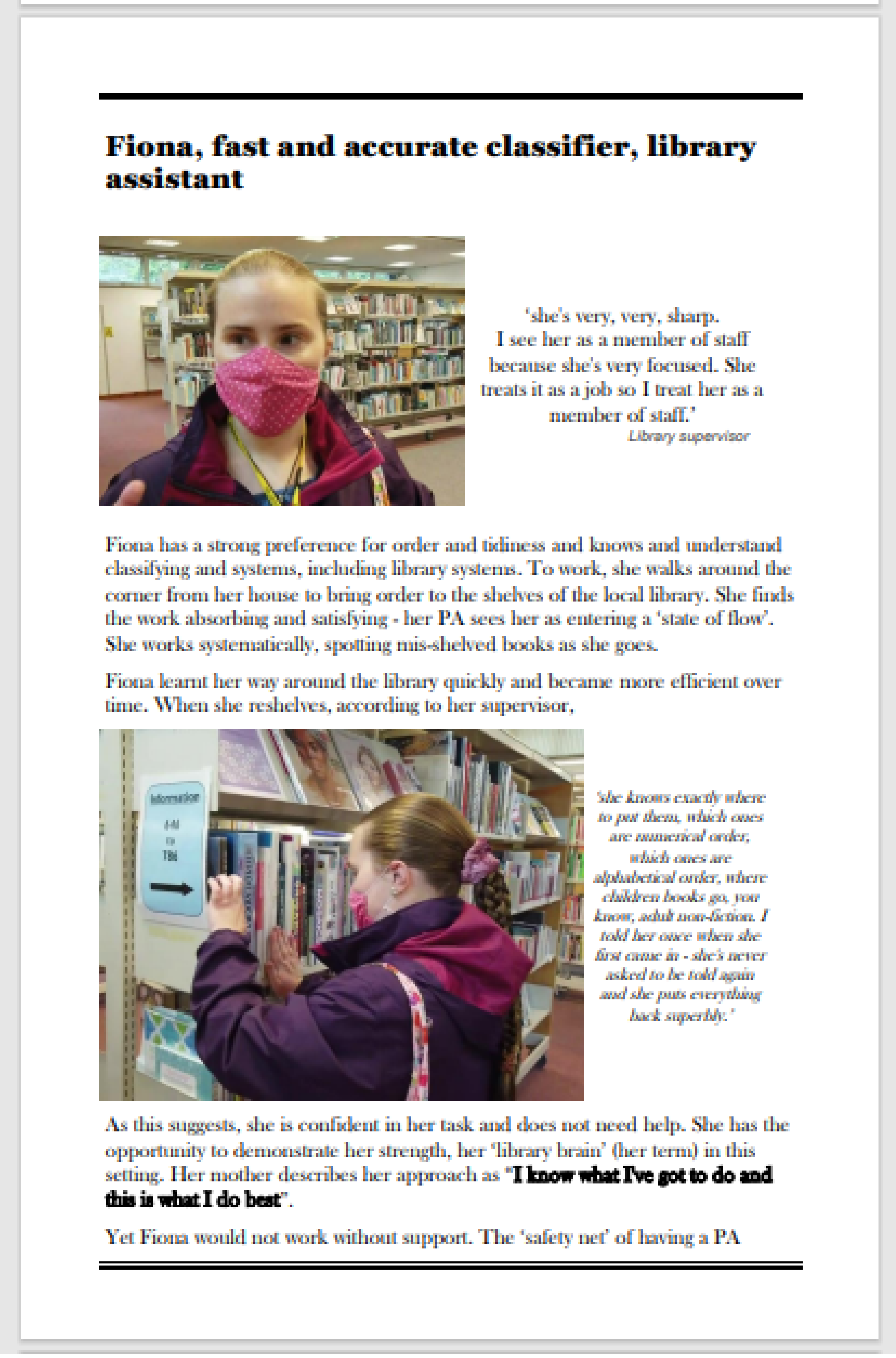
'he's very much one of us and he doesn't get treated any differently. I personally value all our help and I express that. I make a point to relate directly to him and to thank him. From my point of view, it doesn't feel repetitive. I very much do mean it'

Supervisor

Ciaran cleaning dispensers.

Ciaran's supervisor goes on to describe the kind of reciprocal learning and mutual adjustment that occurs as they collaborate,

> We haven't really changed things to accommodate him. **It's a two-way sort of process, you could say it's a reactive process.** When I notice something, I react. And I'm sure he does too. So we are accommodating all the time, and I'm sure he does accommodate us as well. The relationship changes all the time, it develops.'



Fiona, fast and accurate classifier, library assistant

'she's very, very, sharp.
I see her as a member of staff
because she's very focused. She
treats it as a job so I treat her as a
member of staff.'
Library supervisor

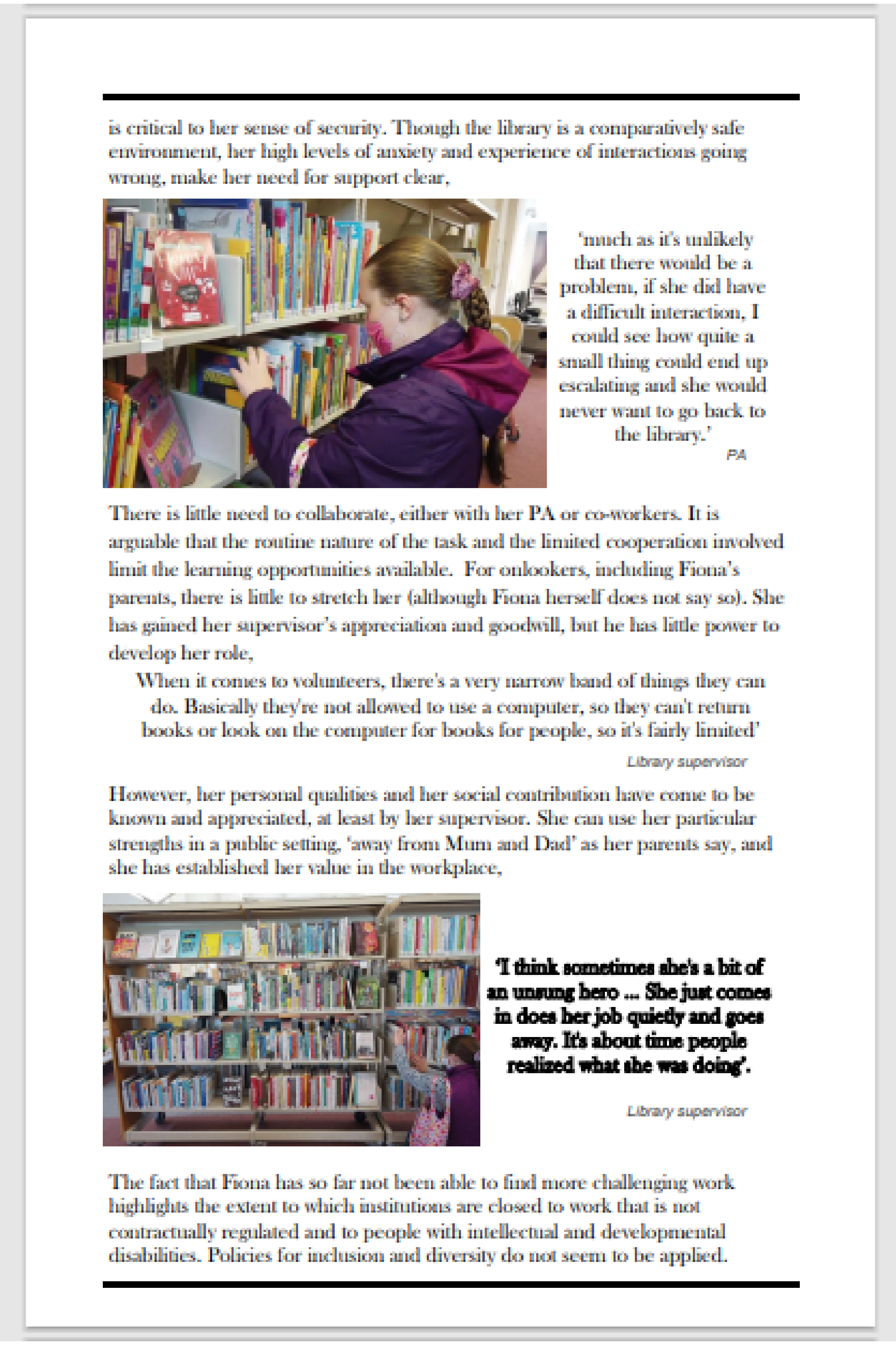
Fiona has a strong preference for order and tidiness and knows and understand classifying and systems, including library systems. To work, she walks around the corner from her house to bring order to the shelves of the local library. She finds the work absorbing and satisfying - her PA sees her as entering a 'state of flow'. She works systematically, spotting mis-shelved books as she goes.

Fiona learnt her way around the library quickly and became more efficient over time. When she reshelves, according to her supervisor,

'she knows exactly where to put them, which ones are numerical order, which ones are alphabetical order, where children books go, you know, adult non-fiction. I told her once when she first came in - she's never asked to be told again and she puts everything back superbly.'

As this suggests, she is confident in her task and does not need help. She has the opportunity to demonstrate her strength, her 'library brain' (her term) in this setting. Her mother describes her approach as "**I know what I've got to do and this is what I do best**".

Yet Fiona would not work without support. The 'safety net' of having a PA



is critical to her sense of security. Though the library is a comparatively safe environment, her high levels of anxiety and experience of interactions going wrong, make her need for support clear,

'much as it's unlikely that there would be a problem, if she did have a difficult interaction, I could see how quite a small thing could end up escalating and she would never want to go back to the library.'

PA

There is little need to collaborate, either with her PA or co-workers. It is arguable that the routine nature of the task and the limited cooperation involved limit the learning opportunities available. For onlookers, including Fiona's parents, there is little to stretch her (although Fiona herself does not say so). She has gained her supervisor's appreciation and goodwill, but he has little power to develop her role,

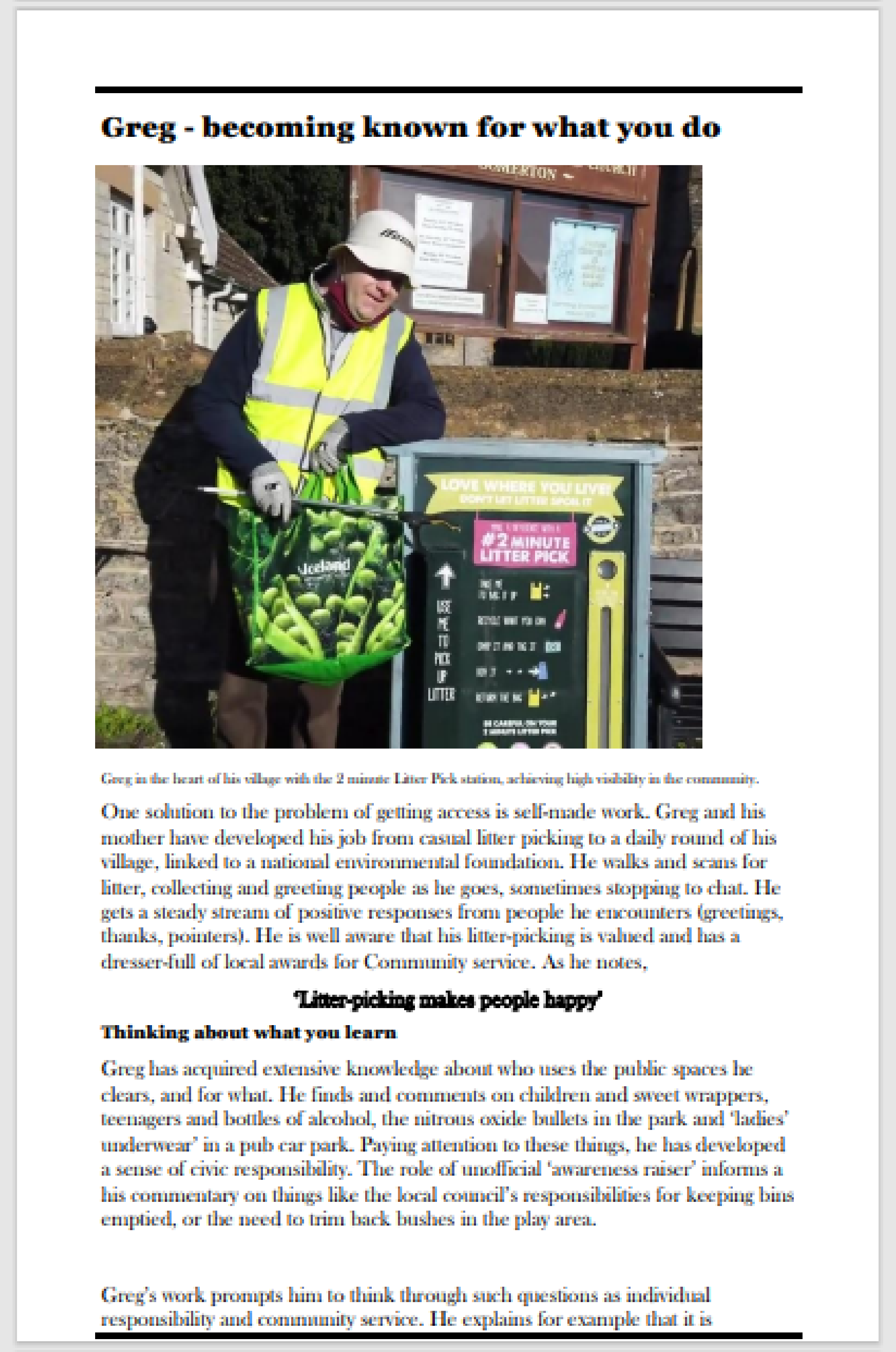
> When it comes to volunteers, there's a very narrow band of things they can do. Basically they're not allowed to use a computer, so they can't return books or look on the computer for books for people, so it's fairly limited'
>
> *Library supervisor*

However, her personal qualities and her social contribution have come to be known and appreciated, at least by her supervisor. She can use her particular strengths in a public setting, 'away from Mum and Dad' as her parents say, and she has established her value in the workplace,

'I think sometimes she's a bit of an unsung hero ... She just comes in does her job quietly and goes away. It's about time people realized what she was doing'.

Library supervisor

The fact that Fiona has so far not been able to find more challenging work highlights the extent to which institutions are closed to work that is not contractually regulated and to people with intellectual and developmental disabilities. Policies for inclusion and diversity do not seem to be applied.



Greg - becoming known for what you do

Greg in the heart of his village with the 2 minute Litter Pick station, achieving high visibility in the community.

One solution to the problem of getting access is self-made work. Greg and his mother have developed his job from casual litter picking to a daily round of his village, linked to a national environmental foundation. He walks and scans for litter, collecting and greeting people as he goes, sometimes stopping to chat. He gets a steady stream of positive responses from people he encounters (greetings, thanks, pointers). He is well aware that his litter-picking is valued and has a dresser-full of local awards for Community service. As he notes,

'Litter-picking makes people happy'

Thinking about what you learn

Greg has acquired extensive knowledge about who uses the public spaces he clears, and for what. He finds and comments on children and sweet wrappers, teenagers and bottles of alcohol, the nitrous oxide bullets in the park and 'ladies' underwear' in a pub car park. Paying attention to these things, he has developed a sense of civic responsibility. The role of unofficial 'awareness raiser' informs a his commentary on things like the local council's responsibilities for keeping bins emptied, or the need to trim back bushes in the play area.

Greg's work prompts him to think through such questions as individual responsibility and community service. He explains for example that it is

important for him to clear the firemen's area ('they're busy fighting fires and that') but questions why other people are not more responsible citizens ('I'm not their slave, am I?').

Mates, motivation and money

On his daily rounds, Greg doesn't have co-workers as such, but he does see his work as part of the picture of safekeeping and maintenance roles in the community. He sees himself as serving in the same sort of capacity as other key male workers, particularly firefighters and bin men, as he explained,

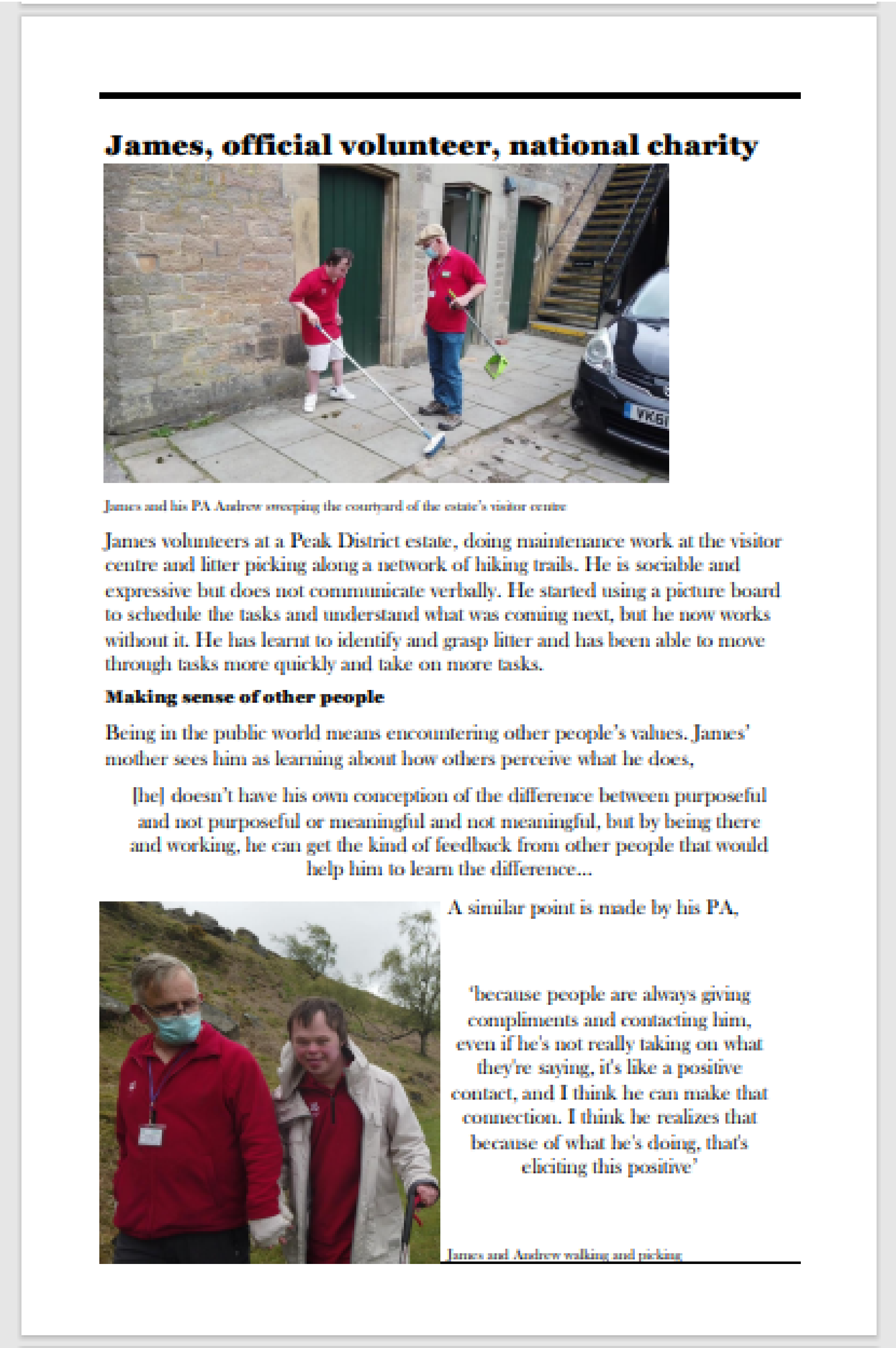
'that's my work mates - that's who I'm doing it for, for them. Keep it in the film, because that's important that is.'

Greg saluting an approaching lorry.

Greg's mother struggles with a sense of unfairness that the benefits system takes no account of the work he undertakes, depriving him of the motivation and equality of earning. In the wake of lockdown and flagging enthusiasm, she introduced a proxy pay system, in which he is paid in cash, from his personal budget, according to the number of hours he completes. Making adjustments in terms of challenge and reward is an ongoing challenge in making work sustainable in the long term, though it is a hard task, unless families, PAs, work supervisors and colleagues can work together.

'he's had to learn tolerance, because dropping litter used to infuriate him. So he'd want to put notices up and tell people off. And he will tell people that are walking past that this is not acceptable behaviour ... gives them an absolute right lecture. And I don't know, maybe in their own way the community learns from him. But also he has to learn about the different members of the public, that what is acceptable to speak out about and what we might think but we don't say ... though yeah, maybe we should.'

Greg's mother



James, official volunteer, national charity

James and his PA Andrew sweeping the courtyard of the estate's visitor centre

James volunteers at a Peak District estate, doing maintenance work at the visitor centre and litter picking along a network of hiking trails. He is sociable and expressive but does not communicate verbally. He started using a picture board to schedule the tasks and understand what was coming next, but he now works without it. He has learnt to identify and grasp litter and has been able to move through tasks more quickly and take on more tasks.

Making sense of other people

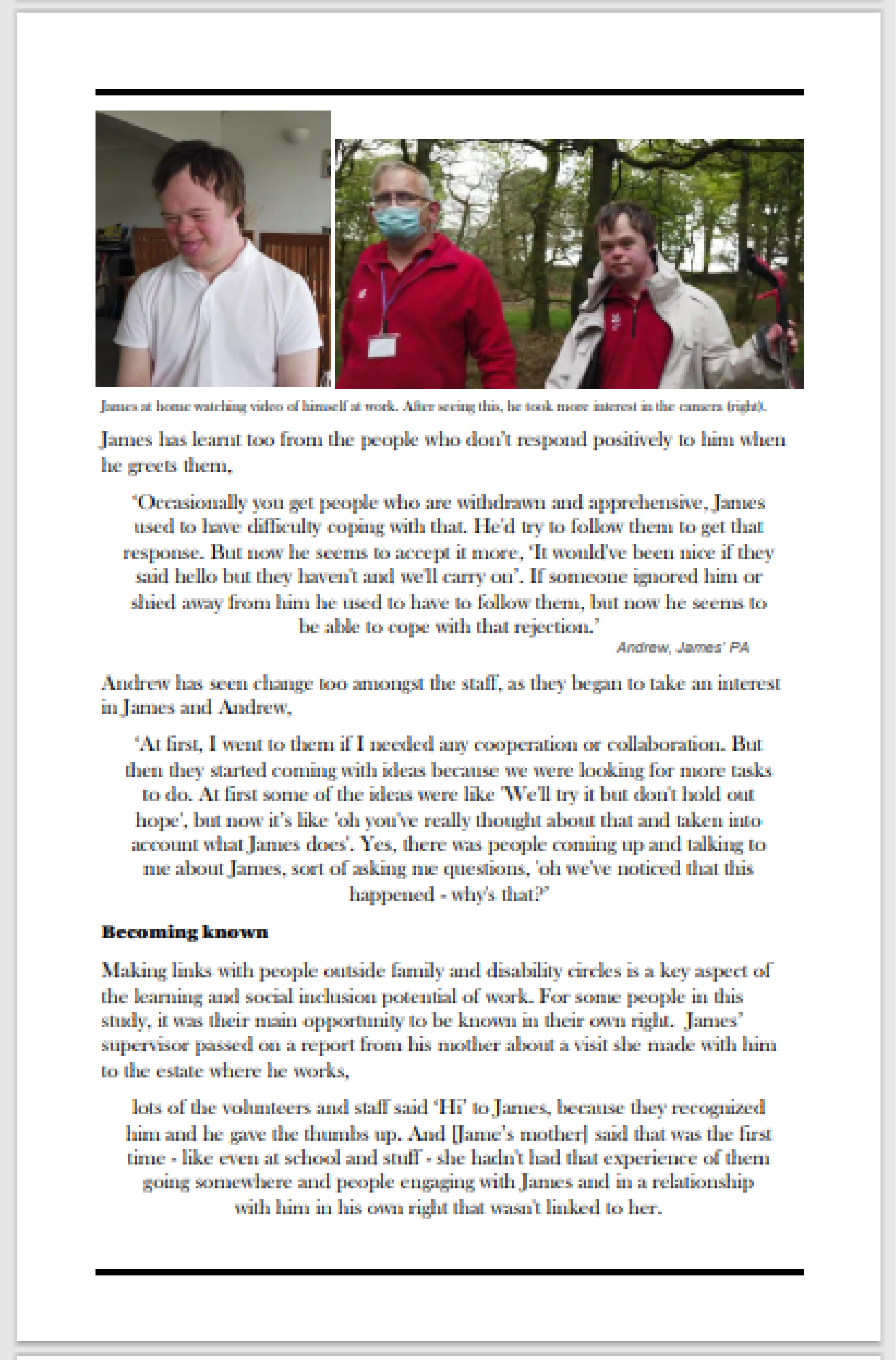
Being in the public world means encountering other people's values. James' mother sees him as learning about how others perceive what he does,

> [he] doesn't have his own conception of the difference between purposeful and not purposeful or meaningful and not meaningful, but by being there and working, he can get the kind of feedback from other people that would help him to learn the difference...

A similar point is made by his PA,

> 'because people are always giving compliments and contacting him, even if he's not really taking on what they're saying, it's like a positive contact, and I think he can make that connection. I think he realizes that because of what he's doing, that's eliciting this positive'

James and Andrew walking and picking



James at home watching video of himself at work. After seeing this, he took more interest in the camera (right).

James has learnt too from the people who don't respond positively to him when he greets them,

> 'Occasionally you get people who are withdrawn and apprehensive, James used to have difficulty coping with that. He'd try to follow them to get that response. But now he seems to accept it more, 'It would've been nice if they said hello but they haven't and we'll carry on'. If someone ignored him or shied away from him he used to have to follow them, but now he seems to be able to cope with that rejection.'
>
> *Andrew, James' PA*

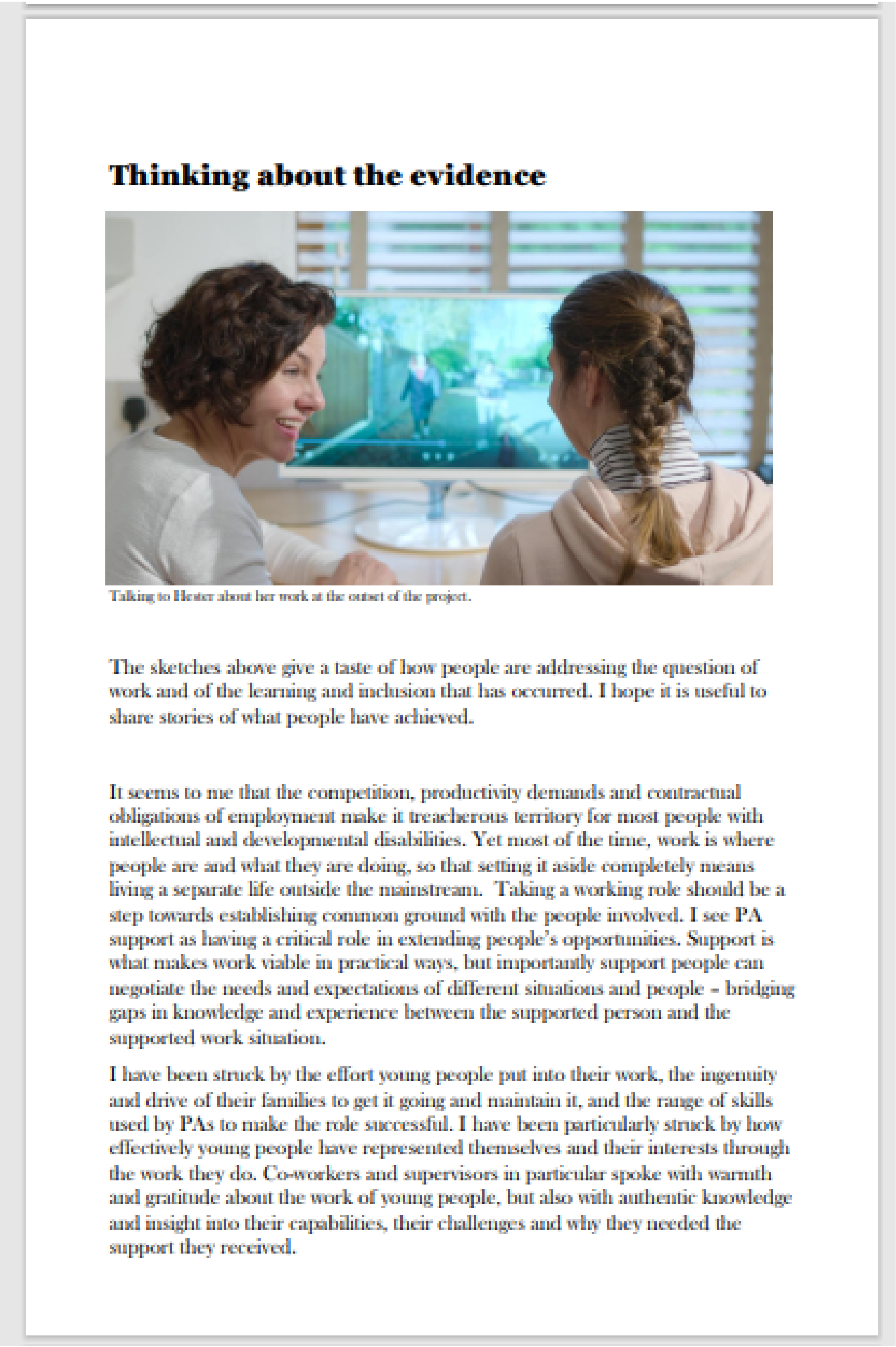
Andrew has seen change too amongst the staff, as they began to take an interest in James and Andrew,

> 'At first, I went to them if I needed any cooperation or collaboration. But then they started coming with ideas because we were looking for more tasks to do. At first some of the ideas were like 'We'll try it but don't hold out hope', but now it's like 'oh you've really thought about that and taken into account what James does'. Yes, there was people coming up and talking to me about James, sort of asking me questions, 'oh we've noticed that this happened - why's that?'

Becoming known

Making links with people outside family and disability circles is a key aspect of the learning and social inclusion potential of work. For some people in this study, it was their main opportunity to be known in their own right. James' supervisor passed on a report from his mother about a visit she made with him to the estate where he works,

> lots of the volunteers and staff said 'Hi' to James, because they recognized him and he gave the thumbs up. And [Jame's mother] said that was the first time - like even at school and stuff - she hadn't had that experience of them going somewhere and people engaging with James and in a relationship with him in his own right that wasn't linked to her.



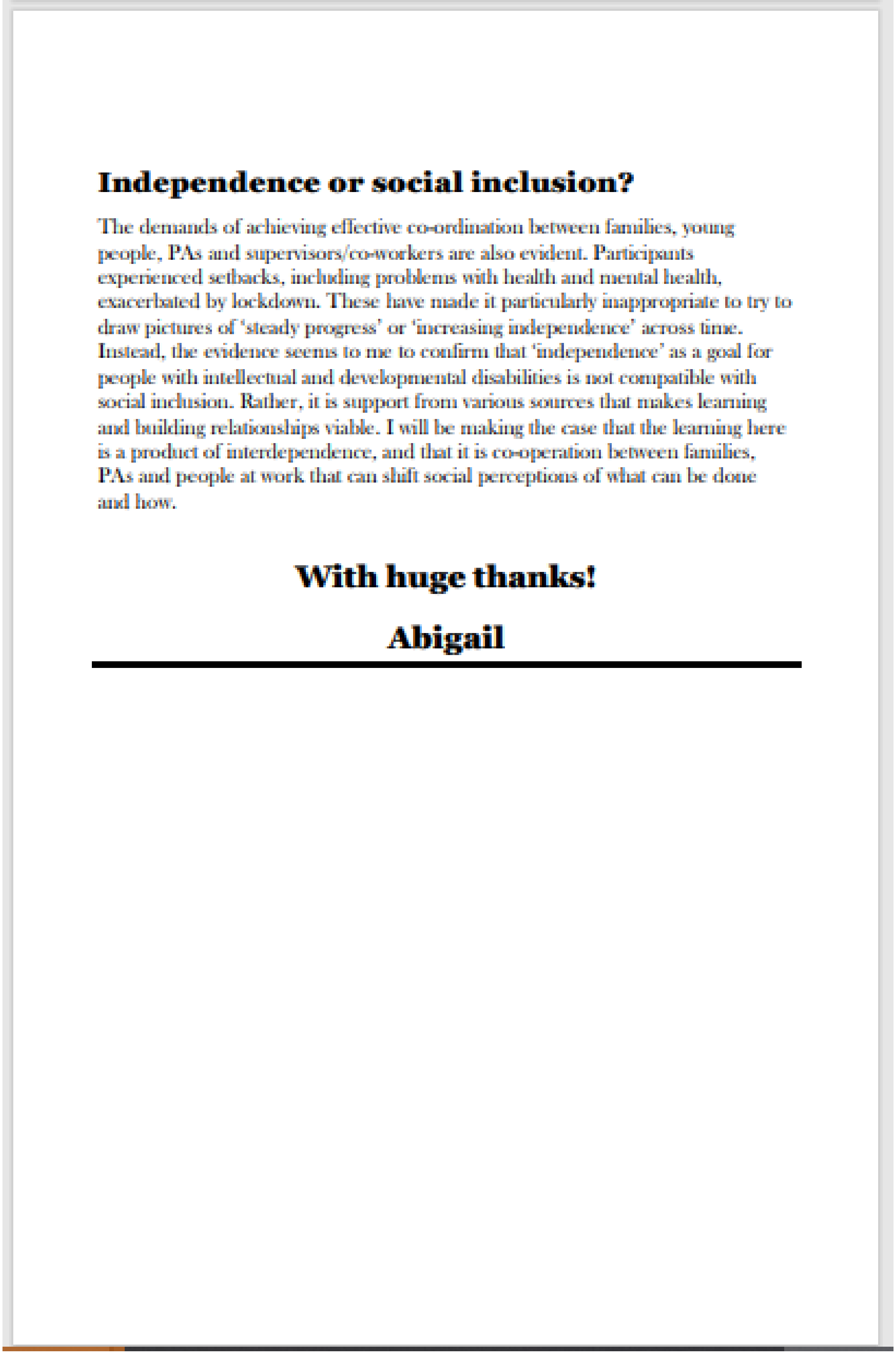
Thinking about the evidence

Talking to Hester about her work at the outset of the project.

The sketches above give a taste of how people are addressing the question of work and of the learning and inclusion that has occurred. I hope it is useful to share stories of what people have achieved.

It seems to me that the competition, productivity demands and contractual obligations of employment make it treacherous territory for most people with intellectual and developmental disabilities. Yet most of the time, work is where people are and what they are doing, so that setting it aside completely means living a separate life outside the mainstream. Taking a working role should be a step towards establishing common ground with the people involved. I see PA support as having a critical role in extending people's opportunities. Support is what makes work viable in practical ways, but importantly support people can negotiate the needs and expectations of different situations and people – bridging gaps in knowledge and experience between the supported person and the supported work situation.

I have been struck by the effort young people put into their work, the ingenuity and drive of their families to get it going and maintain it, and the range of skills used by PAs to make the role successful. I have been particularly struck by how effectively young people have represented themselves and their interests through the work they do. Co-workers and supervisors in particular spoke with warmth and gratitude about the work of young people, but also with authentic knowledge and insight into their capabilities, their challenges and why they needed the support they received.



Independence or social inclusion?

The demands of achieving effective co-ordination between families, young people, PAs and supervisors/co-workers are also evident. Participants experienced setbacks, including problems with health and mental health, exacerbated by lockdown. These have made it particularly inappropriate to try to draw pictures of 'steady progress' or 'increasing independence' across time. Instead, the evidence seems to me to confirm that 'independence' as a goal for people with intellectual and developmental disabilities is not compatible with social inclusion. Rather, it is support from various sources that makes learning and building relationships viable. I will be making the case that the learning here is a product of interdependence, and that it is co-operation between families, PAs and people at work that can shift social perceptions of what can be done and how.

With huge thanks!

Abigail

Appendix D: Table of themes

Question	theme	sub-theme		Files	Refs
Participatory learning and capabilities	What kinds of participatory learning do participants identify? How far did the work and the learning involved enhance the capabilities of the young people?			46	952
	Support enabling agency	Support making successful work / learning possible, balancing agency and care. Relational agency. Impacts of having or not having support.		36	354
		PA functions/ relationships	What PAs do, did, or should do; how relationships work.	31	197
	Legitimacy	Importance of work being authentic; impacts and markers of this; how participants understood/responded to them.		33	230
		Situated knowledge and skills	Work-related learning through legitimate role, e.g., specialist cat knowledge.	19	86
		Learning - contributing	Perceptions/reports of legitimate usefulness/ value of contribution to workplace or community.	18	46
		Learning - social	learning socially enabled by legitimate work, distinct from/ extension of work-specific knowledge and skills.	12	31
		Social public learning	Work connecting person to social/public learning/knowledge, e.g. ‘I hope somebody is asking themselves, “Why aren't there more James?”’	14	29
	Effort/ recognition	References to effort, conscientiousness in work and reciprocal recognition.		32	145
		Challenge/ problem solving	Challenge/ decision making inherent in work/ work relationships. e.g., whether or not to risk transmitting cat flu.	17	45
		Conscientious-ness	References to primary participants' invested effort/conscientiousness in work.	12	24
	Affiliation/ social bonds	Bonds through reciprocal relationships/shared experience; being part of team; co-workers’ empathy/understanding/valuing; consideration, warmth, between parties.		22	122
		Liking/rapport	Liking/rapport as aspects/facilitators of participation/learning.	14	55
	Mutual adaptation	Changes in knowledge, behaviour, understanding by primary participants/ co-workers and publics in response to participation; mutual adaptation as a form of learning. Failures of mutual adaptation.		18	101

Work arrangements and rationale	Why and how did young people with intellectual and developmental disabilities come to work in public settings? How far did personalisation promote or support this choice?				
	Critique of services	Critique of official provision of all kinds – day care; employment services; inappropriate expectations, etc.		21	105
	PA support makes work viable	Relationship between support and viability, co-ordination building viability - family, PAs, employers - or not. Effects of this.		22	101
		support needed	Specific support or conditions that make arrangements viable.	14	39
		work vs 'care'	Balancing care/support/'back up' and individual agency	9	13
		Organisational-public	absence/presence of formal/informal organisational support for work arrangements	8	12
	Work-structure-agency	Work providing structure and support that is enabling/ develops capabilities.		17	97
		activity and agency	Where structure of work activates; structured activity extends agency/ capabilities	11	21
		interactions and relationships	work structure supports/enables interactions relationships with others.	9	18
		ambivalence around control	difficulty/care around respecting primary participants' agency and exerting influence/control.	9	16
	access to participation	'Getting into society' - motivations to achieve it, what it means/offers.		15	32
	Purpose/ meaning	Finding or seeking purpose or meaning through work/participation		11	29
	Intrinsic motivation	Intrinsic motivation for this work/workplace; pleasure, excitement in work.		11	18
Methods	Camera/ Film		Use/impact of film, filming process or reviewing film.	19	38

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