Phan, Thu Thuy (2021) *Sketches of a citizen: An ethnography of learning disabilities, artmaking, and citizenship.* PhD thesis, University of Glasgow. PhD thesis.

http://theses.gla.ac.uk/82304/

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

Enlighten: Theses
https://theses.gla.ac.uk/
research-enlighten@glasgow.ac.uk

SKETCHES OF A CITIZEN

An ethnography of learning disabilities, artmaking, and citizenship

Thu Thuy Phan, BA, MSc

Submitted in fulfilment of the requirements for the degree of PhD
Institute of Health and Wellbeing
College of Medical, Veterinary & Life Sciences
University of Glasgow

Abstract

Today, few people would contest the idea that people with learning disabilities are equal citizens, and that as such, they have equal political, civil, and social rights. But what does citizenship mean in the day-to-day lives of those who require extensive support to complete basic tasks, have limited verbal language, and have little to no prospects for independent living and paid employment? How is their citizenship lived? And how is it facilitated or hindered by those working with them?

Through an ethnography of an art workshop in Glasgow, UK, this thesis draws on anthropological perspectives to explore how abstract ideals of citizenship manifest in the everyday lives of people with learning disabilities who have high support needs. In my enquiry, I divert from normative and rights-based understandings of citizenship, in order to foreground alternative meanings that can be ethnographically derived from everyday practice and interactions.

This thesis explores the complexities of choice-making, independence, sociality, and social value through examples of artmaking with people with learning disabilities. It examines the material conditions, relational aspects, and affirmative measures that practicing citizenship requires. In doing so, it articulates more inclusive understandings of citizenship, whose implications do not only pertain to people with learning disabilities but are relevant for everyone.

Table of Contents

Acknowledgements

First of all, I would like to thank my supervisors, Professor Craig Melville and Professor Nicholas Watson for providing guidance, advice, and thoughtful feedback along the way. I would also like to thank my funders at the Scottish Government. I am further thankful to the staff at the Institute of Health and Wellbeing for their continuous support: my annual reviewers, Professor Andrew Jahoda and Dr Philippa Wiseman; the admin team, Antonia Gates, Afshan Fairley, and Rachel Allan; my colleagues in the Mental Health and Wellbeing research group and the Strathclyde Centre for Disability Studies. I would like to express gratitude to Professor Don Kulick and the Engaging Vulnerability research group at Uppsala University – their academic generosity and insights helped me find my writing voice.

I would like to thank my family who have never read anything that I wrote, but continue to support my life choices unconditionally nonetheless. I am further grateful for: Grant, for the many adventures and life coaching that helped me through my existential crises; Fran, who gave me courage; Ben, who made Glasgow my home; and the many friends whose paths I crossed while living here.

Finally, I would like to offer my sincere thanks to all the people whom I met during my fieldwork at Project Ability: the director and staff members, the tutors, support workers, and most importantly, the participants of the art workshops. Their kindness, patience, and generosity taught me about ethics, equality, art, and beauty. I dedicate this thesis to them in hope that it does justice to the experiences they shared with me.

Author’s declaration

I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Thu Thuy Phan

Introduction

Why study the citizenship of people with learning disabilities?

Aysha is a woman in her mid-thirties. She loves colourful dresses and wears her dark hair in a slick ponytail. Sensitive and affectionate, she has unconditional adoration for her support worker, Diana, whom Aysha considers her best friend. Because of her outgoing personality, Aysha is a popular character in her neighbourhood. However, she sometimes gets into trouble with strangers for hugging them and talking too much. Aysha is one of three sisters, all of whom have significant learning disabilities. Aysha lives with her parents. She needs help with basic tasks like crossing the road, and her carers have to remind her to eat because otherwise she would go without food for extended periods of time.

Kenny is a man in his early forties. He is lean and tall, and he sports thick framed glasses and a buzz cut. Kenny is gentle and shy: he mostly speaks when someone asks him a question. Even then, his answers are curt one-word responses, uttered in a stuttering rush. Kenny used to be institutionalised at a long-stay hospital for people with learning disabilities, where he had little say over things like what he wanted to do with his day, or who he wanted to spend time with. He now lives in supported accommodation. With the help of this support staff, he has dinner with his father every fortnight, regularly hangs out with his friend (also a man with learning disabilities), and partakes in a multitude of leisure activities devised by his care organisation. The extent to which he has a say in his everyday life is difficult to ascertain: according to his support staff, Kenny often seeks to please people, therefore he says what he thinks people want to hear.

Jack is a soft-spoken man in his late thirties, who has an expansive pop-cultural knowledge. His arms are covered in tattoos of anime characters. Jack lives alone and, unlike Aysha or Kenny, he does not need support with everyday tasks. He receives financial support from the government for his housing and living costs, but he is worried that his benefits will be taken away when his support needs are reviewed. Jack has partaken in sheltered employment programmes, but has not had a paid position because of his difficulties with reading and writing. Since his mum passed away a couple of years ago, Jack’s primary companion is his aunt, whom he visits once or twice a week: together, they have dinner and watch television. Jack goes to art class twice a week, and spends most of his time hanging out in his flat with his cat or strolling around the streets of Glasgow.

Aysha, Kenny, and Jack are artists with learning disabilities whom I met at Project Ability's art workshops during my ethnographic fieldwork. Had they lived in the 1960s – sixty years prior to the writing of this thesis – their lives would have been very different. They might have lived with their families, like Aysha is currently. However, if their families had not been able to afford to provide for them, they would have been committed to a long-stay hospital like Kenny had been, except they would have had very few prospects of returning to a life outside of institutions. Former residents' accounts give an indication of what Aysha's, Kenny's, and Jack's lives would have looked like in a long-stay hospital (e.g. Bentley et al., 2011; Cooper and Atkinson, n.d.): they would have had no say in when they got up and went to sleep, the food they ate, the clothes they wore, and the people they spent time with. They could have left the hospital grounds with permission only, and would not have been allowed to freely interact with their neighbours, have pints with their parents, go to art class, or have a pet. They certainly would not have been allowed to have their own accommodation and they would not have been supported to be independent. They might have been subjected to abuse by hospital staff and discrimination by the outside world. They would have had little support and opportunities to pursue education, enter employment, or start a family. They would have been denied voting and participation in political life, and would have had few options for recreational activities.

Much has changed since then in Scotland, where Aysha, Kenny, and Jack live. The long-stay hospitals are gone: people with learning disabilities who do not live with their families are provided accommodation in their own flats, supported housing, or small residential care homes. Instead of locking them away in segregated institutions, social policy now encourages them to participate in the so-called mainstream society. Their rights to do so are internationally recognised by the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006). This covers the right to live independently and be included in the community, respect for home and family, health and education, rehabilitation, work and employment, adequate standards of living and social protection (including housing, financial assistance, respite care), and participation in public life as well as recreation, leisure, and cultural life. In the UK, these rights are upheld by the Equality Act 2010, which grants people legal protection against discrimination.

The concept of citizenship has been key in propelling changes in the way people with learning disabilities have been treated. It has been a keyword in learning disability activism, advocacy, and scholarship for a long time (Duffy, 2017): the parent and the disabilities rights movement, (self-)advocacy groups, and academics all deployed the concept to advocate for what they regarded as better treatment of people with learning disabilities. Citizenship is also a recurring concept in British social policy: in the past three decades, every major government publication reiterated the importance of treating people with learning disabilities as citizens (Duffy, 2017). Writing in 1991, learning disability scholar Jan Walmsley (1991) observed increasing social policy interest in the concept, noting it had become a "fashionable topic" (p. 219). While she remained optimistic of citizenship as a tool to further claims to rights, justice, dignity, and inclusion for people with learning disabilities, she warned that if the practical limitations to these claims were not addressed in practice, citizenship would be no more than a "hollow claim" (p.226).

Thirty years later, Walmsley's warning remains relevant, as the figures demonstrate prevailing experiences of injustice and inequality among people with learning disabilities in the UK. Although they make up 0.5 per cent of the population (Scottish Learning Disabilities Observatory, 2011), people with learning disabilities have poorer health than their non-disabled peers (Krahn and Fox, 2014). They also die, on average, thirteen years younger, many of them from preventable causes (O'Leary et al., 2018), and a higher proportion of them live under the poverty line (Emerson, 2007). Many of them are subjected to harassment and hate crimes (Walters et al., 2016). Despite having been relocated from segregated institutions into community-based facilities, many of them continue to experience loneliness and isolation (Alexandra et al., 2018; Bigby et al., 2017; Gilmore and Cuskelly, 2014; Kamstra et al., 2015).

These figures raise several questions. While citizenship as a legal status guaranteed people with learning disabilities equal rights and protection – which is a significant progress – there is still much to be achieved in terms of their social inclusion, belonging, and participation. Citizenship has granted them economic, social, and cultural rights (United Nations, 2006), but in practice it is yet to counter poverty, inadequate housing, poor health, and limited prospects for employment and further education. All this raises the question whether there is further potential in the concept of citizenship to be deployed in service of addressing the prevailing inequalities people with learning disabilities experience?

This is the central question I explore in my thesis. In part, I set out to examine how ideals of citizenship guide engagement between individuals with learning disabilities and their communities. In addition, I aim to document the particular inequalities and injustices people with learning disabilities face, and the related support they need, lack, or are provided.

Of course, issues of inequality and injustice are not limited to people with learning disabilities: poverty, unemployment, discrimination, and isolation constitute the everyday experiences of many other groups who are also considered citizens by their legal status. One may ask, why should we focus on special provisions for people with learning disabilities who constitute only a small minority of those who suffer from the consequences of inequality and injustice? Some people may argue that people with learning disabilities are already provided with basic material support, opportunities for employment and education, options for socialising and leisure. How much more additional support should they be given by their family, community, and the state? I have heard these questions voiced with the well-meaning intention to avoid offence and stigmatising, worrying that surely people with learning disabilities would not want to be, for instance, employed out of charity, or have people spend time with them out of pity.

In practice, many people with learning disabilities do need extensive "atypical social arrangements" (Nussbaum, 2006: 99) to enjoy basic activities, like socialising, leisure, or work. The atypical social arrangements I discuss in this dissertation extend beyond patronising charitable interventions. Rather, I focus on the personal and institutional support that, first of all, enables people to develop capabilities to engage with other individuals and communities, to establish meaningful relationships, to participate in public life and social activities, to experience joy and affection, and to live a dignified life; and secondly, that enables individuals and institutions to ethically engage with people with high support needs - who experience inequalities and injustices. When the support needs of people with learning disabilities are framed like this, they become a question about ethical engagement with issues that do not only pertain to disabled people but are relevant for everyone.

How this thesis approaches the concept of citizenship

I have had a long-standing interest in questions of belonging prior to this doctoral project. As someone who was born to Vietnamese parents, grew up in Hungary, and then spent a decade moving from country to country, I have always been interested in what citizenship meant for those who were not considered first-class citizens. During my graduate studies in medical anthropology, I became interested in embodiment, non-verbal interactions, and their possibilities in shaping belonging and collective action. That is where my primary interest lay when I first started this project. For me, learning disabilities had been first and foremost a concept through which I could explore the margins of belonging and the possibilities of mobilisation – the notion of citizenship, when tested against the lives of people with learning disabilities could reveal the fundamental gaps in the way belonging, justice, and equality are thought about and practiced.

Although my priorities and views on learning disabilities have changed significantly by the time I completed my fieldwork, the reason I found the concept of citizenship compelling for such an enquiry is due to its ambiguous and fluid nature that allows it to be deployed by a wide range of actors in pursuit of diverse aims. Writing on the definition of citizenship, anthropologist Sian Lazar (2013) observed that the concept has been used by political actors of all interest and scale. It is not only evoked on the level of nation states but also serves to organise local communities and international movements; it is used in the context of healthcare, education, governance, protests, even by multinational big corporations like Coca Cola and BP. Lazar (2013) notes that the wide appeal of citizenship lies in its ability to evoke themes of equality, liberty, community membership, political and cultural participation, and social and economic entitlements. Fundamentally, it is about ethical engagement between individuals and their communities.

Citizenship is thus what theorists refer to as an essentially contested concept (Duffy, 2017; Gallie, 1956; Lister, 1997), meaning not only that there is no consensus over its definition, but that its ambiguity provides a platform on which broader philosophical and political debates can take place.

Having said that, the definition formulated by T. H. Marshall (1950) in his seminal essay *Citizenship and Social Class* is a common starting point for scholars and theorists:

> "Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to rights and duties with which the status is endowed. There is no universal principle that determines what those rights and duties shall be, but societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measures and towards which aspiration can be directed" (p.28).

Seeking to theorise the historical development of citizenship, Marshall came to distinguish between three of its facets: civil rights (including liberty, equality in face of the law, and the right to own property), political rights (such as the right to vote), and social rights (like welfare and social security). It is the last point that denotes Marshall's major contribution to the citizenship literature. For Marshall, social rights marked a significant progress in the development of citizenship: he saw these rights as a counterpoint to protecting people from the effects of capitalism and social inequality. Marshall's work continues to frame writings on citizenship in the field of disability studies: this is apparent in field's preoccupations with equal rights in relation to material injustice and inequality (Duffy, 2017) – a point to which I will return in my next chapter.

It is not my intention to provide an in-depth critique of Marshall's works, but for the purposes of this thesis, there are two important points to note. Firstly, as critics of Marshall have argued (e.g. Beckett, 2006; Lazar, 2013; Lister, 1997; Turner, 1990), his formulation of citizenship exemplifies a liberal tradition of citizenship. Liberal traditions – that have a long history going back to the 17th century social contract theorists – understand citizenship in terms of individual status that grant members of a certain community the right to pursue their interests with minimal interference. In exchange for these rights, members – citizens – are expected to fulfil certain duties, such as pay taxes and partake in political deliberation (Lazar, 2013). Although Marshall was a proponent of social welfare, which classical liberal traditions would see as excessive state interference, for him the purpose of social rights was not to erase inequality, but merely to protect the most vulnerable individuals from fluctuations in the economy (Beckett, 2006). In fact, Marshall has been critiqued for essentially justifying inequality because of his conviction in equality of opportunity, especially of educational meritocracy: he argued that achieving upward mobility by demonstrating unequal abilities was the right of every citizen (Turner, 1990).

This leads to my second point: Marshall's vision of citizenship is static. In her feminist analysis, Lister (1997) argues that approaching citizenship as a status fails to take into account the struggles that surround claims-making. The liberal tradition, often implicitly, assumes equality among individuals, and fails to take consider the social and economic inequalities that prevent people from pursuing their aspirations. In practice, Lister (1997) observes, the concept of citizenship does not only function to grant people freedom from interference, but provides social movements a language with which they can demand and defend existing civil, political, and social rights, *as well as* claim new ones, such as reproductive rights. "A focus on citizenship as a process and not just an outcome, in which the struggle to gain new rights and to give substance to existing ones is seen as being as important as the substance of those rights," Lister (1997) writes, "citizens appear on the stage of both theory and practice not simply as the passive holders of rights but as actively engaging with political and welfare institutions, both as individuals and in groups" (p.6).

Martha Nussbaum's capabilities approach provides some guidance on what citizenship as a process of active engagement may look like outside of political movements, for people who rely on extensive support in their daily lives. Drawing on economist Amartya Sen's work, Nussbaum (2006, 2009) argues that for humans to be able to live a life with dignity, society is obliged to provide measures that foster their abilities, support them to flourish, and enable them to engage with others to the fullest of their capacities. For Nussbaum, capabilities are entitlements without which human dignity and basic functioning are not possible. She gives an outline of ten human capabilities, which are subject to continuous revision and cultural adaptation. These are:

1) Life: being able to live until the natural end of life and not die prematurely.
2) Bodily health, including having good health, as well as nourishment and shelter.
3) Bodily integrity: being free to move, free from violence, and having a say in matters of reproduction.
4) Being able to sense, imagine, think.
5) Being able to experience a range of emotions, develop human connections, and feel love and care for others.
6) Engaging in practical reasoning, including having a conception of good.
7) Affiliation: this includes being able to live with others, and being treated with respect.
8) Being able to live with other species and nature.
9) Play and enjoying leisure activities.
10) Having control over one's political and material environment.

In formulating my understanding of citizenship in this thesis, I draw on two aspects of the capabilities approach. The first one is the idea that human dignity requires more than simply guaranteeing individuals' basic rights; it also means enabling them to engage in activities they find valuable. Secondly, the capabilities approach foregrounds the affirmative measures needed for individuals to function and flourish, and makes their provision a matter of social justice. A just society ensures that human's basic entitlements are met and that citizens are supported to live life to their full capacity; justice hinders when these needs are ignored or impeded upon.

I will draw on Lister's and Nussbaum's arguments to frame my approach to citizenship as a process in which individuals are actively engaged, and as a set of capabilities that can be developed with the help of affirmative measures. In this thesis, I take an anthropological approach to exploring what all this means for people with learning disabilities in their everyday lives.

The field of anthropology seeks to contextualise citizenship as practice (i.e. what people do that construes them as citizens), and examines the social, historical, political, and cultural contingencies in which these practices take place (Lazar, 2013). This involves an interrogation of political and philosophical ideas associated with citizenship (e.g. community membership, rights, ideals of good life, rules of social participation), as well as the lived experiences of these ideas.

So far, little has been written about what citizenship means for people with learning disabilities in day-to-day existence. An anthropological examination is timely, firstly, because it further complicates taken-for-granted and rather idealised images of what being a citizen means. This is important because the seemingly neutral language of equality and liberty in classical liberal citizenship theories often assumes that citizens are able-bodied and able-minded individuals. Because of this, they often exclude people with learning disabilities, and fail to take account of their needs and interests when articulating the principles of equality, justice, and community membership (Carey, 2009a; Davy, 2015). Secondly, reformulating citizenship to be more inclusive for people with learning disabilities holds strategic political value: it provides a powerful language to claim justice, and address the persisting inequalities they continue to face.

An anthropological study of citizenship thus comprises two tasks. It requires 1) addressing the challenges that learning disabilities pose for prevailing ideals of classical liberal citizenship, and 2) comparing and contrasting these ideas with the everyday experiences of people with learning disabilities.

This thesis takes upon these challenges by exploring how citizenship is lived by people with learning disabilities and by describing how their citizenship is facilitated (or hindered) by those who work with them. I approach citizenship not as a normative starting point to study service provision; rather, I treat it as a concept that can be ethnographically derived from everyday practice and interactions (Ootes, 2012). I thus ask: how do different understandings of citizenship manifest in the day-to-day activities of people with learning disabilities? How do these understandings guide their activities and social life? To what extent do certain understandings help or impede inclusion? Which aspects of citizenship do people with learning disabilities practice, and to what end? What kind of support do they need to be able to do so?

The ethnographic material focuses on people who present complex challenges to pre-existent frameworks of citizenship: people with significant disabilities. The people I discuss have never had paid employment. They often have high support needs: most of them depend on their family members and carers to perform basic tasks. Many of them have physical impairments. In addition, they have little or no verbal language, and have a limited capacity to express themselves. I am interested in exploring how they are engaged with and recognised as citizens.

The context of this ethnography is a Glasgow-based organisation called Project Ability, which provides art workshops for people with learning disabilities. Scottish social policy, much like the other countries within the United Kingdom, upholds the support of people with learning disabilities as a priority. Its social care sector provides them financial and personal support, assistance with housing, and social activities. Project Ability presents a compelling and complex case, as it distils different aspects of citizenship into day-to-day artmaking. It provides a safe space for its participants to socialise, and supports with (artistic) choice-making. It engages with them as responsible subjects. Importantly, it provides them with a platform to contribute to society in ways other than paid employment. Yet, Project Ability exist in an austerity-struck Britain, where public services have been continuously cut over the past ten years, exacerbating the injustices people with learning disabilities had been facing. This raises question of how participants at Project Ability experience citizenship under austerity, and whether citizenship can be re-appropriated and made emancipatory in the context of spending cuts and shrinking pubic services.

This thesis explores these issues by examining the following research questions:

1) How do people with learning disabilities practice – i.e. negotiate, manipulate, and reconstitute – ideals of citizenship in their everyday lives?
2) How are they supported and hindered in developing capabilities associated with citizenship?
3) What new understandings of citizenship can be derived from their practices?

///

Chapter one starts with examining the different ways in which social policy understands citizenship. This reveals broader assumptions about personhood and belonging that are rooted in long traditions of Western political philosophy that, for the large part, ignored people with learning disabilities. I argue that an anthropological study of citizenship as everyday practice can help formulate alternative, more inclusive definitions.

The **second chapter** explores approaches to learning disabilities. I discuss why there has been relatively little theorisation on the social position of people with learning disabilities. I also explore the conundrums social theories and disability rights movements have encountered when facing the realities of learning impairment and the idea of inability. Then, I suggest theoretical frameworks that approach learning disabilities as a productive condition.

The **third chapter** describes where the empirical material came from: the site of my fieldwork, the participants, and my methods, with a discussion of inclusive research and its ethical and epistemological implications.

The **fourth, fifth, sixth, and seventh chapters** present the ethnographic material. Through examples of artmaking, I examine the ways in which the different aspects of the citizenship of people with learning disabilities are recognised, supported, negotiated, or hindered. The **fourth chapter** looks at the complexities of choice making. The **fifth chapter** asks what independence means in the context of risk management. The **sixth chapter** explores sociality and friendship. Finally, in the **seventh chapter**, I ask, what kind of artists can people with learning disabilities be and how can they be valuable to the lives of others.

In the final, **eighth chapter**, I return to the initial question of what alternative formulation of citizenship can be derived from the way it is lived. I discuss what this means for community participation, ethical engagement, and the institutional and structural support.

A note on the language

Regarding the language of this thesis, I use the term *learning disabilities* to be consistent with the British context in which my ethnography takes place. Having conferred with disability scholars, I decided to use the term *significant learning disabilities* instead of *moderate to profound and multiple* disabilities in order to avoid the medicalised undertones of the latter. I follow the convention regarding the use of *impairment,* by which I mean a loss or difference in physical or cognitive functioning caused by illness or injury. I use *disability* to denote the limitations caused by social and environmental barriers.

Chapter one:

Citizenship in learning disability policy and service provision

Introduction

Citizenship is a relative newcomer to British learning disability policy and service provision (Johnson et al., 2010). Since it first emerged in the 1950s, it has become a keyword in and organising principle of social services. “The lives of people with learning disabilities have changed,” starts the ministerial foreword to the 2019 governmental publication detailing the framework and priorities for the Scottish learning disability policy. “People with learning disabilities are citizens who want to play a full part in their communities across Scotland” (Scottish Government, 2019a: 2). Successive British publications have reiterated the same sentiment. “Rather than being a passive recipient of services, citizens can become actively involved in selecting and shaping the support they receive,” wrote the strategy paper, the Keys to life in 2013 (Scottish Government, 2013b: 17). Even before that, the review of Scottish services published in 2000 starts by quoting the United Nations Declaration on the Rights of Disabled Persons (Scottish Government, 2000). “People with learning disabilities are citizens too,” states simply Valuing people, the paper defining the direction of British service provision for the 21st century (Department of Health, 2001: 23). Despite the common occurrence of the term, policy and service provision never defines what they mean by citizenship. In fact, a closer examination reveals how different meanings of citizenship have been deployed to advocate for a wide range of changes in the treatment of people with learning disabilities.

This chapter has three aims. The first one is to explore the different meanings of deployments of citizenship in learning disability policy and provision. I will not employ a pre-defined meaning to evaluate policy and service provision; instead, my goal is to derive the meanings from policy rhetoric and implementation. By doing do, I argue that these policies have a complex legacy that often ended up curtailing the ideals they set out to promote. My second aim is to demonstrate that some of the shortcomings these are of a philosophical nature: namely, that their underlying assumptions of what makes a citizen comes from liberal philosophical traditions that are unequipped to address the challenges people with learning disabilities face. Finally, I contend that an anthropological investigation of citizenship not only addresses these philosophical challenges, but also provides a lens through which the impact of these philosophical assumptions can be investigated.

In the following sections, I first provide a brief historical overview on the trends in learning disability policy and service provision, with a focus on how people with learning disabilities came to be thought of as “citizens”. Then, I contextualise their citizenship ideals within the liberal philosophical traditions. Finally, I make the case for an ethnography examination of the citizenship of people with learning disabilities, and consider how it could contribute to both the field of anthropology and disability studies.

Constructing the learning disabled citizen in social policy and service provision

In 1961, Enoch Powell announced the government’s plan to halve the number of long-stay hospital beds in the upcoming fifteen years. These were bold visions from a Conservative health minister; at the time and for the most part of the century, long-term hospitals were the primary statutory provision for people with learning disabilities and mental illness. Powell’s speech radiated optimism. “[I]f we are to have the courage of our ambitions,” he declared in front of the National Association of Mental Health, “we ought to pitch the estimate lower still” (Rivett, 1998).

The announcement was preceded by reports raising concerns about the abuse, mistreatment, and lack of safeguarding in these institutions (Concannon, 2005). Amongst them was the pamphlet titled 50,000 Outside the Law, published by the National Council for Civil Liberties just ten years prior to Powell’s speech that read,

> “The idiot, the imbecile and feeble-minded are an integral part of the human race; their existence constitutes an unspoken demand on us. The extent to which we guard their right to the fullest and most useful life, the extent to which we guarantee to them the maximum freedom which they can enjoy and the extent to which we help their families to give them the love they need, is a measure of the extent to which we ourselves are civilized” (quoted in Concannon, 2005: 29).

The language of this pamphlet is notable: it was one of the first publications in the UK that explicitly evoked ideals of citizenship (“right to the fullest and most useful life”) to appeal for a better treatment of people with learning disabilities (Johnson et al., 2010).

In this section, I provide a brief overview of how subsequently citizenship came to be a central concept in learning disability policy and service provision. I do not aim to give an in-depth historical account of learning disability care. Rather, my aim is threefold. Firstly, I seek to demonstrate that citizenship is an ambiguous concept whose meaning in social policy has changed over the past decades. Secondly, I argue that many of the inequalities people with learning disabilities face today are a result of decade-long systemic measures, and that individualist policy formulations of citizenship are constitutive of these inequalities.

To do so, I look at three eras in learning disability service provision: deinstitutionalisation, personalisation, and austerity. I discuss how the term citizenship was deployed in these periods by various actors, and examine the practical impact that some of the staple policies in these periods had on the everyday lives of people with learning disabilities.

The beginnings: deinstitutionalisation

Prior to the Second World War, policy and service provision did not consider people with learning disabilities citizens in any sense. They were denied basic civil and political rights, such as the right to vote or get married, and were often exempt from duties like military service (Carey, 2009a). Although most people were cared for by their family and relatives, long-stay hospitals were the primary mode of formal care provision (Walmsley and Rolph, 2001). These hospitals were partly established to provide sanctuary for the disabled and poor people (Wright, 1998), but by the turn of the 20th century, people with learning disabilities were often institutionalised involuntarily. These institutions later came to represent the prevailing social exclusion of people with learning disabilities: segregation, abuse, and lack of choice and control.

It was the Second World War that brought about major changes in the practice and ideology of care provision (of which learning disability scholars like Welshman (2007) and Walmsley (2007) have written a detailed historical overview). Broadly speaking, some of these changes were due to the practical circumstances created by the war: for instance, while the eyes of the medical establishment were on the fronts, hospital workers found a freedom that enabled them to experiment with mixed care arrangements (Bennet and Morris, 1982; Thomson, 1998). Some changes coincided with an ideological shift, including the emergence of the disability rights, anti-psychiatry, and parent movements that inspired seminal sociological essays challenging the effects of mental institutions (e.g. Foucault, 1961; Goffman, 1961). These movements corresponded with reports on the abject conditions and abuse in hospitals (The Herald, 2002), erupting in subsequent conversations on the rights of residents and society's responsibility towards them (e.g. National Council for Civil Liberties, 1951).

In England and Wales, the process of hospital closures started in the 1950s, in response to demands by advocacy groups and families of institutionalised people. Calls for its necessity came to a head in 1979 with the publishing of the Jay Committee report, which, somewhat unusually for the time, started not by reviewing services but by outlining the rights of people with learning disabilities to "enjoy *normal patterns of life* in the community" (Concannon, 2005: 41). Subsequent policies proceeded to formalise community provisions by carving out the space and funding, while simultaneously closing down long-stay hospitals. All this culminated in the 1990 National Health Service and Community Care Act, which made community services the primary providers for social care (Stalker and Hunter, 1999).

///

In the UK, deinstitutionalisation frames current citizenship debates in complex ways. Advocates of deinstitutionalisation emphasised the civil rights of people with learning disabilities (Marshall, 1950), such as the freedom from repression by challenging the overt restrictions, control, and exploitation that took place in institutions. Deinstitutionalisation also asserted individuals' right to be free from discrimination based on their disability by putting forward their entitlement to normality.

However, deinstitutionalisation – both as an ideology and practice – also created new forms of exclusion, thus leaving a complicated legacy. Evaluations on the impact of hospital closures and moving residents into community care are still split between those who applaud the intentions but take issue with the implementation, and those who are more critical about the underlying idea that moving care from hospitals into the community can foster the sociality of people with learning disabilities (Hazelton, 2005). From the 1950s to the 1970s, parent organisations, disability rights advocates, and academics welcomed deinstitutionalisation as a milestone in changing perceptions of learning disabilities (Welshman, 2007). However, in the 1980s, the Conservative government recognised that increasing reliance on informal care networks could help their cost-cutting agenda: it is during this period that attitudes towards deinstitutionalisation and community care grew more ambivalent among academics and advocates (Walmsley, 2007).

The 1980s was marked by disillusionment in Scotland in particular, which was lacking in both commitment and coordination to undertake a task of such magnitude: up until the 1990s, there were no substantial resources nor adequate planning in place for the establishment of community care (Long, 2017; Stalker and Hunter, 1999). In Glasgow, the process was further exacerbated by problems related to deep poverty: the task of setting up community services created additional strain on the already underfunded and understaffed Department of Social Work (Long, 2017). Later appraisals sharply criticised the lack of governmental commitment to resource allocation (Jones, 2006; Thomson, 1998), including accounts that saw deinstitutionalisation as an attempt largely driven by the economic expectation to reduce costs (Walmsley, 2007). More recent critique suggests that deinstitutionalisation left the power of the medical establishment untouched despite hospital closures: policies simply relocated participants from segregated institutions to often similarly segregated facilities that happened to be located in community settings (Hall, 2010, 2011; Ootes et al., 2013; Power, 2013; Power and Bartlett, 2015).

Without the funding, deinstitutionalisation’s commitment to civil rights alone was inadequate to in addressing systematic inequalities. Ideologically, deinstitutionalisation put forward a vision of citizenship in which people with learning disabilities had the right to be part of the community. However, it said little about that what the right to be part of the community really meant for someone with learning impairment: deinstitutionalisation policies did not discuss the kind of interactions community “participation” could entail, and the ways in which substantial participation could be enabled and sustained. The lack of funding invested in community care did not allow enough space and resources to be invested in exploring these questions. All this suggests that deinstitutionalisation might have missed a trick: in lack of a comprehensive vision for citizenship, it cleared the path for a particular political agenda to co-opt its language to promote market interests.

Privatisation, personalisation, and the consumer citizen

By the late 1980s, the discontent voiced by disability activists and advocacy groups surrounding the underfunding of community care reached the Conservative government, which subsequently tasked Sir Roy Griffiths with examining these issues. During his investigation, Griffiths received numerous complaints from local authorities about the lack of resources in community-based services. While he acknowledged these, he also stated: resource allocation was outside the scope of his work. Instead, he offered an alternative explanation and thus solution for the funding issues. Rather than the ineffective resource allocation by the government, he suggested that the problem was in fact the lack of incentives in community care which led to cost-inefficient services. Community care, Griffiths famously wrote, was “everybody’s distant relative but nobody’s baby” (quoted in Wanless, 2006: 10).

Conservative prime minister Margaret Thatcher responded with government measures that incentivised the care sector through competition, deregulation, privatisation, and commodification (Langan, 1990). In the old social care system, the residential care for people with learning disabilities was paid for by the government's financial support. Griffith's concern was that this form of financing created services based on the budget that was available rather than the need of service users: his report suggested that this system did not allow for funding to be invested in exploring alternative ways into supporting people, outside of residential care (Wanless, 2006).

The reforms thus aimed to enable the diversification of care. In the new system of care provision, local authorities and social workers went from being care providers to care coordinators, whose primary task became assessing people's needs and then referring them to third party providers. These providers – a mixture of private and third sector organisations – were to compete with each other for governmental funding and clients. The stated goal was to create a system which was more cost-effective, flexible, responsive, and offered people more options and independence (Langan, 1990).

It is important to note that these changes corresponded well with the demands of the independent living movement, which gained prominence in the UK about the same time in the 1980s. For many of those living with physical disabilities, these reforms allowed them to have more control over their support and their finances by enabling them to receive their support in cash and employ a personal assistant (Pearson, 2012). However, the new care arrangements conspicuously refrained from addressing the care providers' primary complaint: inadequate funding for community care services that people with learning disabilities relied on. Observing these changes, policy researcher Mary Langan (1990) noted, the new provisions bore "a striking Thatcherite synthesis of the principles of the free market and the attitudes of the strong state" (p. 59). These social care reforms shared ideological principles with a wide range of reforms introduced under Thatcher's government, such as the restriction of trade union power, the privatisation of water, gas, and steel industry: they all demonstrated trademarks of economic liberalism, privatisation, and tight public expenditure.

Ten years later, by the late 1990s, the subsequent New Labour government inherited a care sector which was further fragmented and poorly coordinated (Hudson and Henwood, 2002; Wanless, 2006). The Royal Commission tasked with investigating the funding issues in the social care sector identified a number of challenges that linked to Thatcherite reforms. Among these were the prioritising of individuals with high support needs at the expense of those perceived as having lower needs. A further criticism was that the system was overly complex, offered little choice, and over-incentivised residential care, despite aiming to do the opposite (Wanless, 2006). The New Labour government sought to salvage the care sector by finding a "third way" between the welfare state and the free market, and by creating services that balanced individuals' entitlements and duties. What resulted was a hybrid "workfare" (as opposed to "welfare") system, in which people's benefits were tied to paid employment: recipients of state welfare were encouraged to develop marketable skills and seek employment in exchange for financial assistance. Paid employment was considered the primary way to inclusion for people with learning disabilities: the government introduced a range of practical support, from job brokers to coaching to adjustments for special needs to supported employment schemes (Redley, 2009).

Central to this era's provision was the so-called personalisation of care: the rearrangement of services, where the care-recipient's personal care plan was rendered to serve their aspirations (Scottish Government, 2009). In Scotland, personalisation offered social care service users four options for arranging their care. Accordingly, they could opt 1) to be paid the cash equivalent in the form of direct payments, 2) to select the support they need, which is then arranged by their local authorities or care organisation on their behalf, 3) to have their support both selected and provided by the local authorities, or 4) to receive a mixture of the first three options (Scottish Government, 2013a). In particular, direct payments and individual budget represented a staple policy, which enabled people with disabilities to design their care package, with the possibility to receive the cash equivalent of their care to employ a personal assistant. With direct payments, care-recipients were given the opportunity to assemble their care plan themselves and employ a personal assistant.

On paper, these measures echo the principles of the independent living movement, which advocated for "all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community" (Scottish Government, 2017: 27). In particular, members of the movement saw the right to cash payments and employ personal assistant as a means to independence on their own terms, beyond pre-existent service structures (Pearson, 2012). Direct payments was also heralded as a victory for social justice (Ferguson, 2012): it was a long-awaited recognition that disabled people were entitled to have control over their care, and capable of managing their finances (Needham, 2014; Pearson, 2000; Riddell et al., 2005).

///

From this era's reforms emerges a new kind of citizen, one who is defined by the ability to exert choice and control through becoming a consumer of social care services. The New Labour government's expectation was that these measures would increase choices and transform care and welfare recipients into autonomous, independent, and responsible citizens (Redley, 2009). This is most apparent in the language of the 2001 government publication *Valuing people*, which presents a clear outline of how policy and service provision imagined a citizen with learning disabilities at the time (Department of Health, 2001). The paper lays out proposals "based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent" (p.10). It further reiterates the government's commitment to people's "enforceable civil rights" (p. 23): the right to education, voting, to have a family, to freedom of expression, and freedom from discrimination.

There is, however, an incompatibility between people with learning disabilities and the image of the citizen upheld by these policies. Later evaluations (Burton and Kagan, 2006; Hall, 2011; Redley, 2009) note an uneasy amalgam of the marketization of welfare and the human rights discourse adopted by much of disability movement. Writing in relation to feminist movements, critical theorist Nancy Fraser (2013) warned that emancipatory efforts which rely on the marketization can simultaneously disintegrate social protections and solidarity, and therefore further entrench the marginalisation of those who continue to be excluded from the market.

Fraser's warning applies just as much to the disability movement at the time. The consumer citizen discourse and subsequent modes of empowerment were largely conceived and supported by articulate, politically active, *physically* disabled people. Little thought was spared for the different needs and capabilities of people with learning disabilities (Hall and Kearns, 2001; Shakespeare, 2006). The policies favoured those whose family members, care-givers, or themselves had the resources and time to take advantage of the purported consumer power offered by mixed provisions (Ferguson, 2007; Lymbery, 2010; Scourfield, 2007). However, individuals and families who needed more guidance on navigating the complex and elaborate service system received little help (Abbott and Marriott, 2013)

The ill-fit between ideology and practice is well-illustrated by the slow uptake of the opportunities offered by personalisation among people with learning disabilities, particularly in Scotland (Pearson, 2004; Priestley et al., 2007). At the time, in her condemning appraisal, Pearson (2004) partly attributed this lag in uptake to provider ignorance, as well as Scotland's anti-market discourse among social workers and care practitioners, which regarded much of personalisation as a sign of further privatisation and a threat to local authority services. But later reviews – which were far more critical of the consumerist ethos of personalisation – note that the low uptake indicates that such empowerment was inappropriate and perhaps undesired by people with learning disabilities, especially those of older age and more significant impairment (Hall, 2011).

The vision of citizenship that these policies outline are strikingly individualistic: a citizen is someone who participates through paid employment, lives independently, and is personally responsible for managing their own care. A problematic consequence of conceiving citizenship exclusively in terms of autonomy, independence, and choice in public services is that it ignores the relational aspects of citizenship (Ootes et al., 2013; Pols, 2016; Redley, 2009). These ideals speaks little to the fact that for those with significant disabilities, their everyday lives are embedded in complex webs of dependency with others: care is an ongoing relationship rather than a market transaction (Mol, 2008).

One of the complications resulting from introducing market relations into care arrangements relates to the question of whether to allow family members to be paid for taking on care-giving responsibilities. Hall (2011) provides a succinct summary of the debate: one side argued that commodifying family care could change the relationship between the family carer and care-recipient, and could cause tensions between the paid and unpaid family members. The other side of the debate was concerned that since care for people with learning disabilities were largely provided by their family members, not allowing family relationships to be financially compensated could devalue these relationships. However, Hall (2011) points out that debates revolving around the cost of care still frames care in terms of the market, which comes at the expense of discussing its implication on social justice, in particular regarding the gendered aspect of the care economy. Currently, care responsibilities overwhelmingly fall on women, much of which is either unrecognised and unpaid, or is low-paid and provided by women of from disadvantaged backgrounds (Lister, 1997). The language of personalisation which emphasises disabled people's rights and empowerment sits uncomfortably with its silence on the rights and empowerment of the people who provide the care (Hall, 2011; Shakespeare, 2006).

Another consequence of personalisation paying little attention to relationships was that policies around it led to the closure of many communal spaces of privacy, safety, comfort, and friendship, such as day care centres (Needham, 2012; Shakespeare, 2006). While the fear that these spaces might have constituted new forms of segregation akin to long-stay hospitals, little effort was invested into preserving the sense of belonging, safety and solidary established in these spaces. This is especially troubling in light of the rejection people with learning disabilities continue to experience when pursuing narrow routes to inclusion through employment.

Despite the mixed impact and experiences of personalised care, social care policy continues to hail it with unvarnished optimism: for instance, in its recent annual report published in 2019, Scotland's Chief Medical Office wrote, "with a growing number of people now living with multiple, complex and frequently fluctuating health conditions, the need for a personalised approach is greater than ever" (Scottish Government, 2019b: 6). Therefore, it is important to reiterate: this form of citizenship excludes many people with learning disabilities, as its expectations bear little correspondence with people's everyday lives, needs, and aspirations.

Care and belonging in the time of austerity

There is, of course, the question of whether the poor fit between people with learning disabilities and some of the personalisation policies were due to bad implementation. It is undeniable that the timing of any change in care provision instituted in the past decade was deeply unfortunate: in 2008, the UK was hit by the global financial and economic crisis that reframed the conversation around public spending (e.g. Hilsenrath et al., 2008; Stewart, 2008). "Trusting people, sharing responsibility, decentralising and devolving power," Conservative candidate and future prime minister David Cameron announced at his party conference the following year, "When it comes to running public services, that's the way you get new ideas, new people, new ways of doing things" (Cameron, 2009). His words stood in stark contrast with his government's subsequent actions, namely, the systematic withdrawal of funding from public services.

These spending cuts frame the everyday experiences of people with learning disabilities to this day. Although it is difficult to put an exact figure to the cuts, some estimate that since austerity was introduced in 2008, a total of £30 billion pounds were taken away from welfare, housing assistance, schools, police, courts, libraries, road maintenance, and so on (Mueller, 2019). In practice, these figures meant rising child poverty (Kingsley, 2018) and hunger (*The Trussell Trust,* n.d.), falling life expectancy (Collinson, 2019), an increase in preventable deaths (Helm, 2019), and exacerbating ethnic inequality (Gentleman, 2019).

People with disabilities were disproportionately affected by austerity (Duffy, 2013; Ginn, 2013). Sheltered workplaces – which had been a primary route to citizenship in the previous government's workfare regime – were deprived of funding and subsequently shut (Brindle, 2011; Hall and McGarrol, 2013). People with learning disabilities further lost spaces that offered opportunities for activity, participation, and socialising. Many local authority day centres closed; those that stayed open restricted their access by, for instance, limiting it to people not living in residential housing (Needham, 2012). Many of the leisure centres, libraries, art, and education programmes also came to a similar fate. No alternatives were put in place to substitute the closures (Hall, 2011; Roulstone and Morgan, 2009). Critics remarked that these were also spaces of safety and belonging; with them gone, people with learning disabilities were pushed into further social isolation (Hall, 2011; Hamilton et al., 2017; Malli et al., 2018; Needham, 2014; Power et al., 2016).

The language of personalisation was often used to justify these closures (Hamilton et al., 2017; Power et al., 2016). Disability studies scholars Power et al. (2016) observe that because spaces dedicated specifically for people with disabilities were often judged as a new form of segregation, closing them catered for both the social inclusion rhetoric and money saving policies. They note that,

> "Whilst the authors do not advocate the return to static, inflexible day centres, given the often poor outcomes involved, the findings nonetheless reveal a growing social precarity in people's lives, an individualization of risk and evidence of deep isolation and boredom when collective sources of support are removed and not replaced or reimagined." (p. 190)

As a result, the third sector organisations – including the charities tasked with providing care and services for people with learning disabilities – that pulled through the cuts became over-subscribed (Walker and Hayton, 2017). To seize a spot in these programmes, one had to be either referred by social services, their private care provider, or pay for the programmes from their own funds. Those who could not get into the programmes had to rely on their family relationships for care and support, presenting a particular challenge for people who did not have close family networks, especially elderly people with learning disabilities, many of whom relied on variable and inconsistent neighbourhood support (Power and Bartlett, 2019).

Even those who could retain their support and gained space at a programme had to reckon with further difficulties of getting to the place of support. Because most people with learning disabilities do not drive, they rely on accessible public transport, and personal and financial support with travel. However, as a consequence of austerity measures, transport infrastructure and support were significantly cut (Power and Bartlett, 2015). Human geographer Andrew Power noted that funding withdrawal "fail[ed] to appreciate the limitations and struggles that disabled people experience travelling through public space on an ongoing basis" (Power, 2016: 283).

Concurrently, the workload of social and support workers increased. Because people often rely on social workers for referrals into care programmes, the chronic understaffing of the social work department resulted in an increase in the unmet needs of disabled people. Stalker et al. (2015) give an account of carers feeling like they had to "fight" for the attention of social workers to be able to receive a referral for services. Care organisations became similarly understaffed, posing a further challenge. A man with learning disabilities interviewed by Bates et al. (2017) said, "People who live in residential places don't really have a choice about whether they can go to a meeting or not. There is no support worker to take them. And the creative arts groups are struggling to get money, there's less people at those meetings" (p. 169). Brimblecombe et al. (2018) spoke to a carer who explained the lack of time support workers had to attend to individual clients: "[the support workers] probably got, you know, ten people to get up in the morning or whatever and. they've been allocated three quarters of an hour to get that person. up, washed, dressed, fed, and – and everything and, you know, three quarters of an hour is not – it's not sufficient" (p. 224).

While social policy continued to emphasise the importance to treat people with learning disabilities like citizens, empirical studies on the impact of austerity highlight that the spending cuts and the subsequent erosion of the public and support infrastructure prevented individuals' ability to claim their rights.

///

Reviewing past trends in learning disability policy and service provision illustrates how citizenship as essentially contested concept functions in learning disability policy and care provision (Duffy, 2017; Gallie, 1956; Lister, 1997). As a term that is much evoked yet never defined, the polyvalence of citizenship is reflected both in rhetoric and practical care service arrangements. Since the start of deinstitutionalisation, citizenship has been deployed to advocate for civil rights and the freedom from repression and discrimination, which in practice served drivers of hospital closures and the establishment of community care. Towards the 1980s, citizenship increasingly came to mean the right to self-deliberation, choice, and control, a trend that continues to this day, albeit with different elements emphasised by various service provision frameworks. For the Thatcherite government (with the backing of disability rights organisations), consumption was the key element to supporting individuals' ability to have control over their support, which was reflected in the privatisation of the care sector. New Labour introduced the element of individual obligation towards society, which was key to their inclusion through workfare regime. Currently, citizenship is deployed to uphold the personalisation framework, which is an amalgamate of social rights and market logic.

When observing the ambiguity of citizenship in Dutch mental health services, anthropologist Sabine Ootes (2010) noted how the heterogenous meaning of the concept allowed various actors (service providers, healthcare professionals, patients) to create a bridges between diverse goals in mental healthcare. For her, citizenship was a productive and inviting concept because it could be used to talk about social obligations, rights, and inclusion, thus creating a common language that binded together an often fragmented sector with conflicting goals.

I only partially share Ootes' optimistic assessment. While British learning disability policy and service provision certainly evokes these powerful ideas, it also confounds them with market interests, which have been used to justify spending cuts in the care sector. In addition, despite the ambiguity of the term, the way citizenship has been used demonstrates common ideals of autonomy, independence, choice, and control. When reviewing the policies of the past decades, it becomes clear that the overemphasis of these ideals came at the expense of fostering care relationships and a sense of belonging.

The root of the problem

It is not a coincidence that policies that emphasised individualistic ideals fell short. In addition to problems with their practical implementation, I argue that these policies suffer from a fundamental philosophical problem, which makes them ill-equipped to address the needs of people with learning disabilities, and serve them justice and equality. These ideals are in fact rooted in long traditions of liberal theories of citizenship, which have, for the large part, ignored people with learning disabilities. In this section, I provide a brief overview of this philosophical tradition and its relation to learning disabilities, in order to suggest a way forward in discussing citizenship.

The perhaps most influential and enduring liberal tradition of citizenship rests upon the idea of the social contract, a thought experiment that outlines a mechanism by which principles of social justice and cooperation are decided. In their classic 17th century form – best represented by the works of thinkers like Thomas Hobbes, John Locke, and Jean Jacques Rousseau – theories of the social contract tell the story of political communities emerging as a result of individuals coming together to negotiate rights. The basic premise of the social contract posits that in a distant past, individuals existed without laws, governance, and society. Life in this state of nature was decidedly unpleasant: "solitary, poor, nasty, brutish, and short," as Hobbes (1651: 62) famously wrote. Seeing that this state of nature always carried a threat of violence, people decided to come together and outline rights that provided them equal entitlement and protection. At the beginning, these rights, negotiated on the basis of mutual interest, mostly comprised property rights. Later thinkers, including Marshall (1950), expanded these to include economic, cultural, and participatory rights (Beckett, 2006).

One of these modern thinkers was political philosopher John Rawls (1971). Rawls's work is highly influential in the liberal tradition because, while keeping the basic narrative premise of the social contract, he addressed some of the gaps left by his predecessors. One of these were the neglected interests of women, children, and the elderly: classical social contract theories assumed that individuals were men of equal capacity. Rawls's rectifies this by accounting for the plurality of interests in an inherently unequal world. He dismisses a common assumption in classical works that everyone has the same conception of 'good'; instead, his central preoccupation was to find a method by which people with different interests could achieve a set of political principles in a cooperative and mutually beneficial manner. The subsequent hypothetical negotiating situation Rawls devises is one where individuals are shrouded by a 'veil of ignorance', therefore they do not know their position: this negotiating position, Rawls posits, compels individuals to moral impartiality.

Despite its comprehensive nature, Rawls's theory does not address justice for people with learning disabilities (Beckett, 2006; Nussbaum, 2006). In fact: no reiterations of the social contract include them (Nussbaum, 2006). Rawls himself recognised this, he deferred the question and suggested that until a solution was found, thus inadvertently admitting that his theory was unprepared to address the problem of learning disabilities (Nussbaum, 2006).

In her in-depth critique of Rawls, political philosopher Martha Nussbaum (2006) argues that the difficulties Rawls faced when trying theorise justice for people with learning disabilities lies within the basic architecture of the social contract. There are two major, but flawed assumptions: 1) the assumption that individuals devise and uphold the social contract in pursuit of mutual advantage, and 2) that the parties at the negotiating table are of equal rationality, verbal self-expression, cognitive capacity, and socioeconomic productivity.

The problem with the former, Nussbaum argues, is that contractarians, including Rawls, conceptualise mutual advantage primarily in an economic sense, and do not have space to account for human benevolence to promote human dignity. The idea that economic advantage is necessary for participating in society is exclusive of people with learning disabilities, many of whom do not have the means or support to achieve paid employment and become financially independent (Redley, 2009). The second, similarly exclusive assumption comes from a long tradition of Western philosophy, which posits that it is the capacity to reason that sets humans apart from animals, while simultaneously denies people with learning disabilities said capacity because they do not fit into this idealised image of a rational person (McKearney, 2018a; Nussbaum, 2006). Accordingly, rational deliberation enables humans to make judgements of what is “good”, and subsequently participating in the social contract. Therefore, according to contractarians, it is a necessary condition of moral agency without which and individual cannot be a member of society. This view of personhood has been extensively critiqued from a disability and the ethics of care perspective (Beckett, 2006; Erevelles, 2011; McKearney, 2018a; Nussbaum, 2006; Vehmas and Curtis, 2017). As Nussbaum (2006) eloquently summarises the major issue with this philosophical construct:

> “[This view of personhood] suggests the idea that the core of our personality is self-sufficient rather than needy, and purely active rather than also passive. In so thinking we greatly distort the nature of our own morality and rationality, which are themselves thoroughly material and animal; we learn to ignore the fact that disease, old age, and accident can impede the moral and rational functions, just as much as the other animal functions” (p.132).

Social contract theories, although they may seem abstract at first glance, continue to shape the social imagination on what citizenship is: they provide the basic narrative on why people live in a community, how they can partake in that community, and who sets the rules for participation. Furthermore, these theories have an impact on the treatment of people with learning disabilities by framing the language and ideals of social policy and service provision, and by governing relationships between individuals (Lister, 1997).

A concrete example illuminates how. First of all, the principle of mutual advantage, defined narrowly in economic terms, is apparent in the fact that, outside of paid employment, there is little discussion on how people with learning disabilities can be valuable and contributing members of society. The fact that people with learning disabilities should be treated with dignity, and that engaging with them has value beyond increasing economic productivity is often an afterthought, rather than something policies actively seek to foster. Secondly, rationality as a condition to participation is apparent in the way choice, inclusion, and responsibility are conceived: as products of rational deliberation, conditional to verbal self-expression and cognitive capacity. None of the paths to empowerment take into account the possible limitations of that learning impairment can pose.

Revising the ideals and assumptions of liberal citizenship is essential in addressing the injustice and inequality people with learning disabilities face today. Social policies that are based on liberal ideals fall short partly because the philosophical theories they draw on do not take into account the needs, interests, and desires of people with learning disabilities. It is important to note here that outside liberal theories, there have been notable efforts in rethinking citizenship in relation to disability. These alternative theories recognise that as long as the people with learning disabilities cannot participate in setting the principles of social cooperation, their rights and citizenship is as case of charity rather than something that is ingrained in the basic architecture of society. I shall return to these theories in the second chapter.

Seeing the exclusionary tendencies of the liberal citizenship – which continues to dominate citizenship theories, social policy, and therefore ethical engagement with people with learning disabilities in the UK – one may ask whether citizenship as a concept has ceased to be theoretically and politically valuable?

Seeing the exclusionary tendencies of liberal citizenship, philosopher Annemarie Mol (2008) argues against its deployment in healthcare policy. She contends that "[i]n a democratic state, people are interpellated as citizens who govern themselves and one another. If this model is introduced into health care, and patients are called upon to overturn the dominance of their doctors and emancipate themselves, something is lost" (p.12). Mol (2008) takes issue with the fact that the liberal citizenship overemphasises empowerment, autonomy, and independence. "Emancipation may well be an improvement over oppression, but at the same time it is a rather limited ideal," she notes (p.30). Because the language of empowerment often comes at the relative neglect of relationality, treating people as (liberal) citizens may lead to poor care. For Mol (2008), good care is not solely a product on rational deliberation, but requires the recognition that we are inherently vulnerable and dependent. It is also tactile and involves the negotiation of sensory pleasures, like unhealthy food and alcohol. It is, above all, relational: a joint venture undertaken by doctor and patient. The idealised rational, immaterial citizen does not have space for bodily vulnerability and interdependency, she argues. Witnessing the entanglement of citizenship with exclusionary individualism, Mol (2008) asks, ought we not discard the concept of citizenship altogether in the context of care?

Although Mol's (2008) analysis focuses on healthcare, her concerns are relevant for the care of people with learning disabilities, whose ability to perform everyday tasks – like bathing, eating, and using transport – is often reliant personal support and care relationships. Due to the enduring and inherently exclusive nature of liberal citizenship in policy and service provision, the question is, can we reformulate the concept of citizenship to make it more theoretically relevant and strategically useful for people with learning disabilities?

Citizenship as practice and self-making

In the works I discussed so far, citizenship has been primarily framed as a philosophical and intellectual project. However, anthropological works demonstrate that citizenship is a productive analytical concept because it exists beyond political philosophy, legislation, and social policy. It is more than just abstract rights: it is an ontological condition, i.e. a way of being which permeates every aspect of everyday life. Anthropology approaches citizenship as a concept that manifests through and can be derived from everyday practices. In doing so, it can provide a lens into how citizenship is lived; it may also help revise the exclusive principles. In this section, by providing an overview of the anthropology of citizenship, I demonstrate that studying citizenship as everyday practice reveals the way it can be manipulated and rearticulated to serve claims-making. I argue that studying the citizenship of people with learning disabilities as a practice helps rearticulate the concept in a way that supports their claims to equality and justice.

Anthropologist Aihwa Ong (1996) famously wrote that citizenship is a dual process of “self-making and being made” (p.737): on the one hand, it is a process by which individuals are “being made” by the disciplinary mechanism of power relations exercised through administrative and surveillance systems. On the other hand, citizenship entails processes of “self-making”, meaning that it is the language by which individuals gain their capacity to act and challenge pre-existing power relations (Ong, 1996; see also Rosaldo, 1994).

Ong (1996) illustrates this point with an ethnographic example of Cambodian asylum seekers, who, upon arriving to the United States, are labelled welfare-dependent subjects by the state administration and public perception. The living circumstances in which these asylum seekers were placed did not help their public perception: housed in deprived neighbourhoods, many of them were left to survive on low-wage, blue collar work. Cambodian men who had been wage-earners struggled to make a living in their country of arrival. In contrast, Cambodian women, who formerly had been confined to the domestic sphere and financially dependent on their spouses, found an unexpected form of agency: some of them learnt to navigate the welfare system to their advantage and to improve their material conditions, which allowed them unprecedented freedom from their husbands. One of Ong’s (1996) informants explained that Cambodian women, as primary carers for their children, were the ones interacting with social workers and welfare services. They were the ones receiving the welfare cheques, and thus became the ones controlling the household’s finances. Ong (1996) recounts that many Cambodian women found ways to claim additional financial assistance by hiding their marital status, child’s age, or work-related income. Cambodian girls who became pregnant were sometimes married to the father of their children with a Khmer ceremony, but did not register their marriage with the local authorities, in order to receive statutory financial support. The hope of these young Cambodian women was to save up the benefit payments and eventually be able to have their own homes. These practices were a source of major frustration for social workers. However, taking disciplinary action to sanction their benefit payments only pushed these women back from the brink of achieving economic independence and reinforced their reliance on welfare (Ong, 1996).

Ong’s (1996) ethnography illustrates that formulations of citizenship, including rules and conditions of belonging, rights, and participation are not monolithic entities. Rather, once articulated by state bureaucracies, they take on their own lives and are used by individuals, often from systematically disadvantaged groups, to define themselves, frame their interactions, and in many cases, to make claims. People – like the Cambodian asylum seekers – navigate, negotiate, and manipulate the entitlements associated with citizenship to improve their living conditions. These examples clearly illustrate that citizenship can provide a theoretically and politically productive lens to shed light on the diverse and unexpectedly emancipatory potential of a seemingly exclusive concept.

Because of this, citizenship has enjoyed a particular popularity among studies of grassroots mobilisation and political movements: these works served to expand the political vocabulary of those seeking to contest the boundaries of national identity and belonging in relation to diasporas (e.g. Siu, 2001; Verdery, 1998), problematize the production of legal categories in migration and displacement (e.g. Feldman, 2007; Genova, 2013), and claim ethnic minorities and indigenous rights (e.g. Blackburn, 2009; Sieder, 2011).

The language of citizenship is not confined to contesting the nation state. Ethnographic accounts document citizenship used to make claims under neoliberal regimes or against market deregulation (e.g. Hale, 2005; Lazar, 2004), to appeal to humanitarian regimes (e.g. Fassin, 2012; Ticktin, 2006), and contest post-colonial power relations (e.g. Lukose, 2005).

Citizenship as a self-making practice is a fertile lens of analysis to explore claims to health and healthcare – an angle that holds particular relevance for people with learning disabilities. In 1996, anthropologist Paul Rabinow observed that new forms of biotechnology – like diagnostic categories or treatment possibilities – produce new forms of identities, subjectivities, and social life: biosocialities, as he called it (Rabinow, 1996). The language of citizenship often underlines these socialities to help describe emergent forms of belonging and claim rights to treatment, protection, and resources.

One of the most poignant and comprehensive examples comes from Petryna's (2003, 2004) ethnography in which she explores the new forms of citizenship that emerged subsequent to the 1986 explosion at the Chernobyl nuclear power plant. Petryna gives account of the disaster and the Soviet leadership's subsequent failure to protect communities, which became central in the Ukrainian government's case for independence, promising generous compensation for those affected. In the context of economic instability and unemployment caused by market transition, being able to demonstrate ill-health linked to the Chernobyl explosion became the only guarantee for citizenship entitlements, such as social and economic rights. What followed was an unprecedented mobilisation among people to master knowledge about radiation, compile evidence on radiation-related sickness, and negotiate with the medical system and the state with the purpose of expanding the diagnostic categories that entitled people for state benefits. In analysing and documenting the new forms of belonging, rights, and claims made on a biological basis, Petryna (2003, 2004) coined the concept of "biological citizenship". Biological citizenship proved to be a remarkably productive analytical tool for understanding claims-making in diverse contexts, as in HIV/AIDS activism (Biehl, 2007; Fassin, 2007, 2012; Kalofonos, 2010; Nguyen, 2007, 2010), the global pharmaceutical market (Biehl, 2007; Ecks, 2005), and civil partnerships in medical knowledge production (e.g. Gibbon, 2006; Rabeharisoa, 2003).

These works are important and informative in providing an empirical guide to studying citizenship. However, a limitation of these approaches is that they tend to focus on organised collective action led by politically savvy, articulate individuals who are often well-versed in the rights discourse, medical procedures, and have extensive social networks. Focusing exclusively on collective action and claims-making can neglect less visible practices of citizenship and community participation.

Not only relationships between the individual and the state hold a potential for rewriting citizenship: there is also potential for citizenry in interactions between individuals. It is these small, everyday interactions that medical anthropologist Jeanette Pols (2006, 2016) focuses on when she observes psychiatric nurses assisting elderly patients with washing in a residential home. There are nurses, Pols says, who help patients wash themselves because they see cleanliness as a precondition to other activities. Others regard washing as an activity through which residents can exert their autonomy. Some, however, see washing as a social activity they can undertake together with the resident. These are three different visions of citizenships, enacted through the act of assisted washing: "In their actions, the nurses and patients can be seen as bringing different social worlds into being," she writes (Pols, 2006: 79).

Pols's work resonates well with many people with learning disabilities who do not participate in collective action, resist, or make claims: people who need support with basic tasks of self-care, and whose main social network often consist of their family members and care-givers (also see Hall, 2010; Ootes, 2012). That Pols sees the potential for citizenry in these mundane relations is helpful. Her focus, however, is centred around care practices and individual interaction: how these relate to broader discourses on citizenship is yet to be explored.

///

These works offer some tools to address the question of what it means to be a citizen with learning disabilities. One is an ethnographic imperative, which, instead of seeking an answer in political philosophy, derive the meaning of citizenship from practices of belonging and claims-making. The second is a recognition that citizenship as a concept manifests in fluid, diverse, and sometimes quiet ways in practice, and that people are active and resourceful in deploying it in ways that could improve their quality of life.

Conclusion

My aim with this chapter has been threefold. Firstly, my goal was to illustrate that the concept of citizenship is polyvalent, and that learning disability social policy and service provision has deployed citizenship in a variety of ways to serve different purposes. Secondly, I demonstrated that these various understandings of citizenship drew on liberal traditions, which, I argued, are fundamentally unequipped to address the needs of people with learning disabilities. Finally, by outlining an anthropological approach to citizenship as a practice, I contended that by examining how people with learning disabilities enact citizenship in their everyday lives, we can articulate a new, more inclusive understandings that bear actual correspondence to what matters to them.

This chapter identified three gaps in the literature. First of all, I showed that without an interrogation of everyday practice, there is a danger that citizenship remains solely a philosophical and intellectual project, thus creating further lines of exclusion for people with learning disabilities. Anthropological works highlight that citizenship is more than just the abstract concept of rights. The concept exists outside of political philosophy and policy papers, and permeates every aspect of everyday life. It is an ontological condition, meaning that its meanings, ideals, and assumptions shape lived experiences. The literature on the citizenship of people with learning disabilities predominantly examines citizenship as a philosophical concept; there is a gap on how it is lived in everyday practice.

Secondly, the academic literature on citizenship has illustrated how the rights discourse, market interests, and political ideologies amalgamated in different understandings of the concept. This analytical approach – i.e. deriving the meaning of citizenship from discourse and practice instead of starting with a predetermined definition – allows us to ground philosophical debates on citizenship in everyday practice, account for the agency of various stakeholders in strategically negotiating and deploying abstract ideals. The literature has primarily focused on how policy measures and service provision articulated ideals of citizenship through practice. Little is known about the different meanings of citizenship that can be derived from studying how people with learning disabilities and those working with them reconstitute the meanings of citizenship. This is the second gap that this thesis will address.

Finally, while the anthropology of citizenship has showcased a wide range of examples on how everyday practices negotiate, manipulate, and reconstitute the meaning of citizenship for claims-making purposes, its primary focus has been organised, collective political action. In addition, anthropology has relatively neglected learning disabilities. In this thesis, I will address these omission by exploring the less visible acts of citizenship that manifest in the process of artmaking by people with learning disabilities.

The literature I reviewed in this chapter illustrates that citizenship is a theoretically and politically valuable concept, which can be re-appropriated by people with learning disabilities to aid their claims-making. In the following, guided by Aihwa Ong’s (1996) framework of citizenship as self-making and being made, I will explore the ways individuals with learning disabilities (and those who work with them) practice pre-existent, predominantly liberal ideals of citizenship. I will further examine how these ideals are negotiated, deployed, and rearticulated in the process. Doing so may do something interesting: not only does it reiterate pre-existent critiques and highlight gaps between rhetoric and practice, but may produce new a language, understanding, and vision of how to engage with people with learning disabilities.

Chapter two:
Engaging learning disabilities

Introduction

Having established my approach to citizenship, I now turn to the concept of learning disabilities: what it means and what we as a society can and should do about it. Margaret's and Deoiridh's example – both of whom I met at the art workshop during my fieldwork – illustrates some of challenges learning disability scholars and advocates have faced when trying to answer these questions.

Margaret is a woman in her sixties who sports a tidy pixie haircut and speaks with a measured voice. Since she retired, she has been accompanying her daughter, Deoiridh, a young woman with learning disabilities and autism, to the workshops. Deoiridh, cannot travel alone. Therefore, each week, Margaret takes the train with her daughter to the workshop (taking one hour, door-to-door), sits with her in the studio, and then travels with her back home. Although Deoiridh lives in supported accommodation, but Margaret remains her primary companion and source of support.

Margaret and I attended a talk at the Project Ability studio, given by an artist, Beth, and her mother. Beth has autism. Since she started at Project Ability, she became a recognised artist. Her small, quirky animal drawings appeared in children's books as illustration, and her work has been commissioned for national public art projects. With the help of her mother, she set up an online shop on Etsy, where they sold postcards, notebooks, and mugs. Beth's talk was a personal account of her experiences of autism in the art and business world. It was part inspirational talk, and part workshop for participants with entrepreneurial aspirations.

I caught up with Margaret in the tea room after the talk. Considering that Margaret and Deoiridh shared similarities with the speakers – mother and daughter with autism and artistic talent, supported by Project Ability – I asked Margaret if she would also consider starting up an online business with Deoiridh.

Margaret sighed. "No," she said and shook her head. She explained that although Deoiridh also had autism, her learning disabilities would not allow her to do what Beth does. Margaret told me that although Deoiridh was a prolific artist and she has sold artwork via the studio gallery, her productivity was not consistent. Margaret pointed out that Deoiridh did not have the concentration to produce large numbers of artworks that were consistent in quality. Whereas Beth could make hundreds of small animal drawings that were identical in style and size within a short period of time, Deoiridh could take days to finish one – that is, if she did not lose interest halfway through.

“It’s great that in this country you can set up your own business,” Margaret said, as if she was looking for a silver lining, “But I don’t think Deoiridh could do it.”

///

Margaret’s and Deoiridh’s example resonates with a broader issue in the disability world. Historically, in order to make a case for people with disabilities to be treated as equal citizens, much of the scholarship and activism set out to prove that having an impairment did not make an individual any less worthy than their non-disabled peers. However, as I discussed in my previous chapter, liberal traditions of citizenship link equal worth to equal capacity. Hence, in the fight for equality and justice, one of the strategies employed by the learning disability scholarship and advocacy – whose language is informed by the liberal language of individual rights, autonomy, and independence – was to prove that having an impairment did not make an individual any less capable. This is apparent in two of the major ideological movements that have shaped the way the citizenship of people with learning disabilities have been imagined: normalisation and the social model of disability (Stalker, 2012).

Following decades of disability rights activism, a growing self-advocacy movement, the proliferation of the learning disability scholarship, and increasing opportunities for people with learning disabilities to tell their own stories through life histories and autobiographies (famously, Hunt, 1967; also see Atkinson and Williams, 1990; Atkinson et al., 2000), it is now widely proclaimed in social policy and service provision that, with support, people with learning disabilities can do what their non-disabled peers do (Department of Health, 2001; Scottish Government, 2013b). People like Beth – a talented artist with disabilities who rose to national recognition with the support of an arts organisation – perfectly illustrate this point.

People like Deoiridh pose challenges to these success stories. Although Deoridh is also a talented artist, her learning impairment poses particular difficulties to her artmaking – and her everyday activities. Like many of the participants I met at the workshops, Deoridh lives in supported accommodation, and has few prospects of becoming independent (Bigby and Fyffe, 2009). She cannot travel alone, and requires assistance with basic tasks like shopping, cooking, taking her medication, planning her weekly schedule, and socialising with others (Mencap, 2016). Like all of those I encountered at the workshop – with the exception of one participant – Deoridh has never been in paid employment (Melling et al., 2011). However, there is little theorisation on the social position of people like Deoridh – people with more significant learning disabilities – in social policy and in disability studies (Stalker, 2012). There is a danger that in focusing exclusively on success stories – which emphasise ability – that the specific needs and interests and interests of people with more significant impairments are side-lined (Johnson and Walmsley, 2003; Mietola et al., 2017; Nind, 2014).

There is thus a dilemma one faces when writing about learning disabilities. On the one hand, describing learning disabilities as a deficit or lack of capacity echoes past discriminatory practices, and risks denying people with learning disabilities their agency, capabilities, and dignity, as well as justifying current injustices and inequalities that people experience. On the other hand, emphasising ability may ignore the difficulties and support needs that people with learning disabilities face.

The central aim of this chapter is to find an approach that engages with people with learning disabilities as individuals with capabilities while recognises the limitations of learning impairment, significant impairment in particular. First, I will provide an overview of the major theoretical frameworks that have dominated learning disability scholarship and service provision, and assess the extent to which these frameworks have engaged with the nature of learning impairment. In the second half the chapter, I turn to an emerging body of works on vulnerability and the ethics of care, and reflect on the ways they can provide an alternative framework for thinking about learning disabilities.

Learning disability and its medical definitions

Although in this thesis I approach learning disabilities from a social science perspective, a significant proportion of the research comes from the medical field, which has defined the ways in which learning disabilities have been theorised.

Besides being a social phenomenon, learning disabilities is also a medical label. However, it is ill-defined, and its diagnosis often relies on clinical judgement more than standardised testing (Mietola et al., 2017). The World Health Organization's (WHO) classification list, the 11th revision of the International Statistical Classification of Diseases and the Related Health Problems (ICD-11) (2018) classifies disorders of intellectual development as a form of neurodevelopmental disorder, which entails:

> "a group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behavior that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests." (Section 6A00)

The ICD-11 identifies four levels of impairment based on standardised IQ tests scores and levels of support need:

1) Mild: characterised by IQ scores two to three standard deviations below average, some difficulties in language and academic skills, but a capability in fulfilling self-care, basic tasks, employment, and independent living.

2) Moderate: IQ scores three to four standard deviations below average, basic language and academic skills, an ability to complete self-care and basic tasks, but support needed to achieve independent living and employment.

3) Severe and 4) profound are both defined by IQ scores four or more standard deviations below average, sensory and motor impairments, limited communication abilities, and the need for substantial and ongoing support. The ICD-11 differentiates these two levels on the basis of adaptive behaviour and the level of support needed with daily tasks.

The ICD-11 recognises potential issues with relying on standardised IQ testing, and specifies that where tests are either not available, not applicable (like in the case of children), or difficult to administer (as in the case for people with severe and profound levels of impairment), diagnosis should be made with reliance on clinical judgement. In addition to issues with availability of administration, social scientists have problematized the practice of standardised IQ testing for a range of reasons. These include the fact that IQ tests essentialise complex and varied abilities by simplifying them to a single score; that IQ testing singles out and measures culturally specific, Euro-American skills, which are then presented as universal intelligence; the way IQ is constructed neglects the importance of social skills and critical thinking; and finally, IQ scores have been used to justify racial discrimination and exploitation (Cohen, 2002).

Other major diagnostic manuals, like the 5th edition of the Diagnostic and Statistical Manual (DSM-V) issued by the American Psychiatric Association (APA) defines learning disabilities as limitation in areas of conceptual functioning, social behaviour, and practical skills. This reflects the APA's intention move away from a reductionist understanding of learning disabilities based on IQ scores, in order to move towards a more ecological framework within the medical field (American Psychiatric Association, 2013).

The majority of the participants I met in the workshops would be categorised as having moderate to profound learning disabilities. However, as Mietola et al. (2017) argue, significant learning disabilities is complex, and these categories only capture part of these complexities. The medical approach to learning disabilities has been thoroughly critiqued by the disability scholarship for being reductionist, framing disability solely in terms of deficiency, and being exclusively interested in problems and solutions on an individual level (for a learning disabilities perspective, see Goodley, 2010, 2014). My aim in the following is to find alternative approaches to learning disabilities (especially significant impairment), which can describe people in their full complexity and outline a vision on how to engage with them as a society.

Normalisation: the right to an "ordinary life"

Normalisation has been and remains perhaps the most influential theoretical framework to guide learning disability scholarship, policy making, and service provision (Johnson and Walmsley, 2010; Stalker, 2012). In the following, I assess the extent to which normalisation engages with the nature of learning impairment, and discuss whether normalisation still holds any unfulfilled potential for people with learning disabilities sixty years on.

At its conception in the early 1960s, normalisation was radical in the way it envisioned the place of people with learning disabilities in society. This is best illustrated by the seminal ethnography by anthropologist Robert Edgerton (1993), who in the 1960s spent a year following up people with learning disabilities who had been residents of a state hospital in California. Edgerton observed their everyday lives after their discharge: their living space, work, spare time, and relationships. He noticed that despite the lack of support and the stigma of the learning disabilities label (or "mental retardation", as it was called), the people he spent time with were able to develop various strategies to pass as "normal". These observations contradicted the medical thinking around learning impairment at the time: contrary to the prognoses of medical models that saw little chance for development, Edgerton argued that people with learning disabilities were capable of adapting to their social environments. The struggles of these former patients struck Edgerton. "[…] we see an eloquent testament to man's determination to maintain his self-esteem in the face of overwhelming cultural rejection and deprecation," he wrote (p. 194).

A few years later in the 1970s, service provision efforts to help former residents adapt to life outside the hospital walls were articulated as a set of principles. These principles came to be referred to by the umbrella term "normalisation" (and later on, Social Role Valorisation). Primarily led by academics and health professionals, normalisation set out to provide people with learning disabilities with "ordinary" living conditions within the "community", as opposed to the highly controlled life inside the segregated long-stay hospitals (Walmsley, 2001). For one of the founders of normalisation, Danish academic Bank-Mikkelsen, ordinary living conditions comprised "making normal mentally retarded people's housing, education, working and leisure conditions" (Bank-Mikkelsen quoted in

Culham and Nind, 2003: 67). Wolfensberger, his US counterpart went further and argued that people with learning disabilities needed not only material normativity but also a cultural one: they needed to be provided opportunities to inhabit socially valued roles (Wolfensberger et al., 1972). Wolfensberger's model expanded the focus from learning disabilities to include all groups who were considered deviant: his theory of normalisation saw integration in all aspects of life – not only in terms of living conditions, but also in behaviour, appearance, experience, and status – as pivotal to one's social value, while negatively perceived social differences could perpetuate social devaluation (Culham and Nind, 2003).

It is easy to see the appeal of normalisation. Its principles of people's right to life in the community, to be treated as individuals first, and to have support to enable personal growth translate easily into clear and individualised goals for policymakers and service providers (Walmsley, 2001). Current policy language continue to reflect this. "People with learning disabilities should have the same opportunities as other people to lead full and active lives and should receive the support needed to make this possible," the British Department of Health wrote in 2001 when setting out their vision for people with learning disabilities (Department of Health, 2001: 17). "Independence in this context does not mean doing everything unaided," they proclaim (p. 23).

However, Mike Oliver (1999), leading figure of the social model of disability famously critiqued normalisation for prioritising individualised goalsetting at the expense of addressing the material needs that people with learning disabilities require to achieve said goals. Oliver argued that normalisation failed to provide a political and economic analysis of the social disadvantage disabled people live with. Because of this omission, he concluded that normalisation had little to contribute to the struggles of the disability rights movement. Normalisation, he wrote, was "at best a bystander in these struggles, and at worst part to the process of oppression itself" (p.163).

It is not only the material needs that normalisation neglects: it says very little about the support needs of those who cannot perform the most basic tasks of said "ordinary life", for instance, taking a shower or crossing the roads. Tensions in the scholarship and service provision that result from this omission are well illustrated in two areas of activity, which aim to promote the social participation of people with learning disabilities: self-advocacy and inclusive research. Both areas purport – amongst other things – to enable people with learning disabilities to participate in socially valued activities, i.e. advocacy and research (Walmsley, 2001). Despite notable efforts to support people with learning disabilities to fulfil these roles, both areas have struggled to involve people with significant learning impairments, and because of this, both have endured recurring – albeit timid – criticisms from some learning disability scholars for sometimes opting for tokenistic rather than meaningful ways of inclusion (Bigby et al., 2014; Frawley and Bigby, 2011; Schelly, 2008).

For instance, Redley and Weinberg's (2007) observational study highlights the limitations of social participation via public speech. They cite several instances from self-advocacy meetings where self-advocates either spoke inaudibly, were perceived to digress from the topic, or did not reply to questions posed by non-disabled facilitators. Redley and Weinberg (2007) argue that although self-advocates were responsive in all these instances, their responses were deemed inappropriate – therefore meaningless contributions – by service providers. Their study highlights that while efforts to include people with learning disabilities in public debates is laudable, it cannot be accomplished without, first of all examining the (conversational) rules by which they are expected to participate, and secondly, addressing the special assistance they require.

Walmsley and Johnson (2003) noted similar normative barriers people with learning disabilities experienced when partaking in research. Specifically, they found that the language and abstract concepts of social research were not easily made accessible for people with learning disabilities who took up the roles of co-researchers. To ensure that the research did not exclude learning disabled co-researchers, they thus had decided to forego theorisation in some of their research projects because they could not find a way to make it accessible for people with learning disabilities. Walmsley's and Johnson's (2003) account highlights their commitment to inclusion. However, what their examples *does* illustrate is that expecting people with learning disabilities to participate in (research) activities the way non-disabled people do is restrictive and ignorant of the specific limitations that learning impairments pose.

Ultimately, these examples of self-advocacy and inclusive research highlight the limit of normalisation's engagement with the nature of learning impairment. Despite acknowledging that people with learning disabilities require support with their everyday lives, normalisation still foregrounds ability at the expense of discussing the impact that learning impairment has on people's ability to participate in "normal" activities. Part of the problem is that in normalisation, the rules of participation are set by people without learning disabilities. There is little alternatives for those who – due to their learning impairment or for another reason – deviate from these rules (Culham and Nind, 2003; Williams and Nind, 1999).

Consequently, in practice, normalisation fails to engage people with more significant learning impairments, for whom the even the most ordinary tasks of "ordinary life" pose serious challenges. This is reflected in the way many of the social policy favour activities that are more suitable for people with mild learning disabilities: these include the closure of specialist services in favour of integrated, mainstream housing, healthcare, and education. All these measures raised ardent criticisms from scholars for setting unrealistic expectations for people living with significant impairments who could not or did not desire to be part of these normative visions (Clegg et al., 2007; Clegg and Bigby, 2017). Yet, no substantial discussion took place in policymaking about what care services could provide for people for whom mainstream education was not feasible, who could not hold paid or voluntary jobs, and who lived in supported, supervised homes with little say over location and housemates.

Again, these issues demonstrate that normalisation is an incomplete framework for policymaking and service provision because it operates with a limited idea of learning impairment and its impact on the everyday life. As Burton and Kagan (2006) aptly noted, policies that follow the normalisation framework often imagine people with learning disabilities as individuals with mild cognitive impairments who live in idyllic, welcoming communities, and do not struggle with additional mental health problems and physical disabilities. This is obviously not the case (Chaplin et al., 2010; Krahn and Fox, 2014; Timmeren et al., 2017). However, unless proponents of normalisation engage with the nature of significant learning impairment, the needs of people with significant learning disabilities will continue to be neglected.

Engaging with people with significant learning disabilities within the normalisation framework entails asking how their diverse inner lives, desires, abilities, and practices could be reconciled with the principles of the "ordinary life". What is meaningful interaction and sociality for people who do not have the capacity to express themselves with verbal language? What are the valuable roles which they could fill beyond employment? What alternative ways are there for them to be advocate for themselves and making their voices heard, beyond public speaking? Answering these questions requires reckoning with the nature of learning impairment: its limitations, its impact on people's everyday life, and its support needs. If normalisation addresses these issues, it could generate new visions for people with learning disabilities, ones that engage them on their own terms.

Disability and impairment: the social model and critical disability studies

While normalisation proposes to extend the privileges of mainstream society to people with learning disabilities, the British social model of disability calls for overturning said mainstream society altogether. In this section, I assess the extent to which the social model addresses the specific support needs of (significant) learning impairment. I do so first by outlining the theoretical foundations of the social model, and secondly, by reviewing the ways in which its propositions have been taken up by the learning disability scholarship and advocacy.

The basic tenet of the social model of disability rests upon a conceptual separation of *impairment* and *disability*. Whereas *impairment* is seen as a biological condition, *disablement* is attributed to the social circumstances that surround *impairment*. For instance, while impairment to one's legs may lead to someone not being able to walk, their limited mobility (*disability*) is the result of their built environment that pose barriers by not considering their needs. A potential solution thus involves altering the social circumstances that cause disablement: in the example of the person with limited mobility in their legs, this would involve removing barriers to mobility introducing wheelchair access to buildings.

The conceptual distinction between disablement and impairment enabled scholars to examine the social conditions of disability, and formulate demands for policy and service provision. It infused the scholarship with a wave of optimism: "Once social barriers to the reintegration of people with physical impairments are removed, the disability itself is eliminated," wrote Vic Finkelstein (1980: 22), disability rights activist and writer.

The social model was first articulated with only physical impairment in mind. In 1976, when the UPIAS (the Union of Physically Impaired against Segregation) formulated the distinction between impairment and disability, it made no mention of learning impairment:

> Disability is the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (UPIAS, 1976 in Stalker, 2012: 122)

Key texts on the social model of the time rarely mention learning disabilities (e.g. Finkelstein, 1980; Oliver, 1990). Subsequently, much of the policy actions derived from the social model focused on physical barrier removal in public spaces, and little effort was made to understand and address barriers that people with learning disabilities faced (Shakespeare, 2013; Stalker, 2012).

What the social model *did* provide learning disability scholars was an analytical lens to examine the material conditions that shaped the lives of people with learning disabilities. Stalker (2012) argues that the materialist perspective of the social model helped address inequalities that disproportionately affected people with learning disabilities, such as housing, discrimination, hate crimes, poverty, and health (Emerson, 2007; Emerson and Baines, 2011; Emerson and Hatton, 1998; Emerson and Roulstone, 2014). This is a significant and lasting contribution of the social model to the learning disability scholarship: material inequalities continues to be one of the major focus in learning disability studies, especially in face of the spending cuts that service provision underwent during the period of austerity (Needham, 2014). It is also notable that the disability rights movement – which was galvanised by the social model – effectively mobilised against the mistreatment and abuse many people with disabilities endured in long-stay hospitals, and their campaigning contributed to the introduction of anti-discrimination legislation (Stalker, 2012).

///

Scholars from the field of critical learning disabilities studies have tried to adapt the theoretical foundations of the social model to learning impairment, and argued that learning disabilities, much like physical disablement, were caused by social arrangements (Chappell et al., 2001; Goodley, 2001; Goodley and Runswick-Cole, 2016; Race et al., 2005; Roets and Goodley, 2008). This theoretical position took inspiration from gender studies, which observed that sex was socially constructed and thus could be studied from a social science perspective. In an effort to repeat "the Judith Butler move" (Shakespeare, 2013: 57) – referring to the gender theorist who famously articulated this – critical learning disability scholars aimed to illustrate that (learning) impairment itself was nothing but a product of discourse.

Part of their objective was to problematise the medical diagnosis of learning disabilities. For instance, some argued that the IQ scores – which provided the base for the learning disabilities construct – were arbitrary in their cut-off points, and measured only a narrow range of intellectual capacities (see Bogdan and Taylor, 1982; Whitaker, 2013). Some scholars challenged the validity of learning disabilities as a product of the education system labelling children's undesirable behaviour (Goodley, 2001; Mercer, 1973; Sleeter, 1986, 2010). Mercer (1973) herself made the case that some children – at the time referred to as the "six-hour retarded child" – who were well-functioning at home were labelled learning disabled at school when they did not do well in performance tests. Furthermore, diagnoses closely related to learning disabilities, such as autism/Asperger's and Attention Deficit Hyperactivity Disorder (ADHD) have been contested on the basis of diagnostic inconsistencies (Schrag and Divoky, 1975). Disability studies scholar Campbell (2009) went as far as to state that all these practices – intelligence testing, school performance exams, the diagnosis of certain behavioural disorders – contributed to a definition of normalcy that serves the interests of dominant groups to subjugate those without power.

A different line of argument points to the fact the concept of learning disabilities has been continuously redefined over the past decades, reflecting changing social concerns, values, and economic circumstances. For instance, in the UK, "idiocy" became "lunacy" when the perceived increase in levels of poverty and shaped welfare policy – hence lunacy was closely associated with socioeconomic strata (Barfoot, 2009; Carey, 2009b; Jones, 1960; Wright, 1998). Lunacy gained further moral character at the turn of the 20th century, when industrialisation-related phenomena – such as accelerated immigration, increasing crime and alcoholism levels, and growing pessimism around care provision – brought about the label of "feeblemindedness", which corresponded with societal anxieties about what some saw as the loosening moral fabric of society (Carey, 2009b; Simmons, 1978; Walmsley, 2000). These findings led Dan Goodley and his colleagues, notably Griet Roets and Katherine Runswick-Cole to conclude that learning disabilities as a concept was unstable and primarily socially produced. Pointing to these discursive practices around learning disabilities, they then sought to undo concepts such as rationality, capability, and independence (Goodley, 2001, 2009; Goodley and Rapley, 2001; Goodley and Roets, 2008; Goodley and Runswick-Cole, 2016; Roets and Goodley, 2008).

These analyses have merits. They, rightly so, demonstrate how restrictive and contingent definitions of normalcy have been deployed to discriminate against people with learning disabilities (amongst other groups of people, like immigrants, ethnic minorities, and poor people). They also highlight the lifelong mistreatment of people who were labelled disabled by flawed systems of intelligence testing, education, the pharmaceutical market, and social anxieties (notably, the institutionalisation of women who were institutionalised because they had children out of wedlock).

However, these arguments centre around people with mild learning disabilities. Those who require high levels of support are either not included in the scope of these works, or are only mentioned in passing. Subsequently, the proposition for political action in these works are also tailored for those with less significant impairments. For instance, Bogdan and Taylor (1982) advocate for autobiographies, and Goodley and Roets (2008; see also Roets and Goodley, 2008) call for more self-advocacy. It is unclear, however, if critical learning disability studies offers any specific call for action for people with significant impairments.

Given their early affinity with the social model of disability, it is rather striking that works in the critical learning disability scholarship rarely includes a material analysis. In fact, they include little reflection on the nature of learning impairment and its impact on the everyday lives of people with learning disabilities. Goodley's (2001; Goodley and Rapley, 2001) assertion that *impairment* is mere *difference* in human cognitive capacity is highly problematic once weighed against the experiences of people with learning disabilities. He argues that once learning impairment is deconstructed, people with learning disabilities will be able "to creatively re-configure and re-invent themselves to resist (professional) control, voyeurism, bio-power, existential challenges and oppressions they have to face in their everyday lives" (Goodley and Roets, 2008: 248). Yet, he is not clear about how this is meant to be achieved, and what it would look like in practice.

Given the lack of engagement with the everyday experiences of their subject matter, it rings rather intellectually facetious to claim that learning disabilities are simply a product of the medical establishment, the education system, and political forces. To say that learning disabilities are entirely a social construct would be denying the everyday difficulties many people face and the level of support some of them require with everyday tasks. "[…] the answer, in my view," writes Shakespeare (2013), "is not to claim that there is no problem, and that if it was not for the social interventions, folks with mild intellectual disabilities would be fine. They would not" (p. 62).

In the absence of an examination of the everyday lives of people with learning disabilities, these works have little purchase on learning disabilities activism, policy, and service provision. They thus offer little more than an intellectual exercise.

Recognising impairment: the alternatives

In the 1990s, disability studies experienced a backlash against the dominance of the social model for ignoring the inherent difficulties caused by impairment, which spurred a discussion on embodiment and the lived reality of physical impairment (Crow, 1996; Morris, 1991). Feminist disability activist and artist Liz Crow (1996: 4) wrote that even if social barriers were removed, "pain, fatigue, depression and chronic illness [were] constant facts of life" for people who lived with impairments. Subsequently, Crow called for disability studies to "bring back impairment" (p. 4), and recognise its impact on disabled people's experiences. She wrote:

> "Many people find that it is their experience of their bodies – and not only disabling barriers such as inaccessible public transport – which make political involvement difficult. For example, an individual's capacity to attend meetings and events might be restricted because of limited energy. If these circumstances remain unacknowledged, then alternative ways of contributing are unlikely to be sought. If our structures and strategies – how we organise and offer support in our debates, consultation and demonstrations – cannot involve all disabled people, then our campaigns lose the contributions of many people" (p. 5).

Subsequent scholars met Crow's call by theorising on the body's role in the politics of disablement (Hughes and Paterson, 1997; Thomas, 1999, 2007). Thomas (1999) coined the term "impairment effects" specifically to examine the limitations caused by physical impairment. Activist and writer Jenny Morris (1991) went further and demanded the recognition of experiences of disabled people in the feminist movement, making the limitations posed by impairment central to her politics. "It is not normal," she wrote, "to have difficulty walking or to be unable to walk; it is not normal to be unable to see, to hear; it is not normal to be incontinent, to have fits, to experience extreme tiredness, to be in constant pain; it is not normal to have a limb or limbs missing" (p. 16). Hughes and Paterson (1997) further politicised impairment-related pain and argued from a phenomenological perspective that suffering was in fact the embodied manifestation of disability. Connecting the personal (impairment) to the social (disability), they urged disability studies to engage with an embodied politics of disablement. Although none of these accounts discussed learning disabilities, they signalled the task ahead, namely to find a theoretical framework that acknowledges the difficulties of learning impairment while engages with it in a productive manner.

Tom Shakespeare's broader conceptualisation of impairment-as-predicament does this by describing impairment as "the intrinsic difficulties of engaging with the world, the pains and sufferings and limitations of the body" (p. 86). Predicament presents a language which acknowledges that impairment makes life harder, but without evoking a sense of personal tragedy. Impairment-as-predicament recognises that impairment may lead to exclusion, discrimination, and disadvantage; true to the spirit of the social model, it proposes that these should be addressed. However, it recognises that even once these barriers are removed, impairment will continue to pose difficulties for disabled people.

Because impairment will always be a fact of life, the task is to explore why specific impairments evoke certain reactions in the social world? Why are some impairments accommodated, others discriminated against? What special arrangements do specific impairments require to minimise their undesirable impact on daily functioning?

When applied to learning disabilities, impairment-as-predicament addresses two issues that the social model, critical learning disability studies, and normalisation all share. First of all, Shakespeare's framework emphasises that people with different impairments have different needs regarding services. Many people with mild learning disabilities identify with the aims of mainstreaming and welcome opportunities to work, exercise independence, or to partake in self-advocacy and research (Shakespeare, 2013). However, the complex mental health and chronic conditions people with significant disabilities often have require specialist provision (Clegg and Bigby, 2017). This may be an obvious distinction; however, few services differentiate themselves accordingly.

This recognition is crucial to devising a strategy for mobilisation, which often assumes a collective disabled identity. Experiential accounts, on the other hand, suggest that many disabled people do not have common goals or necessarily identify as disabled at all (Beckett, 2006; Watson, 2002). This is the case with people with learning disabilities too, evidenced by the credo of the largest learning disabilities advocacy in the UK, People First: "label jars, not people" (Stalker, 2012). People with learning disabilities often do not feel they share much commonality with other (learning) disabled people. In fact, people with mild learning disabilities tend to reject similarities with people with significant learning disabilities (Clegg and Bigby, 2017; Shakespeare, 2013).

Shakespeare's impairment-as-predicament allows us to ask, what intrinsic difficulties, limitations, and pains are associated with learning impairment? There is an important body of scholarship that examines this question in relation to the impact of health and social inequalities and injustices – I have discussed these in my introduction. In addition, thinking of learning impairment as predicament enables difficult discussions about capacity and behaviour. As disability scholar Simplican (2019) points out, some people with learning disabilities are at risk of injuring themselves or are prone to aggressive behaviour towards others, yet challenging behaviours have little attention in disability studies. Learning impairment means that people with learning disabilities can be more vulnerable to exploitation and ridicule (Fyson and Kitson, 2010). For some, learning impairment can make it hard for them to hold a job, perform well in education, or accomplish basic tasks. How all this connects theory, policy, and activism is yet to be explored: Shakespeare's work does not specifically discuss issues related to learning disabilities. However, by foregrounding dependency and care as an ontological fact for people with disabilities, he drives forward theorisation about disability in terms of the relationships it generates and the care obligations it evokes.

Disability as a productive condition

The works I discussed so far outline a dilemma one faces when describing impairment. Focusing entirely on its negative impact poses the risk of defining it in terms of lack. Yet, overemphasising ability may lead to the ignoring impairment-specific needs. Kulick and Rydström (2015) caution that "without simultaneously acknowledging *and documenting* the fact that certain physical and intellectual impairments also entail dependency can lead to an emphasis on independence and privacy at the expense of a careful consideration of engagement and responsibility" (p. 269).

An emergent body of literature on vulnerability and the politics of care advances this conversation by asking how vulnerability could be reconceptualised as constitutive instead of antithetical to one's ability to exert agency. Judith Butler (2016) makes this point when she observes that in protest and resistance, often it is the deployment of vulnerability that enables political mobilisation. Butler argues that when protesters expose their bodies to police brutality, subject themselves to imprisonment, or make visible the embodied effects of austerity, they also expose the violence that power inflicts on their bodies, deploy exposure to violence to mobilise, and assert their right to *not* be exposed to that violence. In this sense, vulnerability is not oppositional to political agency; it is constitutive of it (Butler, 2016).

Butler's interest lies in organised political mobilisation and resistance, neither of which are practices in which the majority of people with significant learning disabilities engage. Her work still offers guidance on how vulnerability – or learning impairment in this case – can enable different forms of agency. Learning disabilities-related works in this genre seek to reconceptualise care and (inter)dependence as not undesirable situations to overcome, but as part of the human condition.

There is a body of literature that borrows from the feminist scholarship to rearticulate autonomy – understood as the capacity to self-determination and live a life according to reason and rationality – as a relational concept (Mackenzie and Stoljar, 2000). For instance, philosopher Davy (2015) seeks to formulate a more inclusive form of autonomy specifically for people with learning disabilities when she argues that support and advocacy are "conceptually necessary" conditions of autonomy (p. 133). Davy argues that liberal philosophical formulations of autonomy have been traditionally exclusive and stigmatising of people with learning disabilities (which I discussed in depth in my first chapter). She proposes that by foregrounding support relationships as a necessary condition to enabling autonomy, the philosophical concept can be made more inclusive of people with learning disabilities.

As a philosopher, Davy does not linger on how exactly learning impairment may impact on one's autonomy, and what relational autonomy looks like for people with significant impairments in practice. Empirical works that apply Davy's framework have been limited to studies examining how support staff enabled or hindered the choice-making of people with high support needs. However, other than observing that rigid environments limited people and body language facilitated communication of preferences, these studies did not quite contextualise nor questioned the seemingly taken-for-granted value of autonomy (Björnsdóttir et al., 2015; Stefánsdóttir et al., 2018; Wehmeyer and Bolding, 2001).

More helpful are the works of those writing in the ethics of care whose specific concern is the inequalities and injustices surrounding care work (e.g. Kittay, 1999; Lister, 1997; Sevenhuijsen, 1998). These works highlight that the care work upon which many people with disabilities rely are mostly done by women in low paid, part-time, precarious work conditions, or predominantly female family members (Christensen, 2010, 2012). These care workers are often rendered invisible by the social model of disability – itself critiqued for its masculine ethos by feminist disability studies scholars (Crow, 1996; Morris, 1991; Thomas, 1999) – for regarding personal support as an emotionless economic exchange between support worker and the disabled person (Shakespeare, 2013). When the gendered injustices are recognised, it becomes clear that the independence of disabled people cannot be truly emancipatory if it is conditional to the precarity of care workers. The politicisation of care work in the context of disability studies takes us one step closer to reconciling impairment (i.e. the nature of impairment, its limitations, and its support needs) with the politics of disablement (i.e. the recognition of people with disabilities as agentive persons in order to improve their quality of life).

Far from being simply an economic exchange, the act of caregiving and receiving entails a process of cultivating personal relationship and emotional connection. For instance, anthropologist McKearney (2018a, 2018b) shows in his ethnography how carers of people with significant learning disabilities tell each other stories in which they imbue the care recipients with a sense of agency, and train themselves receptive and vulnerable of their charisma and eccentricity. This recognition reconceptualises the idea of care itself. The act of giving care ceases to be paternalistic; instead, it highlights the care-giver's vulnerability and emotional labour. Similarly, the act of receiving care stop being passive but becomes be an act of agency.

Philosopher Eva Kittay – who is also mother and carer to Sesha, a daughter with significant disabilities – reflects on what such a recognition would mean for the way engagement with people with learning disabilities is understood. Kittay (1999, 2005) argues that even though Sesha may never be able to be self-sufficient, she is undeniably responsive to people in her environment. Sesha may never be autonomous, but she is just as deserving of justice and dignity, as she is capable of love and social relations – what would development and growth mean for someone like her? Although environmental modification is crucial to enhance Sesha's capabilities, Kittay comes to the conclusion that no amount of support could make Sesha independent. Instead, a novel vision for social participation may prove more productive: "when we think of mothering a disabled child as enabling and fostering development, we must also reconceive development, not only toward independence, but toward whatever capacities are there to be developed. Development for Sesha means the enhancement of her capacities to experience joy" (p. 173). Kittay's vision is a good starting point in thinking of alternative capacities people with significant disabilities have, the type of engagement these capacities generate, and the support they require.

One limitation to Kittay's framework is that in focusing on the capacity to love and have social relations, she restricts the productive potential of disability to the realm of the private and personal, dependent on kindness and generosity. This may divert attention away from the fact some people with learning disabilities are *systematically* denied agency and engagement. Continuous funding cuts to public services, inadequate support, and an increasingly shrinking social care sector subject many people with learning disabilities to undignified, isolated lives. Engagement is not simply a personal obligation but also a matter of social justice.

Martha Nussbaum’s capabilities approach, which I discussed in my introduction, provides some theoretical directions in this regard. For Nussbaum, a just society provides circumstances that enable and nourish individuals’ ability to develop, engage with others, and partake in activities they deem valuable to the best of their capacity. In her more recent work, Nussbaum (2009) makes a compelling case for, first of all, systematically examining the diverse forms of capabilities people with learning disabilities have the potential to possess. Secondly, she urges scholars to document the extent to which the social circumstances that enable these capacities are met or hindered in practice.

A recent examination of Nussbaum’s capabilities approach in relation to significant learning disabilities is Kulick and Rydström’s (2015) ethnography on the sexual lives of people with significant impairments in Denmark and Sweden. Drawing on Nussbaum’s framework, Kulick and Rydström systematically examine where Danish and Swedish disability policy and advocacy facilitates or hinders the sexual lives of people with significant disabilities. Drawing on ethnographic material from several care homes, they make the case that even for people with significant disabilities, sexual lives – along with preferences, relationships, sensoriality – can be explored and developed, and that such facilitation is a matter of dignity and social justice.

///

The works I cited in this section all sought to rethink relationship between learning disabilities, vulnerability, and capacity/agency. Specifically, they sought to reconceptualise the relationship between vulnerability and agency not as oppositional to but constitutive of each other. In the process, these frame disability not as passive state that disempowers and should be avoided or overcome, but as what Kulick and Rydström (2015) call a productive condition, which produces creates new relations, responsibilities, practices, and ethics of engagement. This provides guidance in thinking about learning disabilities and impairment: it demands the recognition of the limits posed by impairment while simultaneously recognising its productive potential, signalling a direction for learning disability studies.

Conclusion

In this chapter, I asked how we can think about learning disabilities in a way that simultaneously acknowledges people’s capabilities and inherent limitations posed by their learning impairment. To answer this question, I provided an overview of the theoretical frameworks on the social position of people with learning disabilities: normalisation, the social model, critical learning disabilities, and the more recent scholarship on vulnerability and the ethics of care. I did this in order to reflect on the ways these bodies of scholarship can provide alternative frameworks to describing learning disabilities as a lack or deficit.

Finding a way to describe the social position of people with learning disabilities is crucial for exploring alternative forms of citizenship. Citizenship is, in essence, concerned with how individuals can engage with each other as a community; to make this community more accepting of people with learning disabilities, it is crucial to reflect on how to engage with them in an ethical manner.

Normalisation sought to redress the institutional unequal treatment by advocating for equal (“normal”) living conditions. Subsequently, it addressed the perceived lesser worth of people with learning disabilities by promoting their engagement in socially valued roles. However, normalisation’s emphasis on integration leaves little space to acknowledge the differences in the needs, capabilities, and desires of people with learning disabilities. The social model of disability, primarily formulated by people with physical impairments, argued that people with disabilities were equally capable – therefore, implicitly, equally worthy – as their non-disabled peers, given that the social barriers are removed. However, little thought has been given to the different impairments and capabilities of people with learning disabilities.

More recent discussions on the material reality of disability, such as Shakespeare’s impairment-as-predicament model, opened the venue for acknowledging the intrinsic limitations and needs of people with disabilities. From this acknowledgement grew a body of literature on vulnerability and ethics of care, which asked how exploring the different capabilities of people with learning disabilities could contribute to novel understandings of dignity and justice. Approaching learning disabilities as a productive condition avoids the pitfalls of describing disability in terms of lack, deficit, and a passive state. Instead, it asks, what kind of relationships, obligations, and forms of ethical engagement does it produce?

This is the approach to learning disabilities that this thesis follows.

Chapter three:
On the empirical material

Introduction

So far, I discussed past works on citizenship and learning disabilities firstly with the aim of finding an approach that can helps us understand what citizenship means in the everyday lives of people with learning disabilities; and secondly, to engage with the concept with learning disabilities as a productive condition (as opposed to describing it as a deficit or lack). In the following, I will explore how the anthropological methodological approach that I undertook meets the needs of people with learning disabilities. These include the particular requirements related to participants' learning impairment, such as building rapport, capacity to consent, confidence to express views, and limited speech (Nind, 2008). However, like many researchers working with people with learning disabilities (notably: Bigby et al., 2014; Goodley, 1996; Nind, 2008; Stalker, 1998; Walmsley and Johnson, 2003a), an underlying question I encountered was: how can we engage people with learning disabilities in social research in an ethical manner? This is partly an epistemological question about how the limitations posed by learning impairment can be overcome or addressed by researchers. It is also a broader question of how research can work with people with learning disabilities collaboratively and inclusively.

For this thesis, I undertook a long-term ethnography. Ethnography – meaning a detailed description of people's lives based on participant observation – has always been the primary anthropological method. As someone trained in anthropology, l followed tradition, and spent twelve months as a volunteer and researcher at Project Ability's art workshops, conducting participant observation combined with semi-structured interviews with the staff members, participants, and their carer providers.

My methods were not inclusive by the standards of inclusive research, meaning that I did not involve people with learning disabilities in formal advisory or co-researcher roles. However, in this chapter, I argue that long-term ethnography, and participant observation in particular, is inclusive in a broader sense of the word, and makes a valuable and ethical addition to the methodological toolkit of social research with people with learning disabilities. I discuss two reasons for this: firstly, participant observation provides insights into participants' experiences without solely relying on their capacity to verbal self-expression. Therefore, it is considerate of the needs of people with significant learning disabilities. Secondly, participant observation is ethical because it requires researchers to adapt to the world of people with learning disabilities and engage with them on their own terms, rather than the other way around.

I start by outlining the ongoing methodological challenges of social research with people with learning disabilities. I do so by discussing the epistemological and ethical debates in inclusive research, the current gold standard methodological approach to research with people with learning disabilities. Then, I provide an overview of the anthropological literature on learning disabilities and discuss what anthropology can bring to the study of learning disabilities. I will focus how participant observation contribute to these debates: I draw on Tim Ingold's propositions (2014, 2017a, 2017b) and elaborate on the epistemological and ethical implications of participant observation on doing research with people with learning disabilities. In the second part of my chapter, I will discuss my fieldwork: the site, my activities, the data analysis, and research ethics.

I focus my discussion on people with significant learning disabilities because they are the group who poses the biggest challenge any form of inclusive research. However, addressing their barriers to participation and accommodating their needs are relevant for all people with learning disabilities.

Inclusive research and significant learning disabilities

Social research with people with learning disabilities is not only an academic project. Treating people with learning disabilities as active agents whose experiences are a valuable subject of study is a political act (Nind, 2008). To live up to this ethos, there are two types of barriers that need to be addressed. One concerns the practical and methodological difficulties that relate to the learning impairment-specific needs. The second comprises a philosophical and political question of how to engage people with learning disabilities in research without exploiting them.

Prominent learning disability scholars responded to these challenges by applying the principles of inclusive research to their methods. In the following, I argue that while inclusive research made significant ethical and methodological contributions to social research with people with learning disabilities, due to its lack of engagement with the nature of learning impairment, it struggles to apply its principles to people with significant learning disabilities.

Inclusive research is a term coined by Jan Walmsley (2001; further developed in Walmsley and Johnson, 2003a) in reference to work that includes people with learning disabilities as more than just participants. Inclusive research can refer to a broad range of approaches, including participatory research, which involves people with learning disabilities in advisory or co-researcher roles; and emancipatory research, which gives people with learning disabilities full control over the research process, from formulating the research questions to data analysis and dissemination. In learning disability social research, inclusive research became the most widely used term due to the simplicity with which its core principles could be conveyed to people who are not familiar with the academic language (Walmsley, 2001).

The fundamental idea behind inclusive research – namely, listening to the voices of marginalised communities – gained prominence in the middle of the 20th century with the emergence of the civil rights, post-colonial, feminist, and disability rights movements. On the one hand, the inclusion of marginalised groups in research was partly a political act to counter their social disadvantage. On the other, it was thought to provide research an epistemic advantage (Harding, 2004): as experts of their own experience, marginalised groups were perceived as the "authority on their own lives, experiences, feelings and views" (Tuffrey-

Wijne and Butler, 2010: 175), and were hence seen to be in best position to lead the research agenda on any topic that related to their social circumstances.

Taking seriously the experiences of people with learning disabilities was not an evident methodological approach: up until anthropologist Robert Edgerton (1967) published his ethnographic study on the experiences of former residents of a long-stay hospital, there had been no studies being interested in the voices of people with learning disabilities at all (Walmsley, 2001). All research prior to this was based on the perspectives and beliefs of medical and social care professionals and, occasionally, parents and guardians.

At the end of the 1960s and early 1970s, Bank-Mikkelsen (1969) and Wolfensberger (1972) articulated the principles of normalisation and social role valorisation (SRV), which laid the foundations for including people with learning disabilities in research (Walmsley and Johnson, 2003a). People with learning disabilities taking up the role of the co-researcher aligned well with the ethos of promoting “ordinary life”, albeit it was valued more as a service user activity rather than as a legitimate mode of knowledge production (Walmsley, 2001; Walmsley and Johnson, 2003a).

It was the growing popularity of emancipatory research that raised the stakes for those involved in inclusive research. In the field of disability studies, disabled academics started to demand that disabled people took full control over research on disability (Oliver, 1992). These demands filtered into inclusive research: the previous aim of promoting an “ordinary life” did not satisfy people with learning disabilities, who now demanded more control and accountability from academic researchers (Walmsley and Johnson, 2003a).

Inclusive research is an ecumenical approach in that it does not prescribe the extent to which people with learning disabilities should be involved in research. Studies that follow the inclusive paradigm range from participatory approaches that build on the principles of normalisation/SRC; and emancipatory approaches, which render all aspects of the research process under the control of people with learning disabilities (Bigby et al., 2014; Frankena et al., 2015). Inclusive research projects have involved people with learning disabilities in deciding on the research questions (Bentley et al., 2011; Williams, 1999), setting up the research (Burke et al., 2003), conducting literature reviews (Burke et al., 2003; Flood et al., 2012), obtaining consent (Cameron and Murphy, 2007), data collection (Bentley et al., 2011; Chapman, 2014; Flood et al., 2012), data analysis (Kramer et al., 2011; Tuffrey-Wijne and Butler, 2010; Williams, 1999), ending research (Northway, 2000), writing, editing, and reviewing papers (Blunt et al., 2012), and disseminating findings (O’Brien et al., 2013).

Since it was first conceived, inclusive research has become not only widely accepted but is now a basic requirement for social research with people with learning disabilities. The United Nation’s Convention on the Rights of Persons with Disabilities specifies that people with disabilities should be included in decision-making processes on matters related to disability (United Nations, 2015 Article 4, paragraph 3). In the UK, inclusion in research forms part of learning disability policy (Department of Health, 2001; Scottish Government, 2013b). Most funding bodies require some form of involvement of people with learning disabilities (Gilbert, 2004) such as the 2014 NIHR guidelines that include a mandatory public and patient involvement component for all social research applications (Di Lorito et al., 2017).

Despite its well-established position, the extent to which its principles are applicable to people with significant learning disabilities has not been discussed in-depth. This is partly because the nature of learning impairment– such as limitation to self-expression and abstract thinking – and its implications on academic activities has not received as much attention among learning disability scholars as it deserves.

Perhaps the most in-depth discussion on the subject comes from learning disability scholars Walmsley and Johnson’s (2003a) reflections on the relationship between emancipatory research and learning disabilities. On the one hand, they endorse the political importance of taking seriously people's views and putting research into the service of positive social change. However, their stance on the emancipatory paradigm remains ambivalent because of the little attention emancipatory researchers pays to the specific barriers posed by learning impairment. Walmsley and Johnson (2003a) argue that because the emancipatory paradigm was articulated by physically disabled academics, it has not considered the unique needs and challenges that people with learning disabilities faced in research. Amongst these are the need for support when engaging with complex and abstract theories, accessing higher education and research training, conducting literature reviews, or even mundane tasks like filling out forms.

These barriers are not limited to emancipatory research alone, but are relevant for any inclusive studies that seeks to involve people with learning disabilities in any co-researcher capacity. To substantiate this point, Walmsley's cites an example from her own project, which she conducted with a group of women with learning disabilities. The project took them five years to finish; at the end, Walmsley decided to forego theorisation and connecting common themes with broader discourses, in fear that it would exclude her co-researchers (Walmsley and Johnson, 2003b).

In their more recent work, Walmsley and her colleagues (2017) further developed these observations in response to the debate surrounding the so-called second generation of inclusive research (Nind, 2016). The debate, in short, comprises two positions. One position – represented by prominent inclusive researcher Melanie Nind – argues that the first generation of inclusive research has achieved its aim in outlining how research could include people with learning disabilities. She subsequently advocates for ushering in a second generation of research, which focuses more on producing high quality outcomes with broader social impact, and less on the inclusive research process. The other camp – which includes Walmsley, Strnadová and Johnson (2017) – contests that the process of research should still take primacy over outcome. Specifically, Walmsley and her colleagues take issue with academic researchers trying to apply rigid academic approaches to inclusive projects, and make co-researchers do what "real researchers" do. What would do better justice to the co-researchers, they argue, is to recognise their unique contributions to research, which entails a deeper level of insight and authenticity about the lives of people with learning disabilities.

This debate represents one of the most comprehensive discussions on the implications of learning impairment on research. Previously, such conversation has been limited to issues of accessible language and the ways in which assistive technologies can aid communication. These include photographic memory aids (Chapman, 2014), visual aids (Aldridge, 2007; Boxall and Ralph, 2011), one-on-one mentoring and consultations (Bigby and Frawley, 2010; Tuffrey-Wijne and Butler, 2010), digital storytelling (Manning, 2010). While these works are significant, in focusing on accessible language as the main barrier to inclusive research, there is a danger that the people with mild learning disabilities will always be favoured as co-researchers at the expense of engagement with people with significant learning disabilities, who face more complex limitations due to their impairment (Fyson et al., 2004; Mencap, 2004).

Visual methods and accessible language may help people with significant learning disabilities express preferences, but learning disability scholar Melanie Nind (2008) warns against conflating the ability to express preferences with the ability to express views. "Views are different from reactions, they are opinions, beliefs, standpoints, notions, ideas and they require the person to be an intentional communicator rather than at a pre-intentional stage in which communicative intent is inferred by others," Nind (2008) writes. "With research participants who have profound learning difficulties, the whole process relies on other communication partners who are emotionally and communicatively involved" (p.11). Note that Nind, Walmsley, and their colleagues address more than language accessibility: they speak about the issues around capacity to partaking in research activities, which favour those who can express themselves with verbal language or assistive technologies. If becoming quasi-researchers is the only venue through which people with learning disabilities can be included in research, this will inevitably lead to tensions between the making the research process inclusive and producing impactful research outcomes (Fyson and Fox, 2014).

These scholars’ expansive and decades-long engagement with the subject attests to their commitment to inclusive research. It is notable however that they represent two of the very few voices to engage with the limits of learning impairment in research. Neither Nind nor Walmsley and her colleagues suggest solutions outside the principles of inclusive research. Nind (2008) recommends that researchers continuously review their interpretations by consulting with care providers and guardians who act as proxy for people with learning disabilities. Walmsley and her colleagues (2017) raise the question of whether a study on the experiences of people with significant learning disabilities "needs to be inclusive research rather than in-depth qualitative study" (p. 5), but they do not elaborate further.

Without addressing the implications of learning impairment on conducting research, there is a risk that social research with people with learning disabilities becomes methodologically stagnant. There are recurring concerns among learning disability scholars that in the absence of a conversation about the nature of learning impairment, inclusive research may become dogmatic and can stifle a methodological debate and the diversification in learning disability studies (Nind, 2011, 2011; Stalker, 1998; Strnadová and Cumming, 2014; Walmsley, 2001; Walmsley and Johnson, 2003b). Walmsley (2001) writes that although inclusive research has led to some empowering projects, it also “acted as a straitjacket, hindering researchers in the inclusive camp from crossing words with others, for fear of ‘speaking for’ people with learning difficulties without their consent” (p. 189). Her and Johnson later argue that “the need to translate research questions and findings has in itself been a barrier to clarifying and theorizing”, which “has inhibited the vigorous growth of inclusive methodologies” (Walmsley and Johnson, 2003a: 15).

Although I did not apply inclusive research in my thesis, I felt the need to engage with it because its conundrums highlight important lessons regarding the nature of experiential knowledge and the ethics of engagement that I seek to further develop in this chapter. First of all, I recognise the methodological contributions of inclusive research to social research: the idea that people with learning disabilities possess unique knowledge and can therefore make significant contributions to research is central to this thesis. The challenge is to find a methodological approach in which this knowledge can be articulated while simultaneously taking into account participants’ learning impairment, most notably the limit to verbal self-expression. Secondly, I aim to further broaden the ethical imperative to engage with people with learning disabilities in a way that recognises their interests above all else. Inclusive research does so by enabling people with learning disabilities to take on the role of the researcher; I, on the contrary, seek to engage them on their own terms. Instead of asking them to conform to the world of academia, I set out to immerse myself in their world of – in this case – artmaking by conducting ethnography and participant observation.

Participant observation and people with learning disabilities

Anthropology offers a different methodological take on recognising, discussing, and sharing experiential knowledge. In this section, I provide a brief overview of anthropology’s primary methods, ethnography and participant observation. Then, I discuss how an these methods can address the challenges of doing research with people with significant learning disabilities.

The body of anthropological works on learning disabilities is rather slim, despite a rich scholarship in related fields examining mental illness, dementia, and autism (Biehl, 2005; Estroff, 1985; Littlewood and Lipsedge, 1997; Luhrmann, 2000; Martin, 2009; Nakamura, 2013). One of the earliest examples of anthropological writing on learning disabilities is Robert Edgerton's (1967) ethnography on former residents of a long-stay hospital, which I discussed in my previous chapters. This sort of biographical approach to mild learning disabilities (along with, for instance, Langness and Levine, 1986) emphasised the social and learnt aspects disablement. Subsequent works (e.g. Dexter, 1962) combined the social model of disability with the cultural, set out to examine disablement through a cultural lens of anthropology, study disablement in "non-Western" societies, and contextualise the meaning and experiences of – primarily physical – disability in their local worlds (see edited volume by Ingstad and Whyte, 2007).

In their overview on the anthropology of learning disabilities, McKearney and Zoanni (2018) suggest that learning disabilities challenged anthropologists the same way it challenged the social model of disability: the constructivist basis on which anthropology resisted the stigmatisation of biological determinacy (in the same way they challenged racism and sexism) led anthropologists to describe learning disabilities in terms of difference rather than a deficit. However, such framing did not – and could not – take into account the very real and material difficulties posed by learning impairment. More recent anthropological studies take note of this tension, and draw on philosophical works on vulnerability and the ethics of care (discussed in chapter two) to study learning disabilities from the perspective of ethical engagement and selfhood (e.g. Ginsburg and Rapp, 2018; Kulick and Rydström, 2015; McKearney, 2018a). These works ask how learning impairment shapes one's engagement with the world, and how we can engage with people with learning disabilities in an ethnical manner.

The anthropological method is central to this enquiry.

Ethnography and participant observation emerged as anthropology's distinctive strategy when the emerging field's interests centred on the study of native peoples who usually lived in small, preindustrial societies. Early pioneering fieldwork by anthropologists like Malinowski (1922) and Evans-Pritchard (1940) – both of whom spent years living with the communities they studied – represented a distinct break from prior traditions of "armchair anthropology", where anthropologists used data collected by fieldworkers.

Ethnography and participant observation are often used interchangeably, as they often go hand in hand. For the purposes of this thesis, I define ethnography as a method of describing knowledge within its local socio-cultural context. Ethnography often combines a variety of field techniques like interviews, focus groups, life histories, genealogical research (Kottak, 2014). However, the basis of ethnographic fieldwork has always been participant observation, a technique whereby anthropologists enter the field as outsiders, establish rapport with insiders in the field, and through a process of cultural learning, they take note of the social and cultural particularities of local practices, knowledges, and meanings. The anthropologists' epistemic advantage derives from them being outsiders (etic) and thus being able to observe particularities that insiders (emic) take for granted (Harris, 1976). But rather than "objectively" observing and describing that knowledge from a realist epistemological stance, the anthropologist views knowledge "as a matter of acquiring habits of action for coping with reality" (Rorty, 1991: 1). When starting fieldwork, anthropologists carry with them a set of assumptions and categories about the field they are about to enter. During the fieldwork process, anthropologists have to work to actively bring into consciousness and systematically undo these assumptions, while at the same time gain understanding of the ones carried by the people in the field.

Participant observation thus can be – and has been – characterised as a form of apprenticeship, whereby anthropologists gain culturally specific skills and habits that enables them to respond to the fieldwork environment in the way insiders to that community do. As anthropologist Jenkins (1994) puts it, “fieldwork is an apprenticeship of signs, a process of entry into a particular world, governed by a variety of factors, including the situation and previous experience of the anthropologist. During an apprenticeship, as well as skills and perceptions, memories and desires are altered, so that every actor, indigenous or ethnographer, is engaged in a personal and experiential capacity” (p. 445).

The relationships established with the people in the field (often referred to as key informants or interlocutors) are central to this process. In anthropological research, it is this relationship that validates and legitimates the ethnographic accounts, analysis, and conclusions. The fact that anthropologists engaged in these relationships in an immersive, long-term, and intimate manner is what imbues them with the agency to know, and endows them with the authority to write about that knowledge (Blasco and Wardle, 2006).

The nature of anthropological fieldwork has changed over the past century. Early anthropological interest often aligned with European imperial powers in establishing and reproducing ideas of racialised cultural difference. Contemporary anthropology is deeply critical of this history and has been examining the impact and legacy of colonialism, and challenge assumptions of Western cultural superiority. The diversification of ethnographic fieldwork reflects these changes. As opposed to early focus on small, native, pre-industrial societies, contemporary anthropology has widened its scope to investigate practices in the anthropologist’s “home” community (Peirano, 1998), online (Buccitelli, 2016; Pink et al., 2015), or spanning multiple sites (Marcus, 1995) to follow a concept or an object.

///

Participant observation addresses some of the issues I discussed in relation to inclusive research, which is why I consider it a methodologically and ethically valuable alternative method for this thesis. Although it does not involve participants as co-researchers, it takes seriously the assertion that people with learning disabilities can contribute to research with their unique knowledge. Similar to inclusive research, it builds on the collaborative relationship between researchers and people with learning disabilities. However, it is better suited to address needs that are specific to learning impairment for two reasons. Firstly, unlike in inclusive research where people with learning disabilities learn to do research, participant observation reverses that dynamic by making the researcher into the apprentice to the world of people with learning disabilities. Secondly, participant observation is practice-based and embodied, therefore relies less one’s the capacity for verbal self-expression.

In conceptualising participant observation with people with learning disabilities, I found the works of anthropologist Tim Ingold particularly helpful. Ingold’s (2017b) basic proposition is to think about anthropological research as an inherently collaborative and embodied mode of producing knowledge. Ingold is not the first one to make this argument. However, I focus on him partly because I do not have the scope to review the rich body of literature on the subject, and partly because Ingold transforms the theoretical tenets of prominent thinkers into both practical suggestions and ethical insights.

The first of these observations is an epistemological suggestion to rethink the nature of experience, and regard it as constituted through bodily sensations rather than through cognitive representations. Drawing on prominent phenomenologists, Ingold’s framework postulates that perception begins not by external objects eliciting sensory information, but the other way around, by the body registering objects through a collage of bodily sensations (Csordas, 1990; Merleau-Ponty, 1945). According to this, experience does not come into existence as a single, coherent unit; instead, it is indeterminate and emergent, subject to the one's shifting attention.

The second observation is that embodied knowledge is inherently social and is co-constitutive of collective practice. Here, Ingold's works resonates with the scholarship on habitus and the sensoriality of ritual (e.g. Bourdieu, 1980; Csordas, 1990; Howes, 2010). Although embodied and sensorial experiences as subjects of empirical enquiry have been discussed in disability studies (Paterson and Hughes, 1999), their methodological implications for involving people with learning disabilities in research are yet to be explored.

Ingold (2014, 2017b) takes these propositions to make the case for participant observation as a research method and a principle for ethically engaging with research participants by acknowledging the collaborative, embodied, and emergent nature of knowledge production in research. Experiential knowledge, he argues, resides in "participatory practice: not in the ways persons and things are symbolically represented in their absence, but in the ways they are made present, and above all, answerable to one another" (Ingold, 2017a: 17). What he means by this is that "authentic" knowledge does not arise from the researcher's ability to help participants accurately describe what they know; rather, it comes from the researcher learning what the participants know through attending to people, and learn from them how to perceive their environment. Participant observation, Ingold (2014) writes, is thus best understood as the researcher undergoing education, or an apprenticeship: learning through such apprenticeship produces knowledge that cannot be attained by simple observation. Participant observation demands that the ethnographer empathetically engages with what is important for the participants: it is not collecting data that can be analysed at a later stage, but producing meaning through shared activity [1](see also Pink, 2011).

There are a few reasons participant observation could be an appealing addition to the methodological arsenal of social research with people with learning disabilities. First of all, it circumvents the problem of solely relying on participants' capacity for verbal self-expression. Instead, it forces researchers to turn their attention to other forms of knowledge, in particular, to embodied, emotive, and sensorial modes of perception. Secondly, it formulates an ethics of engaging with participants: instead of including them in research on academia's terms and forcing them to do what academic researchers do, participant observation requires the researcher to engage with activities that the participants find valuable. Finally, participant observation does away with the awkward distinction between the academic researcher and the co-researcher; instead, it elevates and emancipates non-academic modes of knowledge production.

---

[1] It has to be noted here that Ingold (2014, 2017b) wrote all this as a provocative way to rebuke the dominance of ethnography in anthropology, which subsequently injected new energy into the methodological debate (e.g. Hammersley, 2018; Howell, 2017; Parker-Jenkins, 2018; Shah, 2017). My take on the debate is that Ingold employs a narrow definition of ethnography, i.e. an "objective" description of social practices from a "neutral" ethnographer. In this sense, Ingold is right to dismiss ethnography as a static, positivist, and objectivist method. On the other hand, many anthropologists conducting ethnographic fieldwork have understood ethnography as a reflexive practice of describing the process of participant observation. It is the latter that I mean when I describe my primary method as ethnography and participant observation.

Participant observation has broader political implications regarding the politics of inclusivity in inclusive research. It may not employ co-researchers, but it is inclusive because it obliges researchers to immerse themselves in the stakes of people's everyday lives; it ethically and politically commits to its subjects and their wellbeing; and it is built on a collaborative research relationship.

There is a long tradition among anthropologists who uphold this commitment in their research by entering their field of study as activists, practitioners, and advocates. Scheper-Hughes (1995) uses the term "militant ethnography" to outline the principles of a "politically committed and morally engaged anthropology" (p. 409, also see Juris, 2007). Ginsburg and Rapp's (2013) "entangled ethnography" describes the authors becoming active participants and activists in the field they studied. In their work on transition for children with learning disabilities, their "ethnographic entanglements" as parents and researchers granted them insights which enabled both their activism and research.

There are strikingly few examples of participant observation with people with learning disabilities (Angrosino, 2004). This is surprising because one of the earliest examples of a researcher demonstrating interest in the voices of people with learning disabilities was an ethnography: anthropologist Robert Edgerton (1967) spent more than a year with former residents of a long-stay hospital to understand after institutionalisation. Yet, apart from early examples ethnographic work on the subject falls within the objectivist framework with an aim to "describe behaviour in its natural settings" (McCarthy, 1999: 80). These works maintain the underlying assumption that knowledge exists "out there", and it is the researcher's responsibility to access and decode that knowledge – this is the approach to ethnography Ingold (2014, 2017b) ardently critiqued.

There is a small number of studies in learning disability research that conceives of the involvement of people with learning disabilities in a more fluid manner (Davis, 2000; Goodley, 1999). Although these are not ethnographies, their conceptualisation of the researcher-participant relationship aligns well with the ethos of inclusive research on collaborative knowledge production and the ethical position of taking seriously people's lived experiences.

Recent anthropological work on learning disabilities involved anthropologists entering the world of people with learning disabilities: Kulick (in Kulick and Rydström, 2015) spent nearly three months living in three different care homes, where he socialised with residents and carers. McKearney (2018a) spent a year living with care home residents and carers while learning to be a care-giver himself. Rapp and Ginsburg (2013) have had a longstanding involvement in the field as researchers and parents of children with learning disabilities. What participant observation allowed these anthropologists to do is observe the particularities of interacting with, caring for, and advocating on the behalf of people with learning disabilities, especially with those who had little verbal language. By doing so, they were also able to examine taken-for-granted ideas of ethical engagement, selfhood, and justice upheld by those without learning disabilities.

For instance, Kulick and Rydström's (2015) ethnography focuses on people with significant learning disabilities and their right to sex. The trust and rapport they built with the residents and carers during their ethnographic fieldwork allowed them explore private and sensitive issues related to the sexuality, and observe how institutional attitudes and practices facilitated or hindered people's sexuality. The immersive nature of their fieldwork contributed to the richness of their data. McKearney's (2018a) took immersion a step further. His study focused on the question of what made engagement with people with significant learning disabilities valuable. By learning to be a care-giver, McKearney (2018a) not only observed how other carers related to the residents of the care home; he also took notes of the process by which he himself learnt to interact with the residents, and came to see them as moral agents.

Arguably, the practices that carers deployed to recognise and sensitise themselves to the residents' agency is something they would take for granted, therefore they may find it difficult to articulate formally, for instance, in an interview. However, by undergoing the learning process, McKearney (2018a) was able to document and analyse it with rich detail and complexity.

Finally, Ginsburg and Rapp's (2013) "entangled ethnography" demonstrates how long-term immersive participant observation blurred the line between their roles as researchers and advocates, thus providing them with a particular epistemic advantage. During the course of their research, the Ginsburg and Rapp – parents of disabled children themselves – faced the lack of prospects for people with more significant learning disabilities in transition to adulthood. They subsequently found themselves involved in expanding training programmes and working with parent groups with children in special education, advocates, teachers, lawyers, and health professionals. They write that their entanglements in the field was simultaneously an ethical commitment to the people they worked with and an epistemological resource that helped them shed light on the invisibility of young people with learning disabilities in transition who were not able to attend college, and thus did not fit into the success narrative. They argue that full immersion helped them remain open and responsive to unexpected events and "envision alternative politics and institutions" (p. 216) that would not have been included in their research otherwise.

///

These examples illustrate how ethnographic fieldwork with participant observation can yield rich data that contribute to theoretically, ethically, and politically complex and nuanced work.

In my thesis, I approach participant observation as an embodied method and as an ethics of engagement, framed by Ingold and the anthropologists discussed above. In my introduction, I argued that the question of citizenship is not relegated to abstract philosophical questions about the principles of justice, but are ideas that guide what people do and how they are engaged with in their everyday lives. As Ingold and the phenomenological scholarship has highlighted, practice is embodied and social – it follows that citizenship, which in the anthropological framework is studied as an everyday practice, can be examined as an embodied and social phenomenon. This means that the meaning of citizenship can be derived ethnographically by undertaking everyday activities together with participants, and learning to attend to them and the way they perceive their environment and activities. The learning process also involves unlearning taken-for-granted assumptions of liberal citizenship by contrasting those ideals to the way they materialise in everyday practice.

I also decided to undertake participant observation because it presented an ethical way of involving people in research. As my study is interested everyday activities, it seemed more appropriate and congruent for me to enter their world, as an alternative to employing them as co-researchers and trying to mould them according to the expectations and standard of academia.

Having discussed the methodological basis of inclusive research and participant observation, I will now turn to describing my methods: the site of the fieldwork, my activities as a participant observer and ethnographer, the data analysis, and ethics.

Project Ability: the site of fieldwork

I spent the majority of my fieldwork at Project Ability, a Glasgow-based charity organisation that provides artmaking opportunities for people with learning disabilities and mental illness. I initially chose this organisation because I intended to examine citizenship practices outside of the employability and skills building programmes, which has tended to be the focus of such studies. My aim when entering fieldwork was not only to seek examples where people's citizenship was hindered: anyone who is vaguely aware of the treatment of people with learning disabilities in the UK could probably recite headlines from scandals from past long-stay hospitals and ongoing campaigns like Justice for Laughing Boy. What is less well known are exemplary practices of facilitating citizenship. I wanted to know what it looks like in practice when the ideals of citizenship are taken seriously. Project Ability seemed an appropriate choice because as an organisation it is well known in the Scottish art scene for having prestigious awards, unique artists, high quality artworks, and strong community presence. Project Ability was also a practical choice: it is a well-respected arts organisation in Scotland, and is known for being open to collaborating with various organisation, including university researchers. I presented my research plan to the director, and visited the workshops a couple of times to introduce myself to the tutors and the participants. After gaining ethical approval from the ethics committee of the University of Glasgow, and permission from Project Ability, I started my twelve-months of ethnographic fieldwork.

///

The workshops reserved for adults with learning disabilities run from morning till afternoon, Monday to Friday. Participants attend the workshops one or two days a week. With the exception of the Friday workshop that runs the whole year around, each block of workshops are eight-weeks long, with by five weeks of break in-between. Project Ability studio also hosts a range of other activities, such as performance art projects, talks and seminars by guest artists from the UK and Europe, outreach programmes around Scotland, and artist collaborations with the Glasgow School of Art and various arts organisations. There are weekly walk-in workshops open to anyone for a small fee, walking groups, and film screenings. Every once in a while, typically around festive seasons, the studio hosts a party for its participants, staff, family members, and support workers.

The organisation is run by the art director and a handful of permanent staff who fulfil various managerial and administrative roles. The workshops are led by professional artist tutors contracted as freelancers. Additional support is provided by volunteers, most of whom are art school students or recent graduates. The tutors and the volunteers help participants make art: this involves preparing art materials, giving technical and aesthetic advice, or providing step-by-step, hands-on support. Some participants enjoy additional help from their support workers, many of whom are art enthusiasts, artists, art school graduates, and former volunteers. With the exception of Fridays, which comprises a five-hour long session, each day hosts two sessions, a morning and an afternoon workshop, each of which are attended by different participants (sixteen at most).

There are several pathways through which one can sign up to the classes. Some participants were referred by their social workers or by their care organisation. Others found the organisation by chance or through word of mouth. There were a few participants who had known the tutors for years, through the hospital where had been treated or institutionalised. There is a fee to attend to the workshops, which is covered by the financial support most participants receive in form of cash payment or through their care organisation.

Project Ability has well-maintained connections with the local art world. It frequently exhibits the participants' artworks in local cafes, music venues, and art galleries. Project

Ability also has its own small gallery space and shop, located next to the administrative offices, two floors below its art studio space. Thanks to its community presence, many of the participants’ artworks are relatively well-known and appreciated within the city’s art life.

Because of the visibility of some Project Ability artists, Lesley, the art director said that visitors of the studio space often assume the participants have mild learning disabilities and low support needs. It subsequently takes them by surprise when they first meet the participants in person, and realise that in fact most of them have significant learning disabilities and high support needs.

The most visible artists of Project Ability – the ones whom, according to Lesley, most visitors expect to see – are participants of the Friday art classes. These classes are attended by twelve people who have lower support needs. They are individuals with more verbal language in comparison to those attending the Monday to Thursday groups. They live in self-supported, council-subsidised housing. Most (but not all of them) are independent travellers, which means they can use public transport as long as they are familiar with the route.

Most of them are well-known in the scene of Scottish artists with learning disabilities. Their works are frequently exhibited in the UK and Europe, and their art sells well. When Project Ability organises outreach programmes, participants from the Friday group are asked to go along as peer tutors. One of them, Colin is one of the six British artists with disabilities who was awarded a lifetime fellowship at the Royal Society for the encouragement of Arts, Manufactures and Commerce. This makes Colin part of a very select group, whose past and present members include Charles Dickens, Karl Marx, and David Attenborough.

Participants that attend the groups that run from Mondays to Thursdays do not hold such accolades. With a few exceptions, these individuals live in supported housing or with their parents. They require support to carry out many activities of daily living such as shopping, cooking and personal care. Most of them need help to safely move about in their community or commute to the studio. Many of them also have physical disabilities: restricted mobility, and limited vision and hearing were common. Some of these were due to their age, as many of them were elderly people. At the time of my fieldwork, the majority of participants were older than fifty; the oldest participant was eighty-three.

Many of these participants have very little verbal language. At first glance, many of them gave me the impression of being completely disengaged from their environment because their responses were quiet and incomprehensible for those who did not know them well, myself included. Some of them were verbal, but not in a conventional manner: they communicated with sounds or non-sequiturs. These are the people that my thesis focuses on.

The ethnographic fieldwork and the empirical material

I partook in four blocks of workshops for people with learning disabilities. During that time, I offered help with facilitating the workshops. Becoming a volunteer was partly a way for me to acknowledge the time and resources I took as a researcher, and partly served as an inroad for me to learn about artmaking with the participants.

Besides spending time with them in the studio space, I also accompanied participants on outreach programmes, seminars and presentations, guest workshops, exhibition openings, field trips, residencies, and social events. Occasionally, I spent time with them (and their support workers, if they had one) outside the workshops: I went on walks with them, travelled with them on public transport, and met them for coffee, food and drinks. I also spent time socialising with tutors, support workers, and participants from the mental health workshops. I attended art events that were linked to Project Ability, such as the participants’ exhibitions at various local galleries. The most notable of these was the Glasgow International Art Festival, a three-week-long contemporary art festival that takes place over several locations across the city, the Project Ability studios being one of them.

I formally interviewed very few people: seven participants, one parent, three support workers, one volunteer, one person who was both support worker and volunteer, and finally, the director. I did not formally interview any of the tutors: by the time I started arranging interviews three months into the fieldwork, I had spent so much time working with them, shadowing them, conversing with them about the workshops, art, and life in general that I felt there was little that formal interviews could add to what I had learnt from and about them already. I had similar feelings about interviewing many of the support workers and volunteers, whom I got to know over the year and with whom I spent a considerable time in the workshop and outside socialising.

I audio-recorded the interviews. I removed all the names from the transcripts, returned the de-identified versions to the participants, and offered to delete any details or responses they did not want to include. I kept these transcripts for analysis, and deleted the originals along with the recordings. I did not de-identify my fieldnotes, but kept them in password protected and encrypted word documents. All the data was stored on my password protected laptop that only I had access to.

Some of the photos of participants' artwork that I included in this thesis are from the Project Ability website, others are mine. I always sought participants' verbal consent to photograph their work, unless I took photos of their works at exhibitions.

At the workshops, I took short notes on my phone. Occasionally, I asked participants if I could write down what they had said. However, I refrained from taking notes in front of people when I felt it impinged on my ability to be fully present and engaging in the interaction. Instead, I sought out quiet corners to write short notes about my conversations and observations. I wrote longer and more detailed fieldnotes with a summary and analysis every evening after returning from the workshop or a fieldwork-related event.

Part of the quotes and dialogues that I present in this thesis are paraphrased from my short notes and fieldnotes. My decision to not take notes in front of participants meant that I missed out on rich quotes to illustrate my point because I could not remember what people had told me in detail in the evenings when I was writing up my fieldnotes. Although some anthropologists carry a recorder to tape their interactions, I have opted to not do so in order to allow conversations to remain spontaneous.

It is a valid question whether presenting paraphrased quotes co-opts participants' voices. I partly addressed this question by only including quotes that I had taken notes of and thus could represent as accurately as possible. However, because the anthropological fieldwork is relies upon the ethnographer's etic and emic positionality, all the empirical I present here reflect my interpretations and perspectives on the encounters, rather than aiming at representing speech in its most objective form. For the same reason, I did not transcribe regional accents and speech impediments. Instead, in my writing, I follow the ethnographic tradition of "deliberately emphasised [researcher] position" (Blasco and Wardle, 2006: 149), and focus on the knowledge I derived from my relationship with the people I met during fieldwork, and the process of learning I undertook as I become more part of the community in Project Ability.

///

Because I do not have a training in visual art, at the beginning, I spent most of my time observing participants make art. To make myself useful initially, I sought to do all the menial tasks: I fetched and prepared art materials, cleaned palettes and brushes. After a couple of weeks, people at the workshops started to relate to me as a volunteer: participants sought my advice, and tutors trusted me to help participants on my own.

Much of the participant observation was thus a process of me learning about artmaking and about the people attending the workshops. The first thing I started picking up on was the basics about techniques, colours, and materials. I understood – experienced – their sensorial qualities: the thickness of different paints, the resistance of various pens and papers, the diverse textures of clay and textile. I developed preferences for colours, framing, and combinations of materials. Although by no means could I achieve the skills of someone who had years of training and practice, I was able to help participants with smaller technicalities, such as priming canvases, preparing clay materials, or picking the right type of paint for drypoint etching.

These basic skills enabled me to work more closely with participants. After a couple of occasions on which I suggested art making techniques that did not suit them (for instance, I handed a big brush with thick paint to someone who liked to work with small, meticulous patterns), I slowly got to know them well enough (and expanded my own knowledge of the different art making techniques) to be able to suggest ideas that were novel, but not completely out of their comfort zone.

Becoming more familiar with artmaking allowed me to get to know the participants better. The first thing I learnt was that there were a lot of ways of spending time with people in addition to having a conversation with them. Despite my initial discomfort at feeling like I could not engage with people who had little to no verbal language and inscrutable facial expressions, I grew increasingly comfortable with and perhaps more knowledgeable about interacting with gestures and touch. I also understood that interaction sometimes comprised sitting with someone in silence.

From the beginning, I was committed to making myself useful to the organisation and the people around it. For that, I had to learn ways to be useful as a volunteer who could be trusted with the art. Increasingly, people asked me for help with other things: I helped them with filling out forms, provided them with company outside the workshops, and shared their everyday concerns.

During this year, I went from someone who had very little clue about art and learning disabilities to someone who had a little bit more. The process of cultivating this knowledge has become the epistemological foundation to this thesis.

The data analysis

I organised all the interview material, fieldnotes, and photographs in NVivo. After I concluded my fieldwork, I conducted a thematic analysis of my fieldnotes and interviews.

Three of the main themes on which I based my ethnographic chapters (choice, independence, and sociality) emerged from the literature review on citizenship and learning disabilities, which had I undertaken prior to fieldwork. These three themes were recurring, key concepts in the policy documents, political philosophy, and the learning disability scholarship.

The thematic analysis was preceded by a more fluid, collaborative, and iterative analytical process I undertook while being in the field. As part of this process, I had ongoing the conversations with the participants, support workers, and staff members about my observations and my initial research questions. I often had long, informal discussions – over lunch, tea, or breaks – during which I shared my ideas and interpretations. These conversations reinforced the centrality of the themes of choice, independence, and sociality. This process further helped me refine my research questions by drawing my attention to the everyday conundrums and practices that comprised the central occupation of those attending the workshops. The overarching questions around of cultivation, sensoriality, and materiality that my ethnographic chapters explore with regards to choice, independence, and sociality all emerged as a result of this iterative analytical process. I can confidently say I would not have been able to identify these themes solely by reviewing the literature and policy publications.

Partly to ensure that my observations were reliable and relevant, and partly to be transparent about my research activities, six months into my fieldwork I wrote a short summary of my preliminary analysis, including the themes, observations, and interpretations, which I presented to staff members, support workers, and participants. I incorporated the feedback into my analysis.

The fourth major theme that serves as the basis for my fourth empirical chapter on the value of engaging with people with learning disabilities emerged after I finished my fieldwork, as I was trying to make sense of my changing perception of the participants' artworks. Over the year I spent at Project Ability, I did not only become more familiar with the art and the community at the workshops; I also developed full appreciation for and investment in their artistry. This was reflected in my fieldnotes, much of which I spent describing the intricacies of artworks people produced at the workshops or exhibited at various exhibitions. The theme of value emerged a few months into writing up, after having immersed myself in the philosophical literature on the ethics of engagement with people with significant learning disabilities..

Ethical considerations

Apart from the broader questions about ethical engagement with people with learning disabilities in research, which I discussed in relation to inclusive research and participant observation, the issues I encountered regarding consent and confidentiality required me to carefully consider general research ethics.

Prior to the fieldwork, I received ethical approval from the ethics committee of the College of Social Sciences, the University of Glasgow. In addition to the University procedures[2], I consulted the ethics guidelines of the American Anthropological Association (2012) and the Association of Social Anthropologists of the UK and the Commonwealth (2011). I further familiarised myself with the ethics of engaging people with learning disabilities in research by reviewing the literature on inclusive research.

During fieldwork, I negotiated consent with the people I encountered on an ongoing basis. I received written consent from the organisation as a gatekeeper to conduct my ethnographic research at the workshops after having met with them and presented them with my proposal. However, I did not seek individual written consent from the participants for the participant observation because I had perceived that to be impractical, disruptive, and intrusive to the workshops and the participant observation. Instead, I opted for obtaining people's verbal consent. I sought explicit verbal consent from everyone I spoke to informally. I did so by introducing and identifying myself as a researcher, and concisely explaining my research aims, questions, and methods. Additionally, I maintained consent by repeatedly asking for people's permission to sit with them and observe their artmaking.

The issue of confidentiality posed ongoing challenges. The decision to name the site of fieldwork – Project Ability – was a result of ongoing discussions with the organisation and was made with the agreement of the staff. At the start of my research, I set out to highlight exemplary practice and positive participatory experiences in service provision. I approached

---

[2] See https://www.gla.ac.uk/colleges/socialsciences/students/ethics/informationforapplicants/

the Project Ability having made this intention clear. My focus corresponded with the needs of the organisation: I was informed in conversations with the director that any research documenting best practice served the organisation well in the context of funding cuts, as it helped them prepare for the eventuality of having to justify their operations. Since Project Ability had limited funding to commission their own research, my project provided them with an opportunity to document exemplary provision and gain feedback on their practices. Naming Project Ability in my thesis thus allows the organisation and its staff members to take ownership of and be recognised for the positive interventions cited in this thesis.

I recognise that this decision comes at the expense of guaranteeing confidentiality and anonymity, with a particular risk to internal confidentiality (Kaiser, 2009; Tolich, 2004), meaning that participants may be identifiable from the descriptions. I further recognise that I displayed participants' artworks in my thesis, some of which I photographed at public exhibitions, and some of which I took from the Project Ability website; all of which makes participants' more easily identifiable, especially by those who attend the workshops. Finally, I acknowledge that staff members may be recognised from my decision to name their position within the organisation (e.g. director, tutor, technician).

To address issues around internal confidentiality in an ethical manner, I drew on ethnographers and anthropologists who have grappled with the same questions during their fieldwork. The risk of participants being identified poses an pertinent and ongoing conundrum in ethnographic research, where the rich and detailed descriptions reveal particularities about the subject of research that can involuntarily disclose their identity. An often-cited example for the breach of internal confidentiality is sociologist Carolyn Ellis's (1995) ethnography of a small fishing community. Despite not using real names, Ellis's participants were able to identify themselves in her book. Having read what she wrote about them made them feel angry and betrayed by Ellis, whose book – contrary to her explicitly stated intention to "write a paper about fishing" (p. 71) – in fact revealed intimate details about their lives, including stories about illness, sex, and poverty. The village residents felt that by disclosing these details, she embarrassed, humiliated, and disrespected them.

To avoid instances like this, the dominant approach in social research is to issue confidentiality statements in the consent form, and to clean the data for analysis and dissemination (i.e. removing names and other identifiers). However, there are no standardised guidelines, and nor can these practices guarantee full confidentiality (Kaiser, 2009). The alternative, anthropological approach to these issues rests upon two principles: sharing the work with the participants during the process of the research process to grant them control over disclosures and interpretations; and practicing researcher discretion in accordance with the principle of "do no harm" (Tolich, 2004).

I addressed the risk of breaching internal confidentiality and anonymity by, first of all, making people aware that complete concealment of their identity was not possible. In addition, in line with the anthropological guidance, I aimed to grant participants control over disclosures by continuously sharing my observations and interpretations with the staff members, support workers, and participants in the workshops. I also returned the interview transcripts to the participants, and removed any information that they were concerned about sharing. To stay in line with the "do no harm" principle, I continuously reflected on the impact that my findings and ethnographic material would have on people, were they identified from the details. This involved considering the following questions: 1) Do my descriptions depict the research subjects in a fair and dignified manner? 2) Can the information about them be potentially damaging for their occupation, relationships, and reputation? 3) How would people feel if they recognised themselves while reading my work?

Ultimately, I decided against sharing any material that I thought would make them feel in any way embarrassed, betrayed, ridiculed, or would do them harm. Over the course of my fieldwork, staff members and participants sometimes confided in me by sharing deeply personal and potentially sensitive information. I have also observed tensions among those present in the workshops. Although all of this may have better contextualised my arguments and enriched my ethnographic descriptions, I decided to exclude this data from my analysis and writing up. This decision corresponded well with my decision to focus on documenting best practice and positive examples in service provision, which enabled me to substantiate my arguments without discussing sensitive material around interpersonal tensions an discontent. More importantly, it was an ethical approach to honouring the “do no harm” principle of ethnographic research.

Conclusion

In this chapter, I discussed how research can engage with people with learning disabilities in an ethical manner. I provided a brief overview of inclusive research, and examined the conundrums of employing people with learning disabilities as co-researchers, especially those with significant impairments. I then examined how the anthropological method, namely ethnography and participant observation could provide an alternative way of engaging people. Specifically, I argued that the anthropological method meets the aims of inclusive research because it is inherently collaborative, ethical, and produces rich and valid knowledge. However, unlike inclusive research, it is immersive and embodied, and does not fully rely on the participants’ capacity to express themselves with verbal language or assistive technologies. Anthropology achieves this by requiring the ethnographer to build rapport and undertake a sort of apprenticeship in the world of people with learning disabilities in order to learn to interact the subjects on their own terms, and to engage with them in the activities that they deem valuable. In the second part of the chapter, I elaborated on how I approached ethnography and participant observation in my own fieldwork: after describing the site of Project Ability, I discussed my activities as a researcher, my data analysis, and addressed ethical conundrums with regards to consent and confidentiality I encountered during my fieldwork.

The ethnographic material I present in the following is an outcome of these reflections.

Chapter four:
On choice

Introduction

I had been quietly watching James pick dried acrylic paint off plastic palettes with a scalpel for half an hour when I walked up to him. I had been preparing drawing materials for workshop participants when I noticed that James was not making art. I was hesitant about approaching him at first, as he seemed preoccupied with the stack of palettes on his desk.

"What would you like to do?" I asked him eventually.

No response.

I decided to take a different approach. "Would you like to draw?" I asked. James started rocking back and forth, making a muffled noise that sounded like a "Yes".

"Shall I get you some paper?" I tried again.

"Yes," James replied, this time clearly, but without looking up.

That I received a response at all made me feel emboldened. "Shall I get you a picture?"

"Yes."

"Would you like to come and have a look with me?"

"Stay."

I went. I fetched some felt tip pens, paper, and a pile of pictures of animals. Felt tip pens and paper are convenient materials: they are not too messy, they are easy to set up, and participants know how to use them. I placed everything in a pile on James's desk, and he took the first picture on top of the pile and started drawing it. Being new and eager, I wanted to make sure he was aware of his options, so I started sorting out the pictures to show him the different ones I had brought.

"No!" he shouted and grabbed my hand. This sudden outburst caught me by surprise. I scurried away and left him alone.

I spent the rest of the workshop assisting other participants. Not long after my interaction with him, Eilidh, one of the tutors, approached James. Without saying a word, Eilidh placed a ceramic bowl in front of him, laid out several brushes, decanted different colours of earthenware glazes, and left to attend other participants. James took a couple of glances at the materials on his desk. He picked up a brush and dipped it into the glaze.

By the end of the workshop, James had painted a lemur onto the bowl.

///

This episode happened during my second week of volunteering at the studio, and I was taken by James's artwork, which I thought was beautiful – like illustrations out of a children's book. James had been attending the workshop for several years. He is easy to spot in the studio: he is a handsome and tall man in his late twenties who always wears a dark blue jumpsuit. James is one of the studio's more "visible artists", Lesley, the director told me. He boasts numerous international exhibitions, well-selling artworks, and a recognisable artistic style. He also has autism and learning disabilities. He lives in supported housing and needs to be accompanied whenever he leaves the house. He barely speaks, and when he does, it is always a one-word response. His words have a sharp and agitated edge, as if he had to press the sounds out of his lungs.

Helping people like James, who have significant learning disabilities, make artistic choices is not as simple as asking them what they want to do. Nor does it involve simply presenting them with different options and leaving it at that. The difficulties I ran into as a volunteer speak to broader challenges of conceptualising the capacity to choose for people with significant disabilities, who are limited in their ability to express themselves verbally or with assistive technologies.

I initially approached James because even though picking paint might have been what James wanted to do at the time, I felt that he was not really presented with options to engage in other forms of art; hence, I wanted to offer him a choice between picking paint and making art. My attempt at helping him was unsuccessful for a couple of reasons. My first mistake was asking him what he wanted to do without offering him any options. By doing so, I expected him to (verbally) articulate a plan and vision for an artwork on the spot, without taking into account the James's limits to verbal self-expression. My second mistake was offering James too many options, which I had thought would aide his choice-making. I did so without knowing (or asking him about) the types of animals he liked, or the artistic technique he preferred. Note that Eilidh avoided all these pitfalls. She did not make James make a decision on the spot, nor did she bombard him with endless options. By preparing the glazing materials for him, she kept James's options limited and did not pressure him into articulating what he wanted on the spot; instead, she left him to make his decision at his own pace.

Choice is a key component of citizenship. In liberal theories, the process of individuals becoming citizens is framed as a choice between remaining in the state of nature in which they are only answerable to their own morality; or joining the social contract, whereby they give up some of their freedom in return for protection. Choice has been central to British social policy and advocacy efforts to promote the citizenship for people who have been historically segregated, institutionalised, and denied choices their whole lives. However, to help people make meaningful choices, the impact of learning impairment on the process of choice-making needs to be addressed.

In this chapter, I argue that the Project Ability workshops demonstrate an understanding of choice-making that takes into account the limitations and support needs related to learning impairment. To substantiate my arguments, I draw on examples from the workshops to explore how participants are helped or hindered in their choice-making. First, I briefly outline the importance of choice in social policy and service provision. Then, I explore the difficulties people with learning disabilities and their carers face when trying to help people make decisions. In the second half of the chapter, I examine how supported choice-making is practiced in the Project Ability art workshops. Throughout, I will highlight the conceptual differences between two understandings of choice, and explore their practical implications regarding engagement with people with learning disabilities.

The conundrums of choice

Choice occupies a central position in the current efforts of learning disability social policy and service provision. Yet, promoting the choice-making of people with learning disabilities in practice runs into a range of problems. In this section, I briefly examine the context of the choice-agenda in social policy and service provision. Then, I juxtapose the rhetoric of these policies with the experiences of participants at the workshop to highlight the conundrums of supported choice-making in practice. I highlight three themes through ethnographic examples: lack of support for choice-making regarding larger existential questions, lack of help with navigating the service system, and difficulties with finding out what people really want. In exploring these examples, I argue that these conundrums emanate from the way social policy and service provision conceptualise choice.

The prominence of the choice-agenda can only be understood in the context of the recent history of segregation and institutionalisation of people with learning disabilities. Promoting choice-making has been an effort to rectify the unjust and abusive treatment people were subjected to in long-stay hospitals (Department of Health and Social Security, 1969). Historical accounts of life in institutions describe the lack of choice people with learning disabilities had over the most mundane aspects of their lives – to get up, what activities they wanted to engage in, who they wanted to spend time with – let alone in larger questions, like where they wanted to live, what they wanted to do for a living, how they wanted to nourish their aspirations for the future (Atkinson et al., 2000; Bartlett and Wright, 1999; Edgerton, 1967; Walmsley and Welshman, 2006; Wright, 1997, 2001). Ex-residents gave account of "batch living" practices in the hospital (Jones and Fowles, 2008: 104), wherein residents underwent a collective routine. These living conditions were reinforced by surveillance and bureaucratic management systems, strict regulations that allowed no free time, and little respite or personal time (Jones and Fowles, 2008).

On paper, there could not be a starker contrast with the present ethos of service provision: today, choice is intertwined with the language of citizenship. For instance, the Scottish Government outlines a direction for learning disability policy which "empowers individuals to have greater choice and control over the support they receive" so that "as citizens can become actively involved in selecting and shaping the support they receive" (Scottish Government, 2013b: 17). Choice is a major part of the Scottish Government's commitment to independent living, meaning "all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community" (Scottish Government, 2017: 27). Choice constitutes a similarly central theme in the support provider mission statements, third sector provision (including Project Ability), and self-advocacy groups. Amongst them are People First, a major self-advocacy group, whose aim is to "establish and protect the same freedom, choice, dignity and control as other citizens across all areas of life" (People First, 2017).

Fyson and Cromby (2013) identify three key elements that are necessary for an individual to make a meaningful choice: 1) the individual must have options, 2) they must understand both the short- and long-term consequences of their choices, and 3) the choice can be reversed without significant harm. In the personalised care approach, care organisations help choice-making by working together with care-recipients, their families, and occasionally their social workers to identify their aspirations, and devise the type of care and support plan that helps them achieve their immediate and long-term goals. The process purportedly increases care-recipients' options and control over the type of support they wanted, and who they wanted to get support from (FAQ - Self-directed Support, 2018).

However, research has questioned the impact of these policies on improving the lives of people with learning disabilities. While people with mild learning disabilities somewhat benefitted from increased choice and control over their lives, the extent to which people with significant learning disabilities could make use of these opportunities remains questionable: although they may have been offered an increased range of options, they have not been given adequate support to choose between the options (Bigby et al., 2017; Pearson and Ridley, 2016).

///

Choice emerged as a central theme of my fieldwork; the question of how much choice to give people, and how to support them to make choices permeated every interaction between participants and the people working with them. All the staff I spoke to agreed that it was important to offer participants choices; this was always followed by a remark on the lack of choices participants were given outside the workshops. “The tutors are really good, but choice-making is really quite complex,” Lesley, the director responded to my question on how much artistic freedom participants had in the workshop. “They spent a lifetime being denied choices over their lives, so it’s important that they get to exert some choices in the workshop,” she said. Lesley was referring to the fact that most participants who had high support needs had tight weekly schedules which were predominantly structured by their care providers. These schedules usually covered a broad range of activities, from social programmes, to sports, to leisure.

Notably, these schedules did not include much unstructured free time.

Connor is a 32-year-old support worker and English literature graduate who often wears purple sweaters with bright mustard socks and a small hat that only covers the tip of his ears. Connor has been working with Kenny, a participant who has significant learning disabilities and autism. In an interview, I asked Connor what supporting Kenny entailed.

“Do you want me to describe a day at work?” He asked me with a hint of surprise. “I can do that very quickly.”

“I go in at half past eight”, he began, launching in. “I say ‘Good morning’ and he says, ‘Good morning’. I say, ‘What are you up to?’ and he says, ‘Can I have a long lie?’. I say, ‘Of course you can,’ because I don’t care when you get up. Obviously I care, but with a capital ‘C’. With a small ‘C’,” meaning small things like when Kenny gets up, “I don’t care”.

“And then I say, ‘I’m just going to leave your door ajar’. He says, ‘Grand’ – well, he doesn’t say ‘Grand’. But then I go in and make myself a cup of tea, and I catch up on paperwork from the day before. I see if there are any appointments that need to be done, and then go and see if there is enough food. By that stage he’s up, and he makes his own breakfast, does his own dishes, does his own laundry, runs his own bath, washes himself. He does his own mopping, does his own hoovering, and makes his own morning cup of tea. He reminds me that I need to give his medication. I then dispense his medication. I sign that I have dispensed his medication.”

Connor’s quick-talking Belfast accent became more pronounced as he continued.

“So that’s 10AM. From 10AM until 8PM we have a different day. He does hundreds of things. He’s recently got a job. He goes to art class. He goes to the cinema, he goes to the gym, he goes to the bank, and does the shopping like every normal person would. We go to the pub and he goes out with his friend another night. So that’s five things immediately that I can think of that he does at night. Once every fortnight, he spends a day at his father’s house. At Christmas, he spends over three days going back and forth to his dad’s. And his brother has recently got married, so he goes to his brother’s house.”

Connor took a breath for what it seemed like the first time since he had started speaking. “Anyway that’s his life, and that’s what I facilitate.”

“Is this all in the care plan?” I asked Connor. “Do you get a schedule of what you have to do?”

“I wrote his schedule. I’ve written every little detail of what happens in his life from a Monday to a Sunday,” Connor said.

Since Kenny has multiple support workers, the care plan is there to ensure consistency in his support. This also means that there is little space for Kenny and his support workers to divert from the prescribed schedule. Ironically, this often ends up leaving Kenny little say in their everyday activities.

The absurdity of the situation did not escape Connor. He told me that because personalised support schemes leave people with little say in what they want to do, small and tokenistic choices were often framed as successfully improving people’s control over their lives. “You’ve got this thing,” he said, “if you ask your client, ‘What would you like to drink?’ and they say ‘I will have a milkshake’, well you are promoting independence because you are allowing him to have a milkshake. Well, fucking hell. Come on. I mean, it’s low standards.”

Connors’s account reveals a discrepancy between the discourse and the practice of choice. Kenny is allowed to pick what he wants to eat, but he is not offered the opportunity to structure his day. From my conversation with Connor, I further gathered that Kenny also does not have a say in questions like which organisation he would like to provide his care (his family made this decision for him), how he spends the money that he receives from the state (his care organisation deals with his budget), or where he wants to live (this is decided by the state).

Connor was aware of the discrepancy between the rhetoric and practice of supported choice-making. However, he pointed out that giving Kenny a say in all aspects of his life was not trivial. “If I wanted to live in a flat, I would walk down to the estate agent and say, ‘I am looking at this flat’. And if they’d say no because I can’t afford it, I could just offer to pay more in order to reach an agreement. I am able to stand up for myself and get something that I want,” Connor said. “Someone with a learning disability might not be able to do that. Even worse, people may take advantage of an individual with a learning disability.”

What Connor was implying here is that granting people with learning disabilities the freedom to make a choice about existential questions like where they want to live does not guarantee an automatic improvement in their living conditions. On the contrary, without someone to protect their interests and advocate on their behalf, they may be exposed to being mistreated and exploited. Navigating the landscape of service provision, the housing market, and the banking system is complicated even for people without learning disabilities, who often have to draw on other people’s expertise and advice. Someone with significant learning impairment may not have the social network they can draw on the seek out such advice (Duggan and Linehan, 2013; Verdonschot et al., 2009); even if they do, they may have difficulties understanding the complex information they are given.

People with significant learning disabilities need extensive support to make choices in the important questions about their lives. Kenny’s care organisation recognises this; this is why they have day-to-day control over Kenny’s housing and bank account. They do not, however, provide Kenny with support to take charge of his housing and finances. Connor and the other support workers do not have the power and space to advocate for Kenny in these matters. For this reason, to maintain some illusion of “choice”, support workers feel that the most they can do is to allow Kenny to make a decision over whether he wants to drink a milkshake from time to time.

///

The lack of support with choice-making presents problems for the families and guardians of people with learning disabilities, who are often tasked with arranging the care. This involves making a decision about how they want to structure the care, what kind of activities they would like to spend their support on, and which organisations that provide those activities they would like to subscribe to. Although the privatised service structure nominally offers them plenty of options regarding providers and types of activities, families receive little guidance to help them pick between these options.

Margaret is a woman in her late fifties who sports an elegant pixie haircut. Since Margaret retired, she has been spending her time supporting her daughter and workshop participant, Deoiridh. "We put a lot of effort into finding services. It was pure luck that we found out about Project Ability," Margaret said. She told me that they met one of the tutors at the hospital where Deoiridh was being treated at the time. It was the tutor who suggested the art workshop. That was more than eight years ago – Deoiridh has been attending ever since. However, had it not been to the tutor, Margaret thought she would have never found out about Project Ability.

Deoiridh, thanks to Margaret's efforts, has a busy schedule: together, they volunteer at the shop and gallery, go on the studio's walking tours, and they attend all the socials, exhibition openings, and specialist workshops. When not at the studio, Margaret arranges for Deoiridh to go out for social events specifically for people with learning disabilities. On Fridays, they walk the dog of Deoiridh's elderly neighbour.

"She's got a busy social life," I said.

"She does," Margaret responded. "But I'm worried that without me, she won't be able to find these services."

Margaret's concerns reflect the same issues that Connor referred to, namely that being free to pick between options does not equate with having more choice. Margaret is a well-educated woman, who has reasonable social networks, financial resources, and time to find out about service options. However, even she finds it hard to choose the right services; this may give an indication of how difficult this may be for someone who does not have similar resources. This is sad and ironic, considering that the past governments encouraged the privatisation of social care in order to provide people with more choice. What they did, however, was providing people with more options, but little support for people to choose between the options.

Even if people with learning disabilities, their families, and their support workers were given all the information and time about available services, there was an additional obstacle they would have to overcome: several parents and support workers I spoke to told me that the person they supported had difficulties with formulating what they wanted, due to their learning impairment. This meant that some of them could not verbally articulate their desires to the people who worked with them; however, just as often, the individuals with learning disabilities did not know what they wanted. A consequence of this was that letting them make decisions resulted in them never leaving the house. Margaret, Deoiridh's mother said, "Deoiridh would just stay in bed. She wouldn't be able to formulate what she wanted to do, and then search for ways in which she could do them."

In the art workshop, this conundrum reflected in the difficulty of asking people like Kenny what they wanted to do. Kenny would always say, "paint". I know this because I asked him every single time for several consecutive weeks. Each time I got the same answer: "paint". Connor, his support worker eventually took pity on me and explained that when Kenny said "paint", he was not referring to the act of painting. He meant just generally being at the workshop. Other participants would say yes to everything, like Angus, whose answer was always followed by a soft smile. Angus seemed keen on trying everything that was suggested to him. However, I have never heard him say anything other than the word ‘yes’, so it was hard for me to discern whether he would tell me if he there was something he did not want to do. Another participant who said yes to everything was Paul. Unlike Angus, Paul’s ‘yes’ was always uttered with a rushed, muffled tone, which gave me the impression that he just wanted me to stop asking him questions.

It quickly became obvious to me that in most cases, simply asking participants what they wanted to do was not an effective way of helping them make a choice. When I did so, I would make the mistake of taking their verbal responses too literally, not realising that I was not equipped to decipher what they really meant. But sometimes, participants simply did not know what they really wanted at the time they were asked to make a choice.

///

I used this section to illustrate that despite heightened policy and service provision efforts to provide people with learning disabilities with choice, in practice, supporting choice-making is riddled with practical and ethical dilemmas. For instance, people with learning disabilities were allowed to make small choices about what they wanted to eat or wear, yet they were not offered the chance to deliberate on larger questions about their care or their finances. In other instances, supporting their choice-making was difficult because they were not aware of their options, or did not know which option they preferred.

What becomes apparent from these examples is that there is a discrepancy between social policy’s choice rhetoric, and the practice of supporting people with learning disabilities making meaningful choices. The practical difficulties entail lack of support for people with learning disabilities to make decisions regarding larger issues about their lives, lack of support for families to navigate the different options provided by the social care system, and finding out what people really want. All this highlights that choice-making entails more than having options and the freedom to pick between said options.

Choice, understood as the freedom from interference to pick between options, echoes the assumptions of liberal citizenship – namely that individuals are equally capable of making choices. Liberal citizenship assumes that all individuals have clear preferences, have the capacity to weigh up all information available to them, and decide on what is best for them based on their self-interest. In reality, choice requires additional interventions: information, time, and advocacy.

More importantly, choice is a capacity that entails the ability to develop and articulate preferences. Currently, people with learning disabilities are not provided with the support to cultivate their preferences and develop their capacity to choose; instead, the way in which service provision is structured assumes that they already have preferences. Furthermore, whereas people with learning disabilities are expected to have an equal capacity to choose as those without learning disabilities, in practice, they are often outright denied that capacity instead of being offered support to develop it.

The conflict between the rhetoric and practice of choice did not escape the staff at the workshops. Lesley, the director, described the levels of choice-making participants were expected to go through to attend the workshop. Participants have to decide on the hours of support they would like to purchase from their budget. Then they have to decide whether they would like to attend. If so, they have to choose how many hours of support they would like to allocate to attending. Some people only get support with transport, so they get dropped off and picked up. Others have their support stay with them in the studio.

“It’s a huge number of decisions to make,” Lesley sighed. “And if you never got to decide when you’re going to bed, when you are going to get up, what you are going to have for breakfast, or what your clothes are going to be that day...” She trailed off.

I asked her how people make the choice about attending the workshops.

“The truth is,” she shrugged, “it’s always going to be the carers making the choices for them.”

On trying new things

Given these challenges around helping people with significant disabilities to make meaningful choices, I now turn to discuss how tutors approach choice-making in the workshop. In particular, I focus on the practice of helping participants trying out new things and the role it plays in understanding what choice looks like for people with learning disabilities.

Deoiridh’s mother, Margaret, told me about a theatre performance she attended with her daughter. The show was put on by an organisation that provides dance classes for people with disabilities, and included disabled and non-disabled performers. Margaret spoke about an act where one of the performers, a wheelchair user, was holstered up in the air as an aerial dancer. “I wonder how that came about,” Margaret said, “Someone must have suggested it somehow. And this performer was so extremely agile.” She paused. “I mean, as a wheelchair user, how do you know that you can dance, that you like dancing?”

Margaret captured the essence – and one of the ongoing challenges – of the art workshops related to choice-making, namely, how to help people with learning disabilities find out about their preferences and work towards what they want? In this section, by examining the ways in which staff members at the workshops help participants make art and artistic choices, I argue that Project Ability demonstrates an alternative approach to choice-making, one which takes into account people’s learning impairment-specific needs.

At the beginning of each workshop, one of the first things the tutors do is trying to find out what participants would like to do; however, as I discussed above, this is not always as simple as just asking them. Granted, there are some participants who come with specific ideas. Take Graham, a young man with Down Syndrome always has a piece of paper at hand with what he wants to draw on that specific day. This mostly falls into two categories: brutalist architecture and superheroes. Or Aila, indie music connoisseur, who knows exactly which 1990s pop-cultural icon’s portrait she will paint at the start of each workshop. Or Ewan, Scottish Paralympics youth champion, who does not seem to hesitate when it comes to choosing colours, framing, and art materials.

The majority of participants, however, look to the tutors to give them suggestions about various aspects of art making. They have plenty of options regarding technique (e.g. painting, clay, printing, collage), technical advice (e.g. how to make sure the clay does not crack in the kiln), material (e.g. would a painting work best with oil, acrylics, ink, or watercolour), picture for reference (e.g. portrait, landscape, animal), colours (e.g. how to mix grey, or what priming colour would make the painting pop). The availability of these options is conditional to the budget that Project Ability can spend on professional-quality art materials.

The generosity and variety of materials at Project Ability does not go unnoticed by attendants. I asked Helen, artist and part-time support worker, what she thought about the other art workshop Anthony – a participant that she supports – attended. “I don’t want to say anything negative about the other art group,” she said, “but I don’t find that the other place gives him the opportunity to try different things.” Helen explained, “Staff at the other art group are quite happy to leave him alone with his picture and his pencils. They seem to think, ‘This is what Anthony does, and we’re not going to change it, or ask him to try anything else’. He seems quite happy about it, but I think it would be good if he was challenged to try something new.”

Helen continued, “Project Ability got so much more different materials, and the possibility to try new things. They have glass making they have got kiln they have got a printing press, they have everything and the staff know exactly how to use it all. The other art workshop gives Anthony crayons, and they are happy to leave him to it. I don’t think that is good.” Helen’s description of the way the other art workshop approaches Anthony’s artistic choices reflects a liberal understanding of choice, i.e. no one interferes with Anthony making pencil drawings every single week. However, it is not choice, understood as a capability that requires positive intervention: leaving Anthony to his devices does not help him improve his creative capacity, develop his preferences, and thereby, in the long run, expand his artistic choices. Project Ability offers the latter kind of choice: not only are there numerous possibilities for materials and techniques, but also professional tutoring to help participants grow as artists.

Given the broad range of options for creative activities, I asked tutors Rory and Joanna how they helped participants decide what they wanted to do at the workshop. “Choice is a moment-by-moment thing,” Rory told me. He emphasised that although choice was an important part of people’s work, there was no prescription on how people made choices, so it was important for tutors to be flexible. He brought up the example of a participant who just wanted Rory to tell him what to do. “He wanted instructions, and then carry them out really well,” Rory said, “And at first I thought, that was not how we did things here. It took me a while to understand this.”

Joanna jumped in. “But then some people tend to be stuck on certain things, especially if they get a compliment on it. It then becomes ‘their thing’”, she said. “Remember the dolphins?” Rory gave her a knowing look. Joanna told me that one participant would only make dolphin-related art for years. “And after a year, you think, not another dolphin,” Rory laughed.

Rory’s and Joanna’s accounts exemplify participants whose preferences do not quite fit with conventional understandings of choice, but could be construed as one nonetheless: participants wanting someone to tell them what to do, or doing the same thing despite the range of available options. But Rory and Joanna were not satisfied with simply giving participants instructions or leaving them to do the same thing for years. Doing so does not cultivate participants’ capacity for (artistic) preferences; it is not different from allowing participants to have a milkshake as a form of choice instead of supporting them to make larger decisions about where they want to live.

For one, leaving participants to do what they say they wanted to do can impede their enjoyment of artmaking. As Joanna explained, “There’s a trajectory. The sensory pleasure people derive from certain types of art making can turn laborious.” She drew a bell-shaped curve in the air with her finger. A painter by training, Joanna always had an air of academic eloquence around her, accentuated by thick framed glasses, perfectly applied lipstick, and well-tailored clothes. “To keep people in the pleasant zone of art-making,” Joanna pointed at the left side of the imaginary curve, “we try to get people to do new things when their enthusiasm goes down, but without pushing them out of their comfort zone.”

Helping participants trying out new things is thus seen as crucial to maintaining the joy of artmaking. However, the changes need to be introduced in incremental steps, especially when supporting participants on the autistic spectrum for whom diversion from their routine can be a source of anxiety. Helen, Anthony’s support worker explained, “Anthony doesn’t like change. If there is change, it has to be with warning of maybe months to work up to it.” Yet, Helen said that Anthony needed a challenge from time to time, otherwise he would get bored. I asked her about the kind of changes she introduced to their schedule. “Just small things, I guess,” she said. “When I started supporting him, he was just baking simple things like muffins and fairy cakes. Every week the same the cake. But now we have got quite a few more recipe books, so we’re quite ambitious. Now we do quite complicated things, like Great British Bake-Off type of cakes,” referring to a television baking competition, known for its elaborate and extravagant cake designs.

In the art workshop, changes can be as small as using a different kind of paint and paper, or drawing while standing up instead of sitting down. As tutor Joanna touched upon, different techniques have a different sensory nature. For instance, acrylic paint has a different tactile sensation than gouache because the former is thicker than the latter. Switching art material changes the rhythm of the art making: whereas colouring with felt tip pens require small repetitive movements, pastels allow participants to work with faster and broader strokes. Finally, standing up readjusts participants’ focus from small details to the whole picture.

Dhillon exemplifies how a small change introduced the material ripples through his whole artmaking practice. Dhillon, a 48-year-old, Indian-Scottish man, is a prolific painter. He is tall, soft-spoken, gentle, and a gregarious person. His brushwork is confident, bold, and tends to get rougher as the workshop draws closer to an end. I sat next to Dhillon, watching tutor Joanna quietly observing him scraping the A1 sized canvas with a brush he held with his fist. Joanna must have interpreted the way Dhillon handled the brush as slight agitation, and she thus decided to suggest Dhillon switched technique. She approached him with a pack of Staedtler fine liners – a generous donation from Margaret to the studio – and a stack of postcard-sized white cardboard paper. She showed Dhillon the fine markers, and asked him if he wanted to try them. She told him that they would make really nice “tiny drawings”. Dhillon hesitated. Joanna put the pens and papers on his desk, and left to attend to someone else. Dhillon contemplated for a few minutes. He then picked up the fine liners and continued with those for the last half an hour of the workshop.

On the left: Dhillon’s painting, acrylic on canvas. On the right: Dhillon’s drawing, ink on paper. Photos by TTP.

Doing something new can be as incremental as that: going from a big scale painting to a small drawing. This is not only a matter of switching technique. It is also the readjustment of the whole body: posture, sensations, and attention. The size of the paper makes the hand movements narrower. The light pens change the pressure applied to the drawing. In contrast to the smooth sensation of layering thick acrylic on paper, fine felt tips pick up the smallest unevenness of the surface texture. Attention is also readjusted, going from broader overall impressions to smaller details. There is a distinctive difference between Dhillon's artwork, once he changed from thick paint brushes to thin pens. While his personality radiates through both, the one he made with thin pens demonstrate fine attention to detail as opposed to the bold impressionism.

Supporting participant engagement in novel artmaking techniques takes attention, patience, and sensitivity from the tutors. As I discussed: suggesting a technique that is out of the participants' comfort zone may cause them anxiety and impede on their enjoyment.

Take the following example of tutor Eilidh helping participant James.

James was picking dried paint as usual, when Eilidh sat down next to him with a piece of laminated cardboard and a picture of elephants. I did not catch what she said to him, but after a few minutes, James put away the palettes, and with the same scalpel in hand, started scraping the cardboard. He was etching a plate for drypoint print.

Drypoint etching is a printmaking technique, where a needle is used to make engravings into a plate. This plate could be plexiglass, or cardboard for a low-budget alternative. The plate then needs to be rubbed with thick printmaking ink or oil paint, making sure that the engravings are thoroughly covered, but that the rest of the plate is otherwise clean. The plate is then pressed against prepped, usually soaked heavyweight paper. The pressure from the pressing will transfer the ink from the plate onto the paper. The same plate can produce several prints.

Eilidh checked on James about an hour later. She held James's plate against the sun, checking the incisions to make sure they were deep enough and that the printmaking ink sufficiently covered the figures. It was a picture of a mother and a baby elephant. The baby elephant missed an eye – James had scraped it off. Eilidh took a piece of the cardboard and cut a small circle. "Does he have an eye?" She asked James. "Where does his eye go?" James pointed at the plate. Eilidh glued the circle to where James pointed, and then they went off to the print station.

On the left: A palette, scraped clean by James. On the right: James's drawing of a swimming pool, felt on paper. Photos by TTP.

Eilidh later explained to me that James seemed to enjoy drypoint etching because it was a sensation similar to picking paint. The glazing, she said, must have been frustrating for him because of all the dripping paint. James's go-to art technique is felt tip on paper. One of his exhibited drawings of a swimming pool was of A0 size (841 x 1189 mm) – all covered with thin felt tip markers. Eilidh said that the original reference picture was of divers lining up at a board. The silhouettes would go well with James's style, Eilidh had thought. But instead, what he decided to focus on was one corner of the pool.

Eilidh noticed the singular attention James paid to minute details and the meticulous, repetitive movements underlay most of James's activities in the workshop: picking paint, drypoint etching, and colouring with thin felt tip pens. She surmised that James would enjoy artmaking techniques that demonstrate similar sensoriality, i.e. small, repetitive, focused movements. I noticed that James would paint, if he had paint and canvas set up in front of him. However, on those occasions, he would spend less time making art, and more time picking dried paint. At the end of my fieldwork, the tutors would sometimes set up his work station such that he would draw standing up. Using soft pastels on paper still shared some of the sensory experiences akin to scraping, but it changed James's posture, and the size of paper required him to use broader movements.

///

I cited these examples in search for an answer to Margaret's initial question, namely how a wheelchair user comes to learn that they like dancing? By the same logic, one could similarly ask, how do participants at the workshop know that they like drypoint etching? Or that they prefer acrylic to felt pens? Or that they prefer animal portraits to landscapes?

On the surface, the answer appears deceptively simple: it is by engaging in new activities and trying out new things. However, if the ethnographic examples should illustrate one thing, it is that there is nothing trivial about supporting people with learning disabilities to explore new forms of artmaking and develop their preferences accordingly. As I have emphasised throughout, it is because understanding choice as a capability that requires affirmative measures stands in contrast with the dominant, liberal conceptualisation of choice as a negative freedom.

Framing choice as a positive freedom foregrounds the extensive material, personal, and institutional provisions that enable it. Project Ability has the budget to provide participants with diverse and high quality facilities and art materials; that is not the case with many service programmes. More importantly, Project Ability provides professional tutors who have extensive knowledge and experience of visual art, thus can provide guidance to build creative capacity at all levels. Secondly, effective support demands that the people working with participants infer preferences without relying on participants' capacity for verbal self-expression. The tutors attend to participants' sensorial preferences and extrapolate participants' likes, suggest artistic activities accordingly, and adjust their suggestions if the participants do not seem to be engaged by the initial activity.

Lesley, the director used the term "art literacy" to refer to the capacity to have aesthetic and sensory preferences for particular artistic techniques, colours, textures, and style. Art literacy is central to artistic choice: it enables participants to become aware of, understand, and imagine different options for artistic activities. All this is conditional to supporting participants' capacity to choose. Without trying out new activities, participants may continue to rely on others to make choices for them, or they may stick with the same option they know; neither of which helps participants to make choices to the best of their capacity.

Art literacy: developing the capacity to choose

Here is an example of how art literacy contributes to one's choice-making capacities.

For two months, once a week I accompanied tutor Rory and participant Joshua – an internationally exhibited artist and comic-book aficionado – on their outreach programme to a community centre in Dundee, a city located two-and-a-half-hour drive from Glasgow. Project Ability received funding to send a pair of tutors and participants from the Friday group to deliver art workshops for groups of people with learning disabilities who did not have local access to art-making facilities locally. Unlike participants of the Glasgow workshops, many of whom had been making art with Project Ability for years, attendants of the outreach programme had few opportunities to engage in art-making; hence, they did not have the high levels of art literacy compared to their Glaswegian counterparts. Over the course of the outreach programme, I observed how the participants in Dundee were supported to expand their artistic vocabulary, which then enabled them to make artistic choices by the end of the eighth week.

The community centre is situated in the outskirts of Dundee. As opposed to the bustle of the art galleries in the district of Glasgow where Project Ability is located, the Dundee community centre is wrapped in the concrete sea of a car park, mountains of high rises in the background, and 1960s-style suburban houses. The room we were allocated in the community centre was light and spacious. Unlike Glasgow’s purpose-built studio, this space was not made for art-making. To begin with, there was no sink in the proximity, which complicated the logistics of painting or clay work. Since the room was also used for other purposes, we had to be mindful of cleaning up the stains left by the paint and clay.

The centre had a limited range of art materials: mostly crayon, print paper, colour pencils, and some small tubes of acrylic paint. Therefore, each time we drove to Dundee, we also brought three boxes of materials from the Glasgow studio, including bricks of raw clay weighing around 20 kg each. Each week, Rory and Joshua demonstrated a new technique participant could try. (If someone had an idea they were set on, there was space for them to do that too. For instance, one participant spent eight weeks painting a chair.)

Blair is a young woman with long blonde hair and an eyebrow piercing. As one of the participants, Blair had been working on the same art piece over the past four weeks, incorporating the novel techniques each week as the workshops progressed. What started out as a demo drawing of an anchor on tracing paper was then followed by acrylic sgraffito motifs, ink background, freehand starfish, block printed fish and stencil printed fish scales.

The sgraffito workshop took place in week three, and it was Joshua’s idea. He said that he was inspired by “this crazy guy” whom Joshua described as a Bob Ross[3]-like YouTube artist who painted by flailing knives around. Sgraffito, on a basic level, does not require more than two colours of acrylic paint and some pointy sticks – we used hardwood tools for clay modelling. Joshua explained to the participants that it was best to pair complementary colours, as they would make the artwork “pop”. Rory quickly demonstrated the process. The first layer of paint serves as a primer. Once that dries, the second colour goes on top of that. While the second coat of paint is wet, one can scrape figures into it – the figures will reveal the colour of the first coat of paint.

Joshua gave each participant a piece of paper on which they could experiment with colour combinations and various tools. Blair chose a burgundy for a base coat and a cobalt and ultramarine blue second. However, her scraped figures did not quite show up the way she expected them to. “It’s not working,” she said, handing me back the clay tools with frustration. Joshua suggested she tried lighter colours with a thicker layer of paint. “Just slap it on,” he smiled when Blair hesitated. “Yeah, that’s it!” The thicker the second layer was, the slower it dried, leaving more time for scraping in motives.

---

[3] A painter who hosted a popular art instruction television show in the 1980s and 1990s.

On the left: Blair's trial sheet of sgraffito, acrylic on paper. On the right: Blair's anchor, mixed media on paper. Photo by TTP.

The yellow-ochre-burgundy colour combination inspired the colours of Blair's anchor. The motifs created with a plastic fork reminiscent of waves seemed to suit the theme. Although she was tentative at the beginning, by the penultimate workshop, Blair had a clear idea of what she wanted for the last session: a starfish and a yellow fish with a golden eye, all under the anchor.

Over the course of the eight-week programme, Blair's short experiments with different techniques helped her explore some of her preferences for colour, motifs, and textures. Each new technique broadened her field of possibilities. By the end of the programme, she was able to make choices about the subject of her painting, the techniques she wanted to utilise, the combination of colours that she found striking. Lesley described the trajectory that Blair underwent as a process of acquiring not only a cognitive understanding of art but also an intuition regarding various aspects of artmaking, like colour combinations that looked striking, or materials that worked well together. The process also comprised a confidence with which participants made art without being hindered by the fear of making "mistakes".

Blair's example highlights a few themes I discussed previously: the material conditions of choice-making (facilities and materials), the importance of trying out new things, the process of becoming acquainted with the sensoriality of art techniques. A new theme that this episode illustrates is this: all this takes time. Rory noted that a challenge of these outreach programmes working within the time constraint. At the beginning, everyone tends to do the same thing to get acquainted with different techniques. It is only towards the end of the eight weeks that most participants acquire art literacy and confidence to make their own choices – and by that time, the programme is over. At the end of the Dundee outreach, Rory took note of the fact that all participants were working on different things; to him, this was an achievement because it meant that everyone developed some basic preferences.

The Glasgow workshops are fortunate in that they do not have to work with such time constraints. "We measure things in years, years and years." Lesley told me. "We do see changes in people over the years, you know, some people will not be obviously engaging. And then three years later you realise that they've actually started choosing their colours, they have shown preference for different materials," she said. "It's the mechanism by which people can start making decisions about things. And it can take a lot of time for people to realise that they can make these decisions."

Conclusion

In this chapter, I examined the ways in which participants at Project Ability are supported to make choices. By analysing ethnographic examples of people making art, I argued that the art workshops provided an approach to choice that differed from choice as understood by social policy and service provision; one that better explains what choice means for people like James, Kenny, or Blair.

As I discussed, the concept of choice in social policy and service provision aligns with the ideals of liberal citizenship, which assumes individuals are equal, rational, and fully capable of exercising choice-making if they are granted freedom from interference to do so. Choice-making, by this logic, is a product of rational deliberation, which results from individual's taking into account all information on options of available services, making a cost-benefit analysis of said options, and deciding on the option that they see most beneficial. By this logic, people with learning disabilities, especially those with significant impairments, are often denied the capacity to make important decisions about their lives, and are only allowed small, tokenistic choices.

This is apparent in the personalisation framework, which has increased the number of options people could pick from, but which offers little guidance on how people can be supported to develop the capacity to choose. It is not sufficient to state that people with learning disabilities have the same freedom to choose as other citizens in all areas of life (as, for instance, in Scottish Government, 2017: 27) because that does not take into account the practical difficulties posed by learning impairment. It does not outline how people with learning disabilities, especially those with significant impairments can go from choosing what they want to eat to deciding on where they want to live. Just by stating that people have the freedom to deliberate on these matters does not mean that they can miraculously do so, without further interventions.

In the second half of this chapter, I offered a different approach to choice, one which does not only enable people with learning disabilities to make small decisions, but can provide some guidance on how those small decisions can lead to building up capacity for them to have a say in larger questions. In the art workshops, choice is not so much a result of rational deliberation, rather an embodied process of individuals exploring and developing their preferences by trying out new things. In this framework, people become capable of making choice not only by picking between options, but by actively expanding their capacity to choose with support and experimentation. Choice, understood so, foregrounds the need of positive interventions, as opposed to freedom from interference.

I highlighted the importance of material conditions. For Project Ability, this encompasses the budget for facilities, materials, staff, studio space, and time. Choice also necessitates personal support provided by the tutors and support workers are able to attend to the participants' bodily language to infer their preferences, and subsequently draw on their professional experience to invest time and effort into seeking out various options that the deem suitable for the person they support.

Approaching choice as an embodied capacity also reframes the debate. Instead of entering circular discussions on whether individuals can or cannot make a choice, whether they have or do not have a choice, whether what they want and do constitutes a choice – choice-making becomes an obligation that demands a response from individuals and institutions alike.

These findings not only challenge the liberal ideals of citizenship by reiterating how emphasis on rational deliberation and freedom from interference excludes people with learning disabilities. This chapter expands this debate by, first of all, demonstrating that key aspects of liberal citizenship – choice, in this instance – are not out of reach for people with learning disabilities. The findings reiterate the centrality of choice to the citizenship of people with learning disabilities. Furthermore, by offering an alternative to the cognitivised, disembodied, and rationalistic understandings of choice through the foregrounding sensoriality, experimentation, and support, this chapter also contributes to understanding how ideals of liberal citizenship can be made more inclusive.

Chapter five:
The risks of independence

Introduction

Allowing people with learning disabilities to have choices about their lives has been fundamental to supporting their independence – another building block of liberal citizenship. Independence as a liberal virtue is apparent in the way social contract theories treat citizens primarily as individuals without caring duties and responsibilities who have basic freedoms to deliberate about their lives (Young, 1995). On paper, the right for people with learning disabilities to be independent is upheld by the UNCRPD (United Nations, 2006), and is supported by policy measures, which encourage economic self-sufficiency through employment, and the exercise of responsibility on various issues, such as healthcare and education (Redley and Weinberg, 2007). In practice, the people exercising this right is surrounded by social anxieties. Stephen's case, which I will discuss throughout this chapter, perfectly highlights the nature of these anxieties.

Aged 25, Stephen was one of the youngest participants at the workshops. His closely shaven head, steel-toe Martens boots, and black band t-shirts all accentuated his youth. Stephen entered each workshop with an energetic, purposeful stride. He would go straight for the trolley on which the materials were laid out, grab whatever he could carry in his hands, and walk to the far end of the studio – usually reserved for temporary specialist workshops – so he could be alone. Stephen's ability and willingness to focus on one task would usually last about ten minutes, after which he would fetch a bulk of different materials, start something new, just to leave that unfinished as well. Tutor Ruby recalled taking half an hour to set up clay materials for Stephen, just to have him get bored after three minutes.

Unlike most participants at the workshop, whose support was provided by private care organisations, Stephen was under hospital supervision. He was considered a high-risk person: he was diagnosed with attention deficit hyperactivity disorder [ADHD], schizoaffective disorder, depression, and mild learning disabilities. He had been in and out of the hospital in the past years.

In the workshops, Stephen often struck me as reckless, impulsive, and moody. He would leave the spray paint machine unattended, or stack his wet paintings on top of each other, leaving them to stick to one another when dry. On occasion, he would place his clay on top of others’ works, potentially damaging them. Stephen’s presence always left a trail of unfinished art that transpired an abandoned vision whose pieces never quite fit together.

I spent much of my time at the workshop working with Stephen. I did so initially at tutor Ruby’s request: although she did not specify why or what she expected me to do, I interpreted my task as making sure that Stephen did not wreak havoc. When I spent time with him, Stephen would occasionally turn to me and ask me for advice, which he would consider for a few seconds, just to shrug it off, tell me he could not be bothered, and continue doing the art in what seemed to me the quickest and arguably most haphazard way.

Midway through the last block of workshops that I attended, Stephen came accompanied by a young blonde woman: his occupational therapist [OT], assigned by the hospital. Stephen’s OT attended two other workshop sessions with him. They left halfway through the third one.

Stephen never came back.

I learnt that the hospital thought Stephen was not provided with adequate supervision at the studio. They were particularly concerned that Stephen was allowed to work unattended around knives, scissors, and other sharp objects. Thus, in order to protect Stephen’s safety, they decided that he should not be attending Project Ability anymore.

///

Supporting people with learning disabilities to be independent is one of the major commitments of social policy and service provision (Department of Health, 2001). Based on the definition of independent living, this means that all disabled people have equal rights and freedoms to make choices, exercise control, and participate in society – a basic principle of treating them as citizens (Scottish Government, 2017: 27). However, giving Stephen complete freedom at the workshop meant that he could disrupt other people’s work, do damage to the equipment, and even put himself in harm’s way, for instance, by cutting himself with sharp objects. Both the workshop and the hospital recognised these risks. Subsequently, they offered two, distinct responses to the question of how Stephen could be supported to be independent without risking him causing damage or getting injured.

My aim with this chapter is to develop the ideas about independence by exploring how risk management in service provision simultaneously supports and hinders it. I open with a brief overview of the learning disability policy and academic literature on independence and risk, before moving on to comparing and contrasting the hospital’s and the workshops’ approaches to risk and independence.

Independence in the context of responsibilisation and risk management

When it comes to supporting the independence of people like Stephen, one of the major concerns is that it may encourage their disruptive behaviour, while making them vulnerable to abuse and harm. I use this section to unpack these concerns: I examine the policy discourse on independence, specifically in relation to individual and social responsibilities towards real and perceived risks around people with learning disabilities.

Concerns about the risks surrounding people with learning disabilities contain a double imperative. Historically, on the one hand, they were seen as a threat to the moral fabric of society, documented by the elaborate measures that sought to control their reproduction, and to prevent them from exhibiting anti-social behaviour (Manthrope et al., 1997; Walmsley, 2000). Simultaneously, part of the rationale behind some of the controlling interventions was to protect them from harm and exploitation (Walmsley and Welshman, 2006).

This double obligation is apparent in present policies. The protection of people with learning disabilities from external abuse and self-injury is a government priority (Department of Health and Social Care, 2000). At the same time, addressing what the contemporary medical literature refers to as “challenging behaviours” been an ongoing preoccupation of service providers. Challenging behaviours include “aggression, self-injury, destructiveness, overactivity, inappropriate social or sexual conduct, bizarre mannerisms and the eating of inappropriate objects” (Emerson and Einfeld, 2011: 1). It is important to note here that definitions of challenging behaviour are socially and culturally contingent, depending on conventions, beliefs, and expectations on what counts as appropriate and deviant conduct, and reflect medical staff’s ability (or inability) to interact with individuals with learning disabilities. However, there is a legitimate concern that challenging behaviours may lead to harm and self-injury (Fyson and Kitson, 2010; McClintock et al., 2003).

Protecting people with learning disabilities from harm thus poses a conundrum for those advocating for their citizenship. This kind of protection is a fundamental part of ensuring that their human rights are respected. Yet, it can clash with the principles of independence (Mackay, 2017). In the previous chapter, I discussed support workers’ and family members’ anxieties about people with learning disabilities being exploited or neglected if they were left to make their own decisions. These anxieties are amplified if choices and control are expanded to all areas of life. Fyson and Kitson’s (2010) research sadly confirms some of these anxieties. They observe that in the name of independence, some people with mild learning disabilities are put in complete charge of their own lives, and thus becoming victims of abuse; on the other end, people with more significant disabilities are completely denied freedom in an effort to protect them from harm (Fyson and Kitson, 2010).

Social policy has sought to address this tension between independence and protection in two ways. On the one hand, as I discussed in my first chapter, the personalisation framework introduced services and interventions that aimed to improve individuals’ self-management skills and encouraged them to improve their own “challenging behaviour”. There is a vast body of medical literature on interventions to improve social skills and reduce disruptive or risky conduct (NICE, 2015). These include education programmes, leisure activities, and support with day-to-day activities, all of which are geared towards helping individuals recognise and tackle their inappropriate behaviours, and improve their ability to manage their health, emotions, and development.

Concurrently, systems of accountability and safeguarding practices have been put in place in social care services to protect individuals with learning disabilities from harm, abuse, and mistreatment, much of which have come from care staff in the past (Tuffrey-Wijne et al., 2013). The history of learning disability services is full of malpractice, which did not end with the closure of long-stay hospitals (Department of Health and Social Security, 1969). More recently, a confidential inquiry found that within a two-year period between 2010-2012, almost half of the deaths could have been avoided, had people with learning disabilities received appropriate care and support. Therefore, increased staff accountability and discussions about safeguarding have been much welcome in light of past and ongoing cases of mistreatment.

Yet, increased responsibilisation and accountability are part of a larger trend, wherein social obligations are shifted from states and collectives onto individuals and markets (Shore and Wright, 1999). As a result, health and wellbeing becomes the individual’s responsibility towards the self, rather than as an outcome of a complex interplay of societal factors (Rose et al., 2006). Problems arise when these trends amalgamate in care practices that limit individuals’ engagement with activities that they hold valuable in order to minimise risk, like in the case of Stephen. Subsequently, Fyson and Kitson (2010) observe that those who work with people with learning disabilities have to face the "unanswerable" questions of how much independence is worth the cost of potential abuse (p. 312).

The art workshops provide some guidance for answering this question. Project Ability makes a compelling case study because, on the one hand, they also operate within the framework of increased responsibilisation and accountability. They too have undergone funding cuts, as a result of which the number of participants doubled while the number of tutors remained the same, meaning each participant has been receiving less individual support and attention. Considering that the workshops hosts vulnerable adults – some of whom have had issues in the past with exhibiting challenging behaviour – may raise concerns. However, I argue that the workshops demonstrate a different approach to independence and risk than the one exhibited by the hospital that removed Stephen from the workshops. Therefore, by discussing how independence, responsibility, and risk is enacted within the workshops, I examine the lessons one can learn about engaging with vulnerable adults.

Independence and responsibility without support

Let us examine Stephen's removal from the workshops from the perspective of responsibilisation and risk management, and see what its underlying logic says about service provision's approach to the independence of people with high support needs, especially in the context of spending cuts in social care.

I learnt from the Project Ability staff that Stephen had been under hospital care for a few months prior to being pulled out of the workshops. Consequently, Project Ability had to start working closely with the hospital-assigned care staff to address how Stephen's support needs could be met.

It became apparent early on that the workshops and hospital staff had different approaches to supporting Stephen. On the one hand, Lesley, the director openly voiced her concerns about the hospital staff speaking about Stephen and his needs in a heavily medicalised language, where everything was framed in terms of diagnoses and treatment risk. "What does this do to someone's sense of self?" she asked. On the other hand, the hospital seemed unhappy with what they saw as a lax attitude that Project Ability demonstrated towards risk management. After a meeting between Lesley and hospital staff, the hospital decided to send an occupational therapist [OT] to the studio to accompany Stephen and conduct a risk assessment.

The OT was a young woman with perfectly manicured nails and coiffed hair who carried a cloud of sweet perfume around her. The first time Stephen attended the workshop with her, they sat down in the corner of the main workshop area. This was unusual, considering Stephen's preference for the empty far-end of the studio. Stephen was quiet, which was a stark contrast to his usual, hyperactive self. While I showed the OT how to mix a black colour acrylic, Stephen was staring out of the windows, looking out at a sunny Glasgow.

The OT accompanied Stephen to the workshops three times. The third time I watched from a distance as the OT pulled tutor Ruby aside and spoke to her in a hushed tone. Then the OT packed up Stephen's works, carefully rolled up and wrapped in newsprint by tutor Eilidh. She left the studio in a hurry, Stephen dragging himself two metres behind her.

We all learnt that the studio had pulled Stephen out of the workshops from Lesley, who sent an email around in the following morning. There was a sense of grief in the air among the staff in response to the news because no one got to say goodbye to Stephen, and there was nothing that the studio could have done to appeal the hospital's decision. In fact, Project

Ability was instructed to contact the hospital if Stephen still tried to show up at the workshops.

Later, Lesley told me that the hospital thought the workshops were a high risk environment for Stephen. “It was high risk in that they couldn’t support him,” she clarified. “We got into a sort of tussle about that. They said we couldn’t address his needs, and we said, ‘You’ve got to be joking, you can’t address his needs!’ In the end, there was no way they were going to give him the support that he needed, so it was high risk. He was put into a high risk situation towards himself. He was starting to really take risks, he started doing things that he knew he shouldn’t be doing,” Lesley summarised Stephen’s situation.

What transpires from these events are two different, but related understandings of what constitutes a risk. The hospital found the workshops a high risk environment. What they meant by that was that the among the art materials, there were sharp objects (scissors, box cutters, and knives), heavy machinery (press print), and materials toxic to human ingestion (basically all paint materials). All these posed a potential danger of Stephen injuring himself or causing damage in the equipment. Lesley did not deny that the studio environment carried risks, but for her, the risk emanated from a lack of support Stephen received. If Stephen had a support worker accompany him to the workshops, there would have been a lower chance of him being injured by inappropriate use of equipment. Lesley suggested that the mere presence of a support worker would have made Stephen less likely to do something that could potentially hurt him. Yet, it was clear from the beginning that the hospital could not provide Stephen with a support worker because he did not qualify for the level of support bracket that could afford him one.

///

The tutors and the support workers often raised concerns about not having the time and resources to provide adequate support for the participants. A reason many of them mentioned was the increase in their workload. Like the staff at Project Ability, many support workers felt that while the number of their clients increased, the number of staff did not. Subsequently, individual support workers became responsible for an increasing number of clients, while the length of time they could spend with each client grew shorter. At the studio, some participants shared a support worker with one or two other people. On top of that, support workers often spoke about the intensification and increased precarity of their work: their complaints about the long, unsociable, unpaid hours of work, low wages, endless paperwork, and little training, reflecting the general experiences of support workers in the UK (Cunningham and James, 2014).

These experiences speak to the two trends in social care provision I discussed earlier: an increased shift from social to individual accountability, and the responsibilisation of care built into the personalisation framework. Social care provision has been undergoing this shift from the early 1990s, when services were privatised in order to improve the competitiveness, efficiency, and accountability under the new public management agenda (Baines and Cunningham, 2015). New bureaucratic procedures were introduced: afterwards, support workers were expected to account for every single minute of their time on support, including all the activities, the money spent, the medication dispensed, the appointments made.

Increased individual accountability and responsibility, coupled with the underfunding of support work can produce unsettling care practices: Kenny’s example clearly demonstrates this. Kenny, whom I have written about in previous chapters, is a quiet and tall man with significant learning disabilities and autism. I learnt from Connor, Kenny’s support worker that although Kenny lived in supported accommodation, there was no one staying with him overnight. Instead, Kenny’s support organisation equipped Kenny’s flat with a camera that watched his stairwell and his front door, and his garden with a geofence. In addition, Kenny wore an electronic tag with a GPS tracker. This meant that the staff knew at all times whether Kenny is in his flat.

"It's sold as his independence has been improved, because he's spending time on his own," Connor said, "But never once have they ever asked him. I have asked him, 'Would you prefer me to go home, or to stay?'. And he said he would prefer me to stay because he likes company."

Kenny's overnight support (or the lack thereof) operates on the same logic as Stephen's removal from the workshops. Kenny is considered to be vulnerable to harm and injury if left unattended. Because Kenny requires help with navigating the streets safely, one of the biggest concerns is that he would – for some reason – leave his flat unaccompanied. There are two potential solutions to this problem: either pay for a support worker to stay with Kenny overnight, or put a technology-assisted surveillance system in place. From what Connor said, Kenny preferred a person staying with him because he liked company, and he got along well with his support workers. However, Kenny's support organisation opted for the surveillance system, which was arguably a more cost-effective solution.

Although this likely contributed to Kenny's experiences of isolation and loneliness, as well as to the devaluing of the care relationship he had with his support workers, it was portrayed by the care organisation as enabling Kenny's "independence". The extent to which this decision fit with the independent living agenda is questionable: Kenny was never offered choice and control over how he preferred his safety was ensured. Instead, his independence was framed as him being on his own, without taking into account his preferences and wellbeing. All this demonstrates that ideals of independence and responsibility are coupled with a lack of support, the impetus to minimise risk to the individual leads to care practices that deny people with learning disabilities engagement and leaves them socially isolated.

Responsible subjects

Ideals of independence and responsibility are not just top-down processes that policymakers "force" onto people with learning disabilities and their care providers; they were introduced at the demand of the disabled peoples' organisation to begin with. Although a recent study with representatives of these organisations expressed a sense of frustration and loss of ownership because they were not adequately consulted in the development of the related policies (Pearson et al., 2020), many of the support workers and participants I met continued to endorse them.

Participant Anna, a woman in her late thirties with long black hair, made her goals very clear to me, as I was helping her to set up the projector, so she could trace the outlines of a photo of a tiger. Anna was new at the workshops. She told me that her support worker had signed her up so that she could spend time with people.

"I need to talk to people if I want a job," Anna said.

"And do you want to have a job?" I asked her.

"Yes, of course," she replied.

Before joining the workshops, Anna had worked in several in charity shops as a volunteer. She had been offered to work at the tills, but she had to decline because she was "bad with numbers". She was not sure what paid employment opportunities were there for her, if any, but she knew that having voluntary work experience and social skills were essential – or so she was told by her support worker.

"What's your dream job?" I asked her.

"Pottery, or something creative," she said after some thought.

Anna was not sure if she was coming to be back for another series of workshops. She told me that one of her acquaintances was trying to get her an unpaid position at a shop, which would change her schedule and available support hours. She told me that she would not be able to work a full time job anyway because any extra income would interfere with the financial support she received. Nonetheless, Anna tried to rely on her support workers as little as possible. She was proud of being able to travel to the workshops independently. “I told my support I didn’t need her,” she told me.

I spent much time with Anna during the block of workshops she attended. She continued working on her tiger drawing. We also made a lavender glazed pot, which was fired in the kiln after the block had ended. The pot came out of the kiln in an excellent condition: a finely detailed work with a smooth and well-saturated layer of glaze. Anna never came back to pick it up – I gathered, she was offered that volunteer position she told me about.

Initially, I was puzzled by Anna’s aspirations. I thought that the workshops offered her free materials and professional help with pursuing her self-professed passion, pottery. Yet, Anna was ready to prioritise an unpaid, menial job because it propelled her sense of independence. Similar to Anna, some of those with mild learning disabilities had experiences of unpaid employment. These work placements usually ranged from helping out in charity shops, to making tea at food banks, to stacking shelves in the supermarket.

These participants were aware that they were not being paid for their work. Some also had little illusion of what they could do. “These are the only jobs that I can really do, packing up shelves,” participant Colin said while smoothing the edges of his clay gargoyle with his thumb. His half-moon glasses slipped down to the tip of his nose. “I’m no good at computer works. If push came to shove, well, packing shelves is the only job I can do. And sweeping the roads.” Colin paused to check on his clay figure he had been commissioned by the studio. His artworks were among the best selling items in the shop. Indeed, Colin was well-known among the Glaswegian art scene as well as learning disability scholars. The staff at the workshops all thought, had Colin been given appropriate support, he could have gone to art school.

What I aimed to highlight with Anna’s and Colin’s example is that ideals of independence and responsibility are not forcefully imposed on people. The drive to gain employment, social skills, and independence are not simply levied onto participants at the workshop. Quite the contrary, they are constitutive of participants’ desires, as they are endorsed, internalised, and inhabited through the everyday activities (Rose, 2001; Rose et al., 2006). But again, it bears repeating that without support, participants are left to pursue these aspirations through unpaid menial jobs that are not necessarily fulfilling, instead of spending time on activities they enjoy, like making art.

///

So far, I have discussed the idea of independence in relation to the impetus to protect individuals with learning disabilities from harm and exploitation, especially when service provision is strapped of resources, yet are made responsible for participants’ safety. I demonstrated that without adequate funding for personal support, supporting people’s independence while simultaneously minimising risks around them often meant that they were denied engagement with people an in activities they found valuable. Although policies around independent living caused disillusionment among many of their early proponents, these ideals continued to shape their aspirations many people with learning disabilities.

In the upcoming section, I will contrast this framing of independence with the workshops’ approach to independence. I discuss how Project Ability strikes the balance between independence and risk in relation to the level of support they are able to provide.

Independence and the obligation to engage

Recall Stephen, whom the hospital withdrew from the workshop because it perceived the studio to be a high risk environment for him. I will now examine how support can minimise the risks of harm and injury while simultaneously enabling his engagement with his environment. I will further the expand on this approach by examining how framing independence and risk as an obligation to engage manifests in the studio environment.

The first time I worked with Stephen, he wanted to redecorate an old wall clock he got from a charity shop. He had already asked Luke, the receptionist, to print him a round Costa Café logo to use as the new face of the clock. When I sat down next to Stephen, he handed me a small scalpel, and asked me to remove the old face – thin paper glued onto plastic – so he could reuse it.

I was just getting started with peeling off the paper with the scalpel when Stephen snatched it out of my hands. His hands shook from impatience as he jammed the scalpel underneath the paper. “No, no, no, don’t do that,” I said to him in a rush of panic. I tried to suggest that he held the scalpel closer to plastic surface and work his way from the outside in. He shrugged me off. I watched as the paper face shred to pieces under Stephen’s scalpel.

Stephen looked at the shreds in front of him for a couple of seconds, as if to evaluate whether any of it was salvageable. He seemed to have decided that it was not, as he brushed the shreds aside, stood up, and headed towards the clay room. By the time I caught up with him, he had already rolled out the clay: he was going to make a clock. I pointed out that the clay was too thick, which meant that it ran the risk of splitting when fired. Stephen did not let me finish the sentence. He waved in dismissal, and told me it was fine. He then proceeded to scrape out the clay from the centre of the plate to fit in a square plastic dial he took out from a charity shop clock. Instead of measuring the size of dial and calculating the potential shrinkage of the clay, Stephen drew a square shape that resembled a tired trapezoid. Exhausted from following Stephen around, I was not quite sure how to convey these complications to him. “Just, hold on a minute,” I said, trying to make him slow down, so I could catch up with his pace.

That was when Bruce, the studio technician entered the clay room. Bruce, a tall lean man in his 40s, always carried an air of quiet sternness around him that felt daunting for most volunteers, but did not seem to register with the participants. Bruce noticed that Stephen was working with clay, and sat down next to him. He pointed at the square hole Stephen scraped out, and said that it would shrink in the kiln. Stephen considered it for a moment, and then asked Bruce what he could do about it. Bruce pulled out a ruler, and explained the proportions to Stephen while measuring the dial and outlining the space it needed. He then gave Stephen an encouraging smile, stood up, and walked out of the room, leaving Stephen to work on it at his own pace.

The difference between the way Bruce and I supported Stephen was that, unlike Bruce, I saw Stephen’s haphazard behaviour as a risk, and my first instinct was to focus on telling him what *not* to do in order to minimise potential damage to the artwork and material. Bruce, on the other hand, engaged with the artwork by giving Stephen suggestions that encouraged rather than further suppressed his artmaking. Whereas my attempt to help Stephen resulted in me trying to prevent him from certain actions and behaviours, Bruce’s approach encouraged Stephen’s engagement with the material.

As someone who has had his behaviour restrained and suppressed in hospital care, Stephen would sometimes misread the tutors offering him help as an attempt to control him. Later that day, tutor Eilidh said that she had had a minor fall out with Stephen who had tried to use the print station alone, and was told off by Bruce, the technician. Apparently, when Eilidh raised the issue of using the print station unattended with Stephen, he snapped at her, saying that Bruce had already scolded him, and that he did not need Eilidh to do the same. However, Eilidh was not concerned about him doing damage to the equipment. Her concern was that he might use the wrong paint and his picture would not come out right. “I told him that he should have just come and get me and I would have come and helped him,” she said. “Maybe we should tell Stephen to work in the main studio space,” Eilidh said to tutor Ruby, who just shook her head at the suggestion: they had done it many times, and he had never listened. “Yeah, but it’s kind of our responsibility to know where he’s at and what he’s doing,” Eilidh replied.

Approaching participants in ways that encourages them to engage with the environment does not eliminate risks, nor am I suggesting that it erases potentially disruptive behaviour. One may catch a particularly gruesome reminder of that by glancing at older participants’ missing fingertips, which they lost during the time they stayed at long-stay hospitals where they worked with hacksaws, knives, and axes without support. Although no one has lost a limb in the studio, some participants acted in ways that would be considered disruptive outside the workshop. For instance, some disperse their energy by running up and down the studio space. Some find it hard to sit in one place for two hours, and may wander off and out of sight of their support workers. The workshop staff emphasised that it was important to provide the space and freedom for participants where they can do that, as a way to counterbalance other areas of life where participants were being constantly told what they could *not* do.

However, things happen, especially when the workshop is busy and the tutors’ attention is spread thin. For example, on one occasion, participant Gregor left the building without anyone realising. Although the door to the studio requires the receptionist to buzz people in and out, and everyone is required to sign a registry, it may be difficult to keep track of it when there are a lot of people entering and leaving at the same time.

Gregor is a mild-mannered, elderly participant. On the day of the incident, to give Gregor space, his support worker decided to wait for him in the tearoom and to leave him to work alone at the desk – a decision that the tutors supported. It was an unusually hectic day at the workshop – meaning that there were a lot of participants with high support needs who demanded the tutors’ assistance and attention – and the staff only noticed Gregor’s absence at the end of the workshop. That participants are not always at their desk is normal – people are free to wander around the studio floor. Gregor’s coat was still hanging on his chair, which probably led the tutors to think that he was still in the room.

The anxiety among staff members and support workers grew steadily as they searched the floor and the building for Gregor. Eventually, the building security was notified: the CCTV footage showed Gregor leaving the building and heading towards the central train station, from where he usually took the train home. Since he left his wallet in the studio, he was not going to be able to get too far, and indeed, it was on his usual platform where the support worker caught up with him. After the incident, Gregor did not attend the workshops for several months: his care provider decided to pause his attendance, due to the shock Gregor had experienced.

This incident illustrates the difficult dilemma of whether to prioritise participants’ safety with close surveillance, or grant them freedom and accept an element of risk. Because the tutors had to attend to multiple participants at once, they could not pay constant attention to Gregor’s whereabouts. One way of ensuring Gregor’s safety would have been for the support worker to sit next to Gregor during the workshop. Note that the support worker’s presence would have only served to keep an eye on Gregor, not to assist him in making art, as Gregor usually worked independently. Both the support worker and the tutors felt that having someone watch over Gregor would have made him feel restricted; all parties felt that Gregor would have appreciated some space. The tutors decided to take the risk and allow Gregor to fully enjoy his time at the workshop, which marks the difference between the workshop's attitude to risk, as opposed to a hospital's or a care organisation's approach, which I discussed in the first half of this chapter. It was fortunate that Gregor did not get hurt; sadly, however, the incident resulted in Gregor not being able to attend the workshops. The ideal solution would have been addressing the staffing shortage at the workshops. The actual solution was withdrawing Gregor's attendance and denying him engagement with the activities he liked.

The workshop's approach to allowing participants' space is evident in the way they let participants use art materials. More minor incidents occur on a more regular basis, most of them art-related, such as participants spilling paint, breaking a needle in the sewing machine, breaking brushes, and generally, damaging various tools and equipment. In particular, pens do not have a long life expectancy in the workshops – the staff's reaction is that these materials are there to be used.

Lesley, the director made it clear to me that the studio was not going to change its approach to risk. "People are not stupid. They are not going to do stupid things," she said, implying that accepting an element of risk was part of treating participants as capable human beings. "We are fully aware that things do happen, but you cannot control everything, and I think there's an expectation that there will be paint, and there will be materials," she continued. We watched Dermott, an elderly participant slap paint over a collage that was made out of so many layers of crunched up paper that it resembled a statue more than a painting.

"We have not had anybody eat paint for years," Lesley said eventually. "It has been a thing occasionally, but not for a very long time."

///

So far, I examined the workshop's approach to independence, and argued that the staff preferred to take on an element of risk and allow participants to engage with their environment as freely as possible. I argued that because of staff shortages, it was not always possible to provide participant with the support necessary to minimise risk. In the following section, I will describe what promoting someone's independence and managing risk looks like if there is adequate support.

The subsequent episode occurred during the annual festival of the Highlands Games, which I attended with participant Colin and tutor Ruby. Colin is a man in his early fifties who has grey but lush curly hair, and attends the Friday workshops. Colin has mild learning disabilities: he can travel alone, but only if he is familiar with the route. Project Ability arranged for Colin to visit Ruby's studio, which was located in a coastal town in the West of Scotland. Their art collaboration happened to coincide with the Highland Games, which took place next to Ruby's town. The Games are essentially a festival celebrating everything associated with the Scottish and Celtic heritage: it is a day filled with the most unapologetic indulgence in tartan, bagpipes, haggis, Highland dance, continuous daytime alcohol consumption, and a game in which Scottish people compete at throwing a variety of things, including a six metres long caber weighing 80 kilograms.

I was greeted by Colin and Ruby's husband, Malcolm at the end of my two-and-a-half-hour journey from Glasgow. Colin was out of his general painting gear and high-visibility vest I was used to seeing him in the studio: this time he seemed to melt into the crowd with his suspenders, tweed trousers, and bushy hair and beard. The main street of an otherwise quiet fishing village was bustling with the carnival crowd. While Colin seemed exuberant walking down the sunny main street, proudly wearing banners of the Scottish St. Andrews'

Cross, Malcolm, a generally laid-back jazz musician who sported a flat cap and a goatee, seemed tense. He explained to me that tutor Ruby was going to join later, and until then, he was responsible to keep an eye on Colin. Malcolm's concern was that Colin could not read, write, and was so averse to technology that he did not own a mobile phone – this meant that if Colin got lost, it would have been very difficult to find him. Although Malcolm did not tell Colin to not wander off, neither did he encourage Colin to go and explore.

Malcolm only relaxed once we set camp on the grass and tutor Ruby joined us. Ruby was not particularly fazed by the crowd. "Colin must be loving this," she whispered to me, and handed him her tablet – an expensive piece of technology – so he could go around and take pictures that could serve as inspiration for their artistic collaboration. Before setting Colin loose, Ruby explained to him how to use the tablet to contact her, and she also showed him all landmarks by which he could orient himself and find his way back to our location: opposite the Highland dance stage, behind the tent with the home baked cakes, left of the food trucks, right next to the green family tent. Colin took in Ruby's words and took off.

The way Ruby approached Colin's activities reveals an ethics of engagement that enabled Colin to explore the Highland Games, without a phone or a map, amidst a large crowd. Instead of deciding on whether an activity was too risky for Colin to engage in or not, Ruby asked, what support did Colin need to enable his free interactions with his environment? This approach requires time, attention, trust, and resources. Ruby could do this at the Highland Games because she did not have other participants to attend to and could solely focus on helping Colin orient himself. She also had the material resources to provide him with a piece of technology he could use to contact her. Ultimately, she treated Colin as an individual who had the capacity to understand and follow her instructions. Of course, there was an element of risk in her approach: Colin could have lost the tablet, or he could have got lost in the crowd. Ruby did not eliminate these risks, but minimised them in ways that encouraged Colin's engagement and provided him support.

It was a productive approach: it enabled Colin to experience the Games, exercise independence, follow his interests, which then generated further engagement with artmaking. The Highland Games inspired Colin to paint a series of prints for coasters and plates, using the photos he took as references. The pieces were exhibited in at the studio galleries.

///

The tutors' obligation to engage with participants does not equate with saying yes to everything. In the workshops, this means facilitating participants' desires, and negotiate a way in which these desires can be carried out to the highest technical and aesthetic standards given the practical constraint, may that be the participants' physical capabilities, enjoyment, safety, and available materials. Sometimes it entails saying no to some ideas and finding alternatives. This can be a particular kind of challenge when working with someone like Stephen, whose has a short attention span and can be highly impulsive.

Here is an example of tutor Joanna negotiating with Stephen.

Stephen was rummaging through a box looking for a grey acrylic, flinging tubes of paint he did not need onto his desk. I suggested he mixed the grey paint instead of using one straight from the tube, but he did not pay attention to me. I felt a sense of relief when Joanna – a painter by training – walked up to Stephen and made the same suggestion. Some blue, brown, red would make the grey more interesting and vibrant, Joanna told Stephen. Stephen considered it for a split second, then shrugged us off.

"Nah, I can't be bothered," he said and delved back into the paint box.

Joanna glanced at the unstretched piece of scrap canvas Stephen had fetched from the recycling station. She asked Stephen if he was going to prime the canvas; her voice was slow and hesitant. Priming entails adding a layer of primer – usually gesso – over the canvas before painting. The primer protects the canvas from disintegrating with time. It also preserves the colour of the paint and prevents the canvas from soaking up the acrylic. It is an essential, if tedious process.

Joanna explained this much, but Stephen did not respond. Some PVA (water-soluble, transparent glue) would do, Joanna told him, in way of a concession.

“I don’t need to prime the canvas,” Stephen snapped.

“No, you do,” Joanna did not budge.

“I can’t be bothered,” Stephen said again.

Joanna insisted that it would make his painting better. After a few seconds, Stephen gave in, and Joanna fetched the bucket of PVA with a satisfied smile.

The exchange sparked my interest; many people, perhaps me included, would have given up and let Stephen get on with his work as he pleased. After all, one may have thought, Stephen had made his choice – letting him use pre-mixed grey paint on unprepped canvas counts as promoting his independence. Someone else may have emphasised Stephen’s self-determination, and left them him to his own device. Alternatively, they would have prevented Stephen from painting, if it was seen disruptive or undesirable, such as using up too much paint by painting on unprepped canvas.

Not Joanna though.

Her interaction with Stephen reflects the crux of what is meant by supporting independence in the workshops. It is an obligation to engage with participants, the creative process, and the artwork. This approach necessitates an ethics of engagement in which any potential undesirable behaviour is neither ignored nor suppressed; instead, it is addressed through negotiation, care, and consensus.

///

In this section, I examined Project Ability’s approach to risk and independence. I argued that the primary aim of the workshop was to encourage participant engagement with the creative activities and with their social environment. The studio’s starting point is that people are capable individuals whose space should be respected, instead of limited and surveilled. I argued that this approach was productive in that it enabled enjoyment and exploration, but it also carried the risks to participant safety. Project Ability minimised this risk by increasing support for participants; however, this was increasingly difficult due to staff shortages.

Conclusion

The concept of independence permeates provision for people with learning disabilities. In this chapter, I examined what was meant by independence in the context of risk management and care responsibilities, and how it was supported or hindered.

I contrasted two approaches to promoting the independence of individuals who are considered vulnerable: one in which the risk was seen as inherent features of the environment, and the primary way of managing it was by removing individuals from that environment. I argued that this approach often relied on control and surveillance, and ultimately denied individuals engagement. The second approach understood risk as a function of support, which carried an obligation to engage. I discussed the diverse ways in which this obligation manifested in the way tutors granted participants space in the studio and demonstrated care for participants’ artwork and the art making process.

At the beginning of the chapter, I cited Fyson and Kitson's (2010) "unanswerable" question on how much granting people independence was worth the risk of exposing people to harm, injury, and abuse. Having discussed the ways in which tutors supported participants, I suggest to reframe this question as: what kind of support is needed to enable people's independence without exposing them to harm, injury, and abuse? As I have argued throughout the chapter: increased independence does not necessitate increased risk, given that individuals are provided with adequate assistance.

From the examples I cited in this chapter, this comprises, first of all, personal support: support workers and tutors, who can assist individuals with difficult tasks, and identify and address potential risks to their wellbeing. The nature of the personal support is also important: instead of approaching participants as incapable individuals who must be surveilled, they need to be treated as capable people whose personal space need to be respected as much as possible. This means respecting their desires and facilitating their pursuit to the best of one's means. In the context of artmaking, this entails taking seriously the participants' creative vision, and helping them realise that to the highest possible standard.

This can be challenging for tutors and support workers in the context of shrinking resources. Project Ability seemed to have adjusted by taking on more risk. For other service providers, limited support, coupled with and enabled by an individualised understanding of personal responsibility often resulted in participants being denied engagement altogether, in the name of risk management.

Western liberal ideals of citizenship operate under the assumption that citizens are independent individuals who have the freedom and agency to deliberate over their lives. However, ongoing social anxieties surrounding independence indicate that in practice, people with learning disabilities are not quite regarded or treated as equal citizens yet. Furthermore, there is a danger that unless these tensions are resolved, this remains the case.

In my second chapter, I discussed the works of prominent learning disability scholars who, writing from an ethics of care perspective, have been making the case for independence as an ideal to be put to rest, and for citizenship theories to elevate relationality as the fundamental organising principle of society (Carey, 2009a; Mol, 2008; Pols, 2016; Sevenhuijsen, 1998). While these works are important in reframing the debate around the citizenship of people with learning disabilities, independence continues to occupy centre stage in social policy, service provision, and disability activism; hence it is constitutive of the aspirations of people with learning disabilities, and shapes the way their support is framed and organised. Exploring how Project Ability navigates the tensions around independence demonstrates that people with learning disabilities are capable of being independent. Additionally, by examining good practice and promoting an alternative conceptualisation of what independence means, it contributes to addressing some of the social anxieties that continue to exclude people with learning disabilities from being regarded as equal citizens.

///

So far, I have discussed choice and independence. These are primary virtues of liberal citizenship, which assumes that all individuals are inherently rational beings capable of self-deliberation. My aim has been not only to negate these assumptions, but to show that although in theory these ideals are exclusive of people with learning disabilities because they were conceived without considering their interests, in practice, they guide what people do and desire. Instead of simply arguing that these ideals are exclusive, my focus was on how individuals with learning disabilities and those who worked with them interpreted and negotiated these ideals. Additionally, I have shown that both choice and independence are can be seen as capacities that people with learning disabilities can develop, given that the material conditions are satisfied and they are provided with adequate personal support.

In the next two chapters, I will examine the relational aspects of citizenship; after all, theories of citizenship are propositions of how individuals can (and should) live together as a society. This requires examining how and why people engage with each other. Although relationships are an important and often discussed topic in learning disability policy and within the scholarship, what they mean for people with learning disabilities, especially for those with significant impairments, is still little understood.

The following chapters aim to address these gaps.

Chapter six:
Sociality

Introduction

Jamie was in a good mood. While I was sorting out the fabric marker pens, Jamie told me about the time he first came to Project Ability at the age of nineteen – that was fifteen years ago. Before Project Ability, he had attended a day care centre.

"That's where I met Mr Reid," Jamie said.

"Anthony Reid?" I asked, and pointed at the far end of the studio where Anthony, another participant, was sitting.

"Yes," Jamie nodded.

"Are you friends?" I asked. I was surprised; I had been volunteering at the studio for almost a year, and I had never seen Jamie and Anthony interact with each other.

"Yes, Mr Reid is a pal," Jamie said without taking his eyes off the concentric circles he was painting with ink on fabric. "Isn't that right, Mr Reid?" Jamie shouted across the room, in Anthony's direction.

Anthony looked up, smiled, gave Jamie a thumbs up, and continued drawing.

Jamie told me that he and Anthony used to live together in a group home. He said that they used to put on music and dance in the living room. "We had a good time together," Jamie said and turned towards Anthony. "Isn't that right? We used to dance!" Jamie asked Anthony.

Again, Anthony smiled and nodded, and returned to his art.

Jamie now lives with his mother in the west end of Glasgow. It is easy to spot him on the busy street leading up to the studio from his long strides and slightly hunched posture. Generally, Jamie is in a foul mood when he arrives at the workshop. He paces around the studio, complains to Luke, the receptionist about the commuters on the train, calls the female tutors and volunteers "witches", and then he goes and sits at a desk behind the drying racks, which is out of sight of the main workshop area.

"Jamie takes an hour and a half to settle," Lesley, the director noted, "And when he leaves, he's got to prepare himself."

Jamie's former roommate and apparent friend Anthony, on the other hand, is a very quiet man in his early thirties. He is always accompanied by a support worker. Anthony does not talk, unless someone asks him a question, and his replies are usually short, blunt, and muffled. He always sits at a single desk in the corner, and makes art with his headphones on. Unlike Jamie, who is loquacious, Anthony rarely speaks to anyone at the workshop.

“So do you and Anthony ever hang out outside the studio?” I asked Jamie.
Without looking up, Jamie replied, “No.”

///

Jamie’s friendship with Anthony surprised me because neither of them appeared particularly sociable at first. Anthony rarely seemed to acknowledge anyone’s presence in the workshops. I had never seen other participants approach him or speak to him, nor had I seen him engage with other participants. Jamie mostly interacted with staff members and support workers; because I did not see him converse with other participants, I surmised that he was not interested in their company. What informed my initial impressions was the assumption that people like Jamie and Anthony socialised the way as people without learning disabilities did, such as by exchanging pleasantries, having conversations, making plans together, and spending time with each other within and outside the workshops. Because I had not seen Jamie and Anthony do any of these, I had (wrongly) concluded that they could not be friends.

However, as I started attending the workshops, it quickly became apparent to me that participants interacted with each other in more diverse ways than what I had expected from my normative preconceptions. With the exception of a few participants, there was little small talk, exchange of pleasantries, or conventional conversations in the workshops. This was because, as I have discussed previously, many of the people I spent time with had very little verbal language.

Up until my conversation with Jamie, it had not entered my mind that he and Anthony could have a history and friendship. My confusion speaks to a broader issue: to this day, there is very little research about what sociality – friendships, relationships, social life – means and looks like for people like Jamie and Anthony. The sociality of people with learning disabilities has been central to promoting their citizenship. However, the handful of studies that exist on the social lives of people with learning disabilities focus on individuals with mild impairments (Mason et al., 2013); the literature offers little insight on the social lives of people with significant learning disabilities. Therefore, there are plenty of questions that are yet to be addressed, such as: what does sociality look like for people who often have very little verbal language, who may appear disengaged from their social environment, who need extensive support to socialise? What are valuable social interactions for them, and how can they be supported to engage in these interactions?

These are the questions that this chapter examines. I first contextualise these questions by discussing the social policy discourse on “social inclusion”. Then, using ethnographic examples, I examine the material and personal support that is conditional to the social lives of people with learning disabilities. I also highlight the different, non-verbal forms of interactions between participants of the art workshops, and discuss the ways in which these interactions are supported, cultivated, or hindered by the people working with them.

The challenges of social inclusion

Social policy preoccupation with the social lives of people with learning disabilities have been defined by the “social inclusion” agenda. In the UK, social inclusion emerged as a key issue since the closure of long-stay hospitals, and remains a central concern to social policy and service provision to this day. Although the term has multiple meanings, broadly speaking, social policy uses the term in reference to access to activities and relationships with non-disabled peers (Bates and Davis, 2004). Ideologically, social inclusion policies draw on the principles of normalisation (Wolfensberger et al., 1972), which advocates for people with learning disabilities taking up non-segregated, “ordinary” activities to counter the past practices of institutionalisation. In this section, I examine the way social inclusion policies envision valuable social interactions, and I discuss their impact on the social lives of people with learning disabilities.

One of the main drivers of social policies are studies that consistently show that people with learning disabilities – compared to their non-learning impaired peers – have fewer friends, are more likely to experience loneliness and social isolation (Department of Health, 2001). One survey revealed that only one third of people with learning disabilities was able to name a close friend (Scottish Government, 2013b). Other studies concluded that most people with learning disabilities only have regular contact with their family and staff (Forrester-Jones et al., 2006; Robertson et al., 2007), but lack a sense of belonging to the local community (Clement and Bigby, 2009; Verdonschot et al., 2009).

The 2001 governmental white paper Valuing People (Department of Health, 2001) has been particularly influential in setting the social inclusion agenda and in introducing subsequent changes to services. The solution that Valuing People proposed was to put forward services that encouraged people with learning disabilities to participate in the “community”, i.e. social life outside of care services. The underlying logic behind this proposition was that people with learning disabilities had poor social lives because they lacked the skills to enable their inclusion. To foster these skills, people with learning disabilities were encouraged and supported to partake in “ordinary” activities and interact with the so-called mainstream society. Policy and service provision set out to achieve this by increasing people’s choice and control over their housing within the community, skills development, and employability. “[B]eing around people encourages people with learning disabilities to develop their social skills,” the Scottish Government (2013b) proclaimed, “Developing social skills helps them make friends and to integrate into the community” (p.72). Social inclusion, both as a concept and as a policy driver has been extensively critiqued (Bates and Davis, 2004; Bigby and Wiesel, 2011, 2018; Burton and Kagan, 2006; Clegg et al., 2007; Hall, 2005). For the purposes of this dissertation, I focus on the critique about its assumptions on what comprises valuable social interactions for people with learning disabilities.

These policies operate on a kind of default principle that people with learning disabilities prefer to conduct their social lives the same way people without learning disabilities do. This assumption has led to the closure of day care centres, eliminated safe havens that protected people with learning disabilities from bullying, and the closures curtailed, rather than expanded, their social networks (Clegg and Bigby, 2017). Many of the services that were introduced under the social inclusion agenda prioritised individual-focused activities aimed at helping people improve their skills to aide their participation in the mainstream, primarily through independent living and employment.

On the other hand, it has been clear that mainstream society was not ready for including people with learning disabilities. To this day, very few of them have achieved employment and independent living. In fact, many parents and guardians see these as aspirations rather than realistic goals (Clegg et al., 2007). The push to move people from specialist provision into mainstream services did not reduce the higher rates of taunting, aggression, and hate crime people with learning disabilities are subjected to (Emerson and Roulstone, 2014). People with learning disabilities often report feeling intimidated and unwelcome, which causes them to avoid public spaces altogether (Hall, 2005: 200).

Prioritising goal-setting and skills development often comes at the expense of supporting people with learning disabilities in developing a sense of belonging because they do not foster nor value collective spaces and experiences (Hall, 2011). The activities promoted by policies foreground individual achievement instead of seeking to understand and promote meaningful interactions for people with learning disabilities. Johannes et al. (2017) cites a government funder, who aptly remarked, "Loading people on the bus and taking them to Tim Hortons [coffee shop] at 2 p.m. in the afternoon is not community inclusion" (p. 47).

These observations point to how social inclusion policies often mistakenly equate community presence with community participation (Clement and Bigby, 2009). People with learning disabilities have been geographically relocated from segregated institutions into the 'community' (meaning non-segregated spaces). But without examining what meaningful interactions look like people with significant disabilities, there is a danger that normative assumptions of their sociality will go unchallenged. This risks policies and services ignoring and discouraging alternative manifestations of sociality, like the friendship between Jamie and Anthony. The task is thus to highlight and document the diverse and non-normative forms of social interactions that make up the social lives of people with learning disabilities, and examine how these interactions can be encouraged and supported.

The material condition of social lives

The social lives of people with learning disabilities rely on extensive personal and organisational support. In this section, I describe the material support that needs to be in place for people with learning disabilities to socialise.

Aysha's example clearly demonstrates the expanse of support needed and the consequences of what happens when that support is taken away. Aysha is a woman in her late thirties who attends the art workshop on Tuesdays, goes to a day centre on Wednesdays, takes a walk in the Kelvingrove park and visits galleries on Thursdays, and once every fortnight she spends a weekend at a centre that provides day care. "I'm going on a holiday!" Aysha usually announces to me with exuberance.

Aysha is always accompanied by her support worker, Diana, a Mexican woman in her mid-thirties who works part-time while completing her PhD studies. Diana helps Aysha dress up and get ready for the day. They then go for lunch, coffee, and walks in the city centre. Aysha's long, thick, dark hair is always perfectly coiffed into a smooth pony tail, and her long-sleeved dresses that follow the rules of modest fashion often have an unexpected pop of colour, all of which showcases Diana's attention to detail.

I learnt from Diana that before they started working together, Aysha had had a bad experience with support workers, as a result of which her social life suffered. Although Diana was not aware of the full details, she knew that Aysha did not have any support for two years following her bad experience. This meant that Aysha was not able to leave her house for two years. With her support gone, so were her holidays at the day care, the art workshops, the bus rides, the walks in the park, and the coffee outings. She consequently suffered from depression, and was put on high doses of anti-depressants. Aysha became isolated and confined in her flat with the sole sources of contact limited to her parents and her two siblings, who all have significant learning disabilities.

Aysha's example highlights the material conditions of social life that people with learning disabilities face. To be able to engage in any form of interactions with people outside of their households, people with learning disabilities need personal assistance with organising their social activities, with getting dressed and ready to leave the house, and with navigating the streets and public transport safely. When Aysha's support was taken away, so was her social life.

Even when people with learning disabilities have a support worker (or they do not need one as independent travellers), they need communal spaces where they can safely socialise with others. For many of the participants, the Project Ability fulfils this function. The example of participants Colin, Alan, and Simon from the Friday workshops illustrates how.

Colin's and Alan's presence in the workshop is hard to miss. Although their hair has gone grey, they both exude a youthful energy. Colin typically enters the studio with long strides, his curly hair bouncing on his shoulders. His deep voice with which he says hi to everyone carries to the far end of the studio. Alan is more soft-spoken, but his smile gives the impression that he has just come back from having caused some sort of mischief.

Alan's and Colin's banter is part of the workshop they attend. When one of them is absent, other participants take note of the unusual silence. Their conversations cover a variety of topics, from pop-culture (Alan likes new films whereas Colin swears by old John Ford westerns), to the weather (Colin's exclamation of "What a miserable day", regardless of the actual weather, is mostly met by Alan's shrug), to politics (where they discuss the various ways in which humanity will cause its inevitable downfall). Simon, sitting in the background, follows their conversations with an occasional giggle, which does not go unacknowledged by Colin and Alan.

"Is that your girlfriend, Alan?" Colin teased Alan, looking at Alan's work-in-progress portrait drawing.

Alan did not answer.

In the back of the studio, Simon burst into laughter.

"Oh, what's so funny, Mr Simon Adams?" Alan snapped at Simon and threw his brush onto the desk with much theatricality.

Simon continued giggling.

"You watch yourself there, Simon," Alan retorted playfully. There was a quiet wave of amusement spreading among those witnessing the exchange.

Simon, Colin, and Alan do not see each other outside the workshops. None of them have extensive social networks. They are independent travellers and do not receive round-the-clock support. Alan was temporarily moved to supported accommodation when his mother was hospitalised due to an illness. Simon and Colin live alone in council houses. Outside the studio, Alan spends most of his time with his elderly mother and his older brother. Similarly, Simon is in most frequent contact with his sister and brother-in-law. Colin, on the other hand, is estranged from his siblings and parents, as he grew up in a long-stay hospital. The few social events they attend are those reserved for people with learning disabilities. They are not employed, do not partake in activities of their local community, and are not part of the "mainstream" society. Their interactions with each other are too precarious to be considered a long-term, sustainable relationship by social policy standards. Although their friendship goes back two decades, it could not be sustained without the workshops. Project Ability enables the friendship between them by providing them with an organised and institutional communal space where they are shielded from the potentially unpleasant interactions on the outside and their interactions can unfold in their own pace.

As I discussed in my first chapter, many of these communal spaces, including day centres, were forced to shut as a result of the significant cutbacks to social care funding during austerity. Advocates of personalisation saw the day centre closures as a positive outcome for service provision rather than a negative consequence of spending cuts: because many of these spaces were perceived by policymakers and proponents of independent living to evoke, in spirit, the segregation of long-stay institutions (Needham, 2014). Some of those who advocated for these closures envisioned a range of alternatives, such as smaller scale collectives and community hubs which would provide both personalised and shared activities and where service users were able to make collective choices (Needham, 2014).

However, no alternatives for socialising were put in place. Social geographer Ed Hall (2005) observes that the closure of these communal spaces also broke up friendships and relationships, and erased a sense of belonging that employment and independent living could not replace. Although the people with learning disabilities that Hall (2005) spoke to all lived in rented accommodation and/or were employed, they continued to experience what Hall refers to as the "double-bind" of marginalisation, meaning that they were excluded from and discriminated against in the spaces that were supposed to promote their social inclusion.

All this gives an indication of how precarious people's ability to attend at the workshops is: it depends on them receiving support with the practical tasks that prepare to leave the house, with travelling from their home to the workshop, and the existence of the workshop, itself dependent on governmental funding. If one element of the support goes missing, participants would not be able to make it to the studio.

What kind of social interactions should be supported and how?

Given that the material conditions are provided, there remains a question about the kind of interactions that people with learning disabilities find valuable and enjoyable. Social policy makes it clear that meaningful interactions are fostered through engagement in "ordinary" activities, like making art at the workshops (Department of Health, 2001; Scottish Government, 2000). This may well be the case; however, it is unclear how exactly engagement in these activities would help individuals "sustain friendships", a goal identified as "one of the greatest challenges faced by learning disability services" (Department of Health, 2001: 81). In this section, I examine the extent to which participants' engagement in the workshop contributes to their social lives. I do so *not* with the intention to evaluate whether or not the workshops are successful at fostering people's sociality. Instead, I focus on the types of interactions that the workshops encourage, contrast them with normative understandings of valuable interaction, and discuss the way they are supported or hindered.

One of the difficulties of discerning how partaking in the workshops develops and sustains relationships arises because many participants do not seem to initiate social activities (like attending Project Ability), and once they are at the studio, they do not appear to instigate interactions. To an outsider, many of the participants may come across as aloof, which may lead the uninitiated to question whether they enjoy being in a social environment at all.

An example is Dave, a young man with short blonde hair who just wants to sit in the corner and listen to Nick Drake. I learnt about Dave's background from tutor Joanna, who had known Dave from the hospital where she led art workshops, prior to either of them joining Project Ability.

During my fieldwork, I perceived Dave as someone who seemed uneasy about interacting with anyone but Joanna, which made me feel reluctant about approaching him. In the workshops, Dave spent only half an hour working on his art. The rest of the time, he wandered around the studio, looked at the DVD shelf, or sat at his desk, located at the corner of the studio, and watched the other participants. The first thing Dave usually did upon his arrival was to fetch the studio's old cassette player and put on Nick Drake' s music. Since he did not use headphones, his desk was always surrounded by a cloud of melancholic fingerpicking.

"Dave always sounds exasperated when I talk to him," Joanna said. "'You again! Leave me alone! Go away!'," she imitated Dave's grimace. "But you can actually see a smile in the corner of his mouth," she added.

Joanna told me that Dave had depression, and barely left the house during the day. She felt that he preferred to stay in and away from the bustle of the outside world. In this context, the fact that Dave would make the effort to attend the art workshops – to leave the house, get on the public transport, and stay among people – meant that he was reaching out.

When Joanna left the hospital where she had worked to tutor at Project Ability, Dave's mother contacted her, asking if Dave could join her. "His mum said that he would only join the workshops that I held," Joanna said. "But she also said that Dave would probably not do any art."

"And then one day," Joanna continued, "I received a Facebook friend request from Dave." Joanna explained that she usually did not accept friend requests from participants, but she took an exception with Dave, partly at his mother's request. "He posts Nick Drake songs on my Facebook wall at Christmas," Joanna said with fondness.

It was through Facebook that Dave learnt about an exhibition that Joanna curated, which took place during a period when he was taking a yearlong break from the workshops.

"He came to the opening," Joanna said simply. "His mother told me that he wouldn't miss it."

"That's really nice," I said.

"Yes, it was," Joanna agreed, "But of course he didn't say a single word to me during the whole event."

"But he showed up," I said.

"He showed up," Joanna nodded.

Like other participants, Dave did not appear particularly social at first; quite the contrary, he seemed to prefer not interacting with people. However, Joanna understood that just because Dave did not seek to converse with those around him (including Joanna), it did not mean that he was antisocial: just the opposite, Joanna recognised that Dave to exerted active, ongoing effort just to be in the workshop. Note that she did not push him at any point to interact with her; instead, she let him engage with her on his own terms. It is important to highlight here that the there are many participants who may never want to interact with others; this may be particularly the case with participants who are on the autism spectrum (Spain et al., 2018). Like Dave, no one is forced to engage in interactions.

Many support workers approach the participants' social activities like this: acknowledging that sometimes, just being around people counts as an achievement, which needs to be maintained and developed with the support of those working with them. One support worker said that the participant she worked with went to the gym once a week to train on the cross-trainer for two and a half minutes. This may seem pointless to an outside observer, but actually demonstrates tremendous willpower from the participant. From this perspective, the simple act of being around people becomes sociality.

///

Social policy is rather unclear on the kind of relationships that are supposed to develop from social participation. Leaving this unexamined is a significant omission because some of the interactions may not be obvious for people who are unfamiliar with the individual with learning disabilities. In the following, I describe these unfamiliar, seemingly unintelligible, quiet, and fleeting social interactions, which, I argue, constitute a valuable part of the participants' social lives.

At first glance, the workshops can appear somewhat lacking of social interactions. There is usually some light chatter among the support workers, and between tutors and participants, but there is very little verbal communication between the participants themselves. Although it is easy to mistake their lack of words and conversation for disengagement, I learnt that there were many other ways in which they could connect with their social environment.

Helen told me about the ways in which the person she supports, Stewart, exemplifies this. Helen is a short, quick-talking woman in her early fifties with a deep, raspy voice and a no-nonsense attitude. Stewart, on the other hand, is a tall, thin man in his early thirties, who carries himself with measured steps and a constantly sombre facial expression. Stewart did not appear particularly sociable to me at first. He does not talk to anyone at the workshop; he is selectively mute. He typically works in silence, and he interacts with the staff inasmuch as the interactions concern his art.

I learnt from Helen that Stewart actually took great pleasure from being around people. It turns out, Stewart had a pretty brash sense of humour: he loved rowdy banters and he cracked a small smile each time someone around him was being rude. “He had a big laugh today on the train because some neds [ill-mannered young men] were swearing at each other,” Helen said. “One was going, ‘Fuck sake, big man!’ And Stewart was pissing himself with laughter.”

Had Helen not drawn my attention to Stewart’s quiet amusement, I might have never noticed. However, once I understood that there were many ways in which people could connect with each other, many of the complex and long-running friendships in the workshops revealed themselves.

Take Jon and Kenny, for example.

Jon and Kenny both attend the same afternoon workshop, and they usually sit next to each other. Kenny rarely talks, and when he does, it is in one-word responses to questions. Jon, on the other hand, is happy to strike up a conversation with participants, support workers, and volunteers alike. His friendly demeanour is reflected in the wrinkles around his eyes that make him look like as if he is always smiling. Jon also demonstrates eloquent enthusiasm when it comes to the two topics he likes: Barack Obama and Pope Francis. While Jon talks to Kenny and Connor about politics and his volunteer work at a food bank, he occasionally turns to Kenny.

“Isn’t that right?” Jon tapped Kenny on the shoulder after a discussion with Connor about Northern Irish border politics.

Kenny let out a grunt that sounded he agreed with what was being said.

“Ah, good man,” Jon laughed, delighted at Kenny’s response.

Jon often talked about his affection for Kenny. “Kenny is a lovely guy. Lovely,” Jon said to me on several occasions. “I would love to meet up with him.”

I learnt from Connor, Kenny’s support worker, that this was usually the dynamic of Kenny’s friendships. Kenny has one other friend he meets up with outside the workshop – another man with a learning disabilities. Their friendship was initiated by their support workers, who noticed that they shook hands, and surmised that they got along. Since then, once a week Kenny and his friend are taken to the pub by a support worker, so they could have a pint with each other. Their support workers have seen them hug, which was a big deal because Kenny does not really touch people. In these encounters, Kenny’s friend does all the talking; Kenny never says a word.

Because of Kenny’s silence, I found it hard to discern how he felt about his friendships and about people in the workshop. I tried to find out by asking him who his friends were, to which he started naming people in the workshop. Overhearing my query, Connor, his support worker laughed. “Kenny’s just listing names,” he said. “He just wants you to stop asking him questions.”

I asked Connor how he knew that Kenny enjoyed the company of other participants.

“You know,” Connor said after a pause, “I sit with a man who can’t be bothered doing art. Kenny usually sits and awaits the inevitable masterpiece that’s going to be achieved by the end of the class. Rome wasn’t built in a day, so he’s still working in that direction. And I’m generally quite patient watching him trying to *not* do the art.”

“But the thing is,” Connor continued, “there are a lot of things there Kenny *can* be bothered with. He *can* be bothered going to the workshop, he *can* be bothered seeing people, he *can* be bothered feeling part of what's there at the studio. Whether he paints like, I don't know, a fucking priceless work of art, or whether he does something shit like Banksy, that's irrelevant."

Connor went on, "Honestly, the shit that he brings home gets flung in the corner. He doesn't give a fuck. What he does give a fuck about is that when he goes in, he's part of something. If you say, 'Do you want to go?' he will say, 'Yes'. I say, 'Do you want to go, or do you want to leave it?' He always says, 'I want to go'. Always."

Notice that Kenny is not just a passive subject in these social encounters: he is not treated as a passive object that his friends talk *at*. On the contrary, Kenny engages with *and* evokes engagement from the people around him. In return, the people around Kenny recognise *and appreciate* Kenny as quiet companion and as an active participant in the relationship.

Once I started paying attention, I noticed many similar quiet friendships. Some of them involved participants sitting in each other's company without talking at all. Other times, it was a quiet person sitting amidst a boisterous banter, seemingly disengaged, apart from a small smile that indicates that they are listening. I also witnessed several occasions on which the talkative participants included silent individuals as equal parties in the conversation, but without expecting them to verbally contribute. Contrary to my first impressions, the workshops revealed themselves to be bursting with silent sociality.

///

In this section I used ethnographic examples to examine the policy assertion that participating in social activities help people with learning disabilities develop and sustain relationships. I discussed the mechanism by which participation can lead to sociality, and described non-normative forms of social interactions that contribute to participants' social lives. In doing so, I demonstrated that sociality is cultivated and can manifests by being in the company of others.

I did *not* do so to evaluate social inclusion policies. Rather, the point I am making is that, first of all, participating in social activities, which are often presented as trivial acts, hide tremendous work and effort exerted by individuals with learning disabilities and the people who work with them. This may be because of participants' personal circumstances, or due to the fact that people with learning disabilities are often not welcome in mainstream spaces, which makes them less likely to participate.

Secondly, my aim was to document the different, non-normative forms of social interactions and relationships that are valuable for people with learning disabilities. In doing so, I echo the findings of learning disability scholars Bigby and Wiesel (2011, 2015, 2018), who recognised that meaningful interactions may take on various forms that might not contribute to conventionally-valued long-lasting relationships. In their studies, they specifically focus on "convivial encounters", meaning fleeting interactions between people with and without learning disabilities. They found that people with learning disabilities valued these encounters despite not building towards long-lasting friendships. Their research highlights that for people with learning disabilities, social life is made up of diverse forms of social interactions, which should be acknowledged and supported on their own right.

The care relationship as a form of sociality

So far, I have discussed how participants' social lives are dependent on the provision of adequate and appropriate support. However, I have not yet examined the engagement between care recipients and support providers *as social relations,* i.e. as interactions between individuals that are constitutive of participants' sociality.

In the following, I make the case that this support relationship is central to participants' social lives, not least because for many of them, apart from their family members, social care staff are the only regular source of social contact (Forrester-Jones et al., 2006; Robertson et al., 2007). Participants often listed their support workers as one of their best friends. Several parents I spoke to arranged a support worker to hang out with the person with learning disabilities in their home. These visits were different from providing support with the scheduled programmes: their focus was not the activity per se (which usually included having tea or watching television with the participants), but the company that the support workers provided them.

Some participants I spent time with at the workshops demonstrated great emotional affection towards their support workers. Recall Aysha, a participant who attends the workshops with her support worker, Diana. Aysha is quite verbose. Her thick voice was often the only source of sound in the quiet workshops. But Aysha did not have conversations as such. She sometimes seemed to be speaking to no one in particular, repeatedly asking the same questions: "What's your name? What are you doing tonight? What are you having for lunch?" She did not seem to mind if no one noticed her and responded to her questions. I often sat next to Aysha and tried to chat with her while watching her work. On these occasions, she would intermittently answer my questions with one-word responses; more often, I was the one answering her usual string of questions.

On the morning of the day I scheduled an interview with Diana, I sat next to Aysha, and watched her draw small dots with a paint pen on a large canvas. Normally exuberant and gregarious, asking me my name and my plans for the evening, Aysha was oddly quiet. I struggled to make sense of her silence: I tried to ask her about her weekend, about her upcoming holiday at the respite care, and her plans for the evening. Aysha hardly acknowledged my questions. Thinking that my presence might have upset her, I left her to her work, and went to get a coffee and record an interview with Diana in the meeting room.

Halfway through the interview, Aysha burst into the meeting room in tears, with tutor Ruby following at her step.

"Aysha is getting a bit distressed," Ruby said apologetically.

Diana looked startled. "Are you okay?" She reached out for Aysha's hand. "Are you still working with Ruby? What are you doing?"

"I was crying," Aysha said in a deceptively light tone.

"Crying? Why?" Diana asked, still holding Aysha's hand.

"I was feeling a bit down," Aysha said.

"Oh my god, but you love art class!" Diana exclaimed.

Ruby quietly noted, "She wouldn't do art."

I looked at Ruby. "Shall we go back inside? We will be done in a minute," I said, reaching for the recorder. I was concerned that my decision to conduct an interview during the workshop interrupted Aysha's work.

"No, no, no," Ruby said quickly. "She just needed to see that you're here." Ruby turned to Aysha. "And now that she's seen you, it's fine, right?" Ruby gently guided Aysha through the door. "I just needed to check with you," Ruby smiled as she walked out.

First of all, this episode reveals that I had wrongly assumed that Aysha's relationship with Diana solely centred around the provision practical support. Because Aysha usually worked individually, I had thought that she would be okay with sitting alone while I interviewed Diana. I had thought that Diana's presence was important only inasmuch as she provided Aysha hands-on assistance with handling art materials. Because Aysha usually did not converse with Diana, it had not occurred to me that for Aysha, Diana's presence was in itself reassuring.

The second thing this episode highlights is a contrast between Aysha's interactions with Diana, as opposed to the ones she has with people from the so-called mainstream society. Aysha is a pretty sociable person. However, I learnt from Diana that her outgoing character sometimes got her into trouble. "She's kind of a popular character around town because even when we stop at a store, she's speaking very loud all the time," Diana said. "The thing is that, when she approaches people on the street, sometimes she annoys them because she speaks too much. They will respond to her sometimes in a harsh way and she will start crying." Diana shook her head and continued. "Then she tries to kiss them right away, tries to hug them, and then they will just push her away. She will then start crying, and she won't forget for a long time. She will still say, 'Remember that guy who pushed me away?"

As much as social policies emphasise the importance of people with learning disabilities socialising outside of care services, they do not quite discuss what to do on occasions like this: when the person with learning disabilities interacts in a way that makes others feel uneasy. This unease does not necessarily stem from malice: research suggests that people without learning disabilities often felt ill-prepared to interact with people with learning disabilities, and worried that their interactions may be misconstrued as close friendships (Bigby and Wiesel, 2015; Hall, 2011; M. van Alphen et al., 2010). But other than suggesting that people with learning disabilities need to learn social skills to be able to interact with people outside of service provision (Scottish Government, 2013b), social policies do not address the affective value of the social interactions they deem valuable. In this context, Aysha's interactions with Diana are significant not only because Diana helps Aysha as a support worker, but because Diana responds to Aysha with attention instead of rejection.

This attentive and emotional responsiveness is mutual. Take, for instance, Kenny and his support worker Connor. I learnt from Connor that Kenny is emotionally sensitive and responsive, which admittedly surprised Connor because he had thought that people on the autism spectrum – like Kenny – did not have empathy. Kenny proved Connor wrong on several occasions, most notably when Connor's grandmother passed away. "I cried in front of Kenny once and he came and put his arm rounds me and said, 'Can Connor be happy?'" Connor remembered. "But he has never asked me how I am," he added, implying that although Kenny may not verbally enquire about Connor's wellbeing, he does pay attention to others' emotions.

That care work requires emotional labour is not a new finding. Philosopher Eva Kittay (1999) – whose work I discussed in my second chapter – famously argued that care work helps people with significant disabilities experience and express love, therefore it contributes to alternative understandings of what makes someone human and valuable in the lives of others. Kittay (1999) discusses care work in relation to her daughter, Sesha. However, focusing on unpaid carers – the majority of whom are family members of the care recipient – risks attributing the emotional labour of care work solely to the family relations. Anthropologist McKearney (2018a) expands this observation to paid carers. In his ethnography, he describes how care workers at a group home imbue the residents – people with significant disabilities – with affective sensitivity, and render themselves open to being emotionally receptive and vulnerable to the individuals they care for. His work demonstrates that caring for people with learning disabilities (who are not family members) comprises meaningful, affective, and mutual interactions.

Social policy and the literature often cite the fact that people with learning disabilities consider their paid carers as friends as a sign of ongoing isolation and exclusion (Forrester-Jones et al., 2006; Robertson et al., 2007). There are two assumptions behind this sentiment. The first one is that these statistics indicate the lack of social networks people with learning disabilities have outside of care services. The second assumptions is that a paid care relationships do not count as part of a person's social life because they are unequal and transactional.

Both of these assumptions are, to a certain extent, true. However, what I aimed to show with these examples is that the relationship between paid support workers and care recipient are also more than transactional exchanges. In many cases, the care relationship carries emotional significance for care provider and care recipient alike. Therefore, it constitutes a significant part of participants' sociality.

Conclusion

"We try to give them a space where they can socialise on their own terms," Lesley, the director of Project Ability said. "But I do think friendship and community means something completely different for them," she said. "And policy wants them to conform to conventional social life."

Indeed, many of the interactions at the workshop go unacknowledged by social inclusion policies. My aim with this chapter was to examine what sociality looks like for people with learning disabilities outside of what Lesley referred to as conventional social life. I did so by documenting the fleeting and sporadic encounters between Jamie and Anthony; the silent, but attentive companionship of people like Stewart; the effort that Dave and makes to just be among people; the blink-and-you-miss-it connection by Kenny; or Aysha's non-verbal emotional sensitivity, empathy, and affection. These interactions do not necessarily contribute to skills-building, employability, or wider community participation. They are often non-verbal, or non-conventionally verbal. They require extensive support, financial and personal. They probably do not fit any common sense understandings of friendship.

If anything, the workshops showcase the diverse ways in which people can connect to each other that do not fit common-sense understandings of friendships or social networks. Yet, the familiarity, affection, and comfort these connections produce for people with learning disabilities are valuable. Therefore, they should be valued and supported on their own right. My aim with highlighting these unconventional social interactions was not to emphasise the differences between the sociality of people with and without learning disabilities. On the contrary, my goal was to advocate for the recognition of these often neglected interactions as constitutive of people's social lives, and to outline some of the affirmative measures they require. Examining the social lives of people at the workshop serves with broader implications with regards to the general assumptions we hold about the nature of human communication, connection, and sociality.

The first lesson is that these forms of sociality need an organised, institutional space where they can manifest. The Project Ability studios serve this purpose well: because there is no expectation for participants to socialise, they can engage with each other at their own pace. It is also a space that is safe of judgement or harassment. With the closure of day centres and the funding cuts befalling on service providers, these spaces are becoming increasingly rare.

Secondly, people connect with their social environment in many different ways: by attending to the conversations around them, by emotionally attuning themselves to others, and by being in the same physical space with people. For many of the participants, community presence can equal community participation, given that they are left to engage on their own terms: to reside in the presence of others without pressures to engage in activities.

Thirdly, for many participants, aspirations to be with others need to be cultivated, which requires extensive support due to the nature of their impairment. Many participants rely on their family members and support workers to suggest activities to them, where they can interact with other people. They further need support to organise their social lives, and help them with the practicalities, such as getting prepared to leave the house and transportation.

Finally, supporting sociality requires support workers and staff to sensitise themselves to, and connect themselves with the emotional worlds of the people they are supporting. Helping people with learning disabilities is therefore not a one-way-street, but it holds value for everyone involved.

Sociality is central to citizenship: ultimately, citizenship theories address how individuals live together as a community (Lazar, 2013). Contractarian theories of citizenship do not say much about the nature of relationships between individuals; interactions between individuals are primarily framed in terms of negotiating the social contract. This kind of individualism has been extensively critiqued by alternative theories exploring social relations, social participation, and the possibilities of democracy in diverse communities (Kymlicka, 1996; Mouffe, 1992; Young, 1990). However, these works often focus on deliberative action in the public domain; even anthropologists examining the multiplicity of citizenship practices favour organised political action as an object of their study over interactions that take place in what is traditionally conceived as part of the private or domestic sphere.

In the introduction and the second chapter, I situated this thesis in a growing body of literature that locates citizenship in interactions in the private sphere, specifically, in care interactions in domestic settings.The ethnographic materials cited in this chapter contributes to this emerging body of literature by bringing attention to the small, fleeting, quiet forms of sociality that people with significant learning disabilities engage in. Recognising and acknowledging the importance of these relationships are a step towards reimagining the citizenship of people with learning disabilities.

Chapter seven:
The value of art

Introduction: a puzzle

Tutor Rory’s tan, weathered face and steel blue eyes watched participant Mack trying to cut a thin, raw clay tile around a paper stencil he modelled after Her Majesty the Queen’s golden carriage. At the age of 85, Mack was one of the oldest participants in the workshops. His hands were so shaky that his cuts hardly scratched the surface of clay.

“I can’t see, my dear,” Mack said to Rory after a few trials, and dropped the wooden clay knife.

“Okay,” Rory said slowly. He then picked up the knife, placed Mack’s hand over his. He then asked Mack to control the direction of the knife while Rory applied the pressure to cut through the clay.

“I still can’t see,” Mack repeated after a couple of attempts.

Rory paused to think. He then turned the clay tile around, placed the knife at a straight edge of the stencil, and told Mack to pull the knife towards himself. Thus they began to cut out a rudimentary shape that bore no resemblance to the carriage after which it was modelled. Mack seemed pleased nonetheless.

Having cut out the shape of the carriage, Rory asked Mack if he wanted to make clay figurines of the Queen, Prince Philip, and the Buckingham guards. He also suggested ways in which Mack could position the figures around the clay carriage. Mack did not wait for Rory to finish; with great enthusiasm, he grabbed a fistful of raw clay from the bag and started kneading it. By the end of the workshop, Mack had gone through 5 kilograms’ worth of professional quality clay, and produced a tile that, in essence, comprised a wonky square with dumplings stuck on top of it.

I watched with fascination the care with which Rory checked the thickness of Mack’s tile (too thick and it can crack in the kiln when fired). He then placed the work-in-progress in a plastic bag to prevent it from drying out, labelled it, and put it in cupboard reserved for wet clay, so that Mack could continue working on it the following week.

Later that evening, when I recounted this episode to my colleague, I was met by her puzzled look. “Isn’t that a waste though?” she asked me. “Why would you spend all this effort on people who can’t even appreciate it?”

///

There was something striking in the whole episode, from Rory's quiet patience when working with Mack, to my colleague's confused reaction. My colleague's question suggested that she saw little value in Mack's work: she did not understand why so much time and expensive material was spent on someone who had, in her view, little artistic competence and produced art that was of no value – economic, aesthetic, sentimental, or otherwise. Although it would be easy to dismiss her question as ignorant and insensitive, it may be productive to examine the reasons behind her confusion, and the broader assumptions that her reaction reveals about the value of supporting someone like Mack make art.

Not least because there was indeed something remarkable about the way Rory worked with Mack. Rory could have saved himself time and effort by cutting the tile himself. Alternatively, he could have suggested Mack did something else. Rory could have just prepared all the materials on Mack's desk, and leave him to make clay dumplings for two hours.

One may argue that Rory helped Mack because Mack enjoyed the process of making art: I have discussed in-depth how artmaking promoted sensorial pleasure, choice-making, sociality, and a sense of independence. However, if Rory's engagement with Mack served only to facilitate the process of artmaking and its corollary benefits, one may wonder why the workshops went to lengths to provide professional quality materials to all participants, and why it made sure that the often tedious technicalities – such as rolling out the clay tile sufficiently thin – were completed.

When I asked the tutors, they said that providing high quality art materials were part of recognising the participants as artists. The motto of the workshops was, after all, to treat people as "artists first" (as opposed to approaching them primarily as people with learning disabilities). The *artist first* motto recognises the participants' artistic capabilities and foregrounds the importance of professional tutoring and high quality materials. However, it raises the question of what exactly treating participants as artists first means in practice. What kind of artists can people with learning disabilities be? What is the nature of their artistry? And how can their art be appreciated?

Ultimately, the reason I found my colleague's initial confusion striking is because it spoke to a larger question, which is at the core of the citizenship of people with learning disabilities. I have so far discussed the labour, material resources, time, attention, and emotional investment spent on the participants to help them make choices, be independent, and live a social life. What my colleague was really asking was: why? Why does anyone care to make this effort? What makes engaging with people with learning disabilities valuable, if at all?

This chapter explores these questions in order to explore the lessons they serve for citizenship and ethical engagement. In the following, I will contextualise my colleague's reaction in relation to the debate about value and (significant) learning disabilities. Specifically, I will focus on the notion of rational agency – i.e. the ability to act with competence and intention, to reason, to express oneself with verbal language. I situate my enquiry between two, contrasting positions. The first position is that of Western liberal political philosophy, which makes rational agency a fundamental condition of valuable engagement between individuals. The second one is that of prominent philosophers like Eva Kittay, who dismissed the relationship between rational agency and value altogether.

In this chapter, I take a third approach. I follow anthropologist Patrick McKearney (2018a), who calls for exploring what valuable engagement might look like if it was not tied to the notion of rational agency at all. By asking how tutors regard the artistry of participants, I outline a particular type of agency: one that does not solely rely on their capacity for rational reasoning, but does not dismiss the importance of agency either.

I start by briefly outlining the philosophical debate about rational agency and valuable engagement with people with learning disabilities. I use this debate as a framework to examine the possible explanations to why the tutors (and Project Ability) help participants make art, and what treating participants as *artists first* means in practice. First, I discuss the extent to which technical mastery and artistic competence plays a role in recognising participants as artists. Then, I look at the tutors' engagement with participants from the perspective of artmaking as a valuable process. Finally, I examine the question of what kind of artists participants with learning disabilities can be, and what that says about the value of engaging with them.

Rational agency and the value of engaging with people with learning disabilities

In this section, I outline the ways in which the concept of rational agency has been central in framing the value of engagement with people with learning disabilities. I briefly present an overview of the position that denies that people with (significant) learning disabilities can be valuable to the lives of others because they lack rational agency. Then, I focus on two ways in which advocates and philosophers have argued *for* the value of such engagement: the first position, which contends that people with learning disabilities *do* have rational agency, and are therefore valuable; and a second position, which dismisses the relationship between value and agency altogether.

As I have discussed in my first chapter, liberal citizenship theories conceive of rational agency as a condition to an individual's ability to participate in society. The liberal framework sees reason as the characteristic that separates humans from non-human animals. Rational agency thus enables individuals to tell right from wrong, to make moral judgements, and therefore to pursue what they see as a "good life".

In liberal political philosophy, people with learning disabilities have been traditionally seen as lacking rational agency, which raised questions about whether they could be valuable to the lives of others. While learning disabilities is not discussed in classical philosophical texts in any depth, whenever it is mentioned, it is to exemplify exceptions to the principles of freedom, justice, and dignity that nominally all persons are entitled to. For instance, Aristotle argued that an individual's ability to deliberate in public affairs was tied to their value for the community. He referred to those who did not – could not – partake in public affairs as "idiots", a term denoting not only lack of competence but also selfishness (Beckett, 2006). Later, classic reiterations of the social contract excluded people with learning disabilities on the grounds that they lacked the capacity to negotiate and consent to the terms of the contract. It is telling that John Locke, the father of the social contract theory argued that people with learning disabilities – whom he referred to as "Lunaticks" and "Ideots" – could not meaningfully participate in society because they lacked the reasoning capabilities of "Free Men" (quoted in Carlson and Kittay, 2010: 4). Even the more recent forms of social contract theories struggle to imagine how people with learning disabilities could be valuable to the lives of others: take philosopher John Rawls (1993), who has provided the most comprehensive reworking of the social contract, and who yet famously postponed answering this question in lack of a solution.

From the field of moral philosophy, Singer (2010) and McMahan (2010) argued – rather controversially – that significant cognitive impairment posed a substantial obstacle for engagement in activities and relationships of value. "The profoundly cognitively impaired are incapable, for example, of deep personal and social relations, creativity and achievement, the attainment of higher forms of knowledge, aesthetic pleasures, and so on," McMahan (1996) wrote. Singer (2010) came to a similar conclusion when he examined the relationship between moral status and moral worth. Singer originally set out to make a case for attributing moral status to non-human animals, a group of beings who have also been denied rational agency, and therefore dignified treatment. For him, significant learning disabilities illustrate that lack of rational agency can still imbue beings – in the eyes of some – with equal moral status and dignity. Yet, instead of dismissing the relevance of rational agency to someone's worth, he concludes that a "more graduated view" should be established in which "moral status depends on some aspects of cognitive ability" (p.338). Ultimately, neither McMahan nor Singer think that people with significant learning disabilities can be just as valuable to the lives of others as non-disabled people.

A number of learning disability scholars rejected this line of thinking. For the purposes of this chapter, I will focus on two ways in which Singer's and McMahan's arguments have been rejected. First of all, some learning disability scholars sought to extend the liberal framework, and contend that with adequate support, people with learning disabilities too can be capable of demonstrating rational agency, and thus act with competence, intention, and reason. For instance, Francis and Silvers (2010) propose that assistive thinking – i.e. the practice of using a trustee's reasoning and communicating skills acting as a prosthetic to the person with learning disabilities – can help people with cognitive impairments meet the standards of rational agency. Francis and Silver's is perhaps the most literal re-imagination of what the learning disabilities equivalent of physical prosthetics would look like. However, the idea that with support, people with learning disabilities could be just as capable as their non-disabled peers is present in many of the theories and principles that guide social policy and service provision. Independent living, supported employment, and self-advocacy all operate on the assumption that people with learning disabilities can achieve social value in the same venues as non-disabled individuals (Department of Health, 2001; Scottish Government, 2013b).

While these are goals that many people with learning disabilities have attained or aspire to, philosopher Eva Kittay (2005, 2010) raises the concern that if the moral and social worth of people with learning disabilities is solely determined by the extent to which they can demonstrate rational agency, people with significant disabilities will always be denied their humanity. Such a view has gained increased popularity in the recent years, in a scholarship which asserts that seeks to foreground vulnerability and (inter)dependence (as opposed to rational agency) as the primary descriptors of the human condition (Beckett, 2006; Davy, 2015; Erevelles, 2011; Sevenhuijsen, 1998).

Although I discussed these positions in depth in my second chapter in relation to theoretical approaches to learning disabilities, in the following, I seek to further develop them by examining the extent to which they explain why the tutors engage with the participants and their art. This debate provides a useful framework to explore why helping people with learning disabilities make art is valuable and what treating people as artists first really means. Do the tutors approach participants as artists who can develop the same level of competence and technical mastery as those without learning impairments? Or is artistry irrelevant, and artmaking with people can be valuable regardless of the quality of the art that participants produce?

Rational agency and artistic competence

In this section, I will examine how much technical mastery and artistic competence play a role in recognising participants as artists within and outside the workshops. I will specifically examine whether the participants artistry is framed in terms of their learning impairment.

Whenever I brought up Project Ability to local academics and artists who were familiar with the studio, I was asked if I knew Colin, the studio's most well-known artist. Colin, is gregarious man in his 50s, who lived in a long-stay hospital when he was younger. He joined the workshops in the early 1990s, and since became one of their most established artists. Colin has collaborated with a wide range of local and national artists, boasts several international exhibitions, and is one of the best-selling and most commissioned artists in the studio. His artistic achievements were recently recognised by the Royal Society of Arts, which offered him a lifetime fellowship.

Colin demonstrates high levels of artistic competence. He has mastered multiple mediums: he is just as comfortable with clay as with oil painting. His style consists of bold colours, strong lines, and intricate patterns. He is also prolific: his portfolio is so abundant that it could fill multiple solo exhibitions at the Project Ability gallery. Colin is a prime example for those who argue that with support, people with learning disabilities could be just as capable as their non-disabled peers.

However, not all participants have the sort of technical competence and recognition Colin has. This is partly due to a lack of access and the precarious position that learning disabilities art occupies in the wider art world. Social geographer Hester Parr (2011) observed that despite the studio's good reputation, there was a lack of non-marginal space for Project Ability's mental health workshop participants to exhibit their artworks alongside professional artists in mainstream arts fairs. Parr argued that while some of the participants were well recognised as artists in the mental health-related artworld, their artistry was usually deemed less accomplished when measured against mainstream professionals.

A reason for this is the historical lack of access artists with disabilities and mental illness have to art making facilities and resources – a problem that persists to this day (Guardian Editorial, 2018). Due to the lack of space in the mainstream art world, one of the few arenas where artists with disabilities can safely create, exhibit, and experience art is within disability arts. Disability arts started as a branch of the 1970s disability rights movement. Informed by the experiences of disability (Solvang, 2012), disability arts transformed audio-visual and performance art into platform through which disabled people could reclaim their experiences of disability from the medical establishment (Wexler, 2012; Wexler and Derby, 2015). Since then, it has grown into a thriving field of academic enquiry, artistic practice, and a political movement, enabling artists to contest the meaning of the disabled identity, reclaiming the power of representation, using art in special education for promoting social inclusion (see Hadley and McDonald, 2018; Hall, 2013).

Yet, the relationship between disability arts and Project Ability is ambivalent: despite disability being at the forefront of the studio's activities, Project Ability does not explicitly align itself with the political objectives of disability arts. On the one hand, the workshops are advertised as an artistic space for people with learning disabilities and ill mental health, and the studio regularly hosts guest artists and exhibitions from other organisations for people with learning disabilities or from psychiatric hospitals – albeit without much mention of disabilities or psychiatric diagnoses. Project Ability also leads outreach programmes to provideg art workshops for people with learning disabilities who would not otherwise have access to art-making facilities. The staff further undertake longer term, collaborative mixed-media art projects to commemorate people's experiences as residents in the now closed-down long-stay hospitals.

On the other hand, unlike disability arts, Project Ability never explicitly mentions disability when presenting its participants' artworks. For instance, an information leaflet for Aysha's exhibition (shared with two other female participant artists) simply states Aysha's style: her colour choices, recurring patterns, and refined lines. There is no mention of disability-related meaning or intent. This omission can be construed as a political statement: few artists with learning disabilities partake in disability arts (Hall, 2013). “Generally speaking, learning disabilities art does not sit within disability arts,” Lesley, the director explained. “Disability arts has a sort of social political history to it, which is well-documented, and learning disabilities arts just doesn’t sit within that at all. It’s often actually been excluded from it, and learning disabled artists not been welcomed into that particular genre.”

What Lesley meant was that disability art, like much of the disability rights movement, was led by people with physical disabilities, with little consideration of how the people with learning impairment could be accommodated. Most studies on disability art focuses on well-spoken artists, curators, and academics – the kind of politically aware individuals who have been at the forefront of the disability rights movement. Kulick and Rydström (2015) observed “[t]hat provocative, talented, eloquent, and politically committed individuals with disabilities are challenging stereotypes, making demands, and staking claims is significant and transformative. Nevertheless, one might wonder: where exactly does this kind of focus on vanguard verbal articulateness, performance virtuosity, and activist “claiming” leave disabled people who can do none of those things?” (p. 269). The problem with disability arts is that – like much of the disability rights movement – in requiring verbal eloquence to articulate artistic and political intention, it inadvertently directs attention away from people with the most significant disabilities. While some of the participants are well capable of articulating artistic and political intent (some with the tutors’ support), many of them struggle or lack adequate support to do so – for them, disability arts has little to offer in terms of recognising their artistic agency.

///

I used these examples to reflect on the value of engaging with people with learning disabilities as artists in relation to the mainstream art world and disability arts. I asked if Project Ability valued artists for their artistic competence, may that be of technical, conceptual, or the ability to communicate political intent.

The examples I cited in this section illustrate that the relationship between the participants and the artworld outside of the Project Ability studios is complex. Although some of the participants have the artistic competence that is on par with mainstream artists, most participants are not recognised simply as artists, without the learning disabilities label. Nor does Project Ability considers itself to be part of the disability arts movement, which recognises the value of the art in the artist’s ability to articulate political intent.

Project Ability presents its artists without emphasising their disability; yet, it does not reject the label either. Artistry and artistic value, as framed by the mainstream art world and disability arts thus do not provide a complete answer to why Project Ability helps the participants make art.

Two of Asha's works exhibited in the gallery. Photos by TTP.

The value of pleasure and process

Of course art is not necessarily about the creative output. Certainly, most people (disabled or not) do not pursue artistic activities with the intention of creating a masterpiece: sometimes, the value of artmaking lies in the process rather than in the final product. In this section, I examine the value of supporting participants' enjoyment of the artistic process.

So far, I have discussed at length how artmaking in the workshops enabled choice-making, sociality, and a sense of independence. It allowed participants to leave their flats, to meet other people, and, generally speaking, to exist in a space where they were supported in doing something they enjoyed. Artmaking is, above all, fun: touching the wet clay, slapping thick paint, or watching complementary colours of inks flowing into each other is gratifying in a fundamental, sensorial, visceral way.

This recognition is shared by the staff members, support workers, and family members. This is why the staff are happy for participants to attend without any pressure for them to produce any artwork. This is why participants can work at their own leisure, leave the workshops when they please, or not attend at all. This is why it is okay for participant to just show up and not make any art at all, if they do not feel like it. Staff engagement with participants is partly aimed at facilitating experiences of joy and pleasure.

Foregrounding enjoyment offers a more comprehensive answer to the question of why one should engage with people with learning disabilities. It resonates with a growing body of scholarship which seeks to articulate what value and development could mean for people with significant learning disabilities. As Kittay writes (2010), "[T]here is so much to being human. There's the touch, there's the feel, there's the hug, there's the smile. To be human is not a bundle of capacities. It's a way that you are, a way you are in the world, a way you are with another" (p. 407). Reflecting on her relationship with her daughter Sesha, who was born with profound cognitive impairment, Kittay resists the idea that cognitive capacity or competence should be central to one's value. Much of Kittay's body of work discusses why engaging with Sesha holds value, despite her lack of competence, intentionality, or verbal skills. Sesha has a great love for music, from Beethoven, to Mary Poppins, to ballets. She is also emotional, responsive, and affectionate to the people around her. Supporting Sesha to flourish means to strengthen her capacities experience joy and meaningful relationships (also see Kittay, 1999, 2005).

I agree with Kittay on her main points. In focusing on affection, pleasure, and relationships, her work invites us to imagine what value may look like beyond cognitive capacities. Applying Kittay's approach to the workshops foregrounds the benefits to artmaking that are not related to the art per se: the pleasure, the sociality, the respite from the outside world.

However, Kittay's framework offers little guidance on how regard the participants' artistry and the quality of their artworks. In solely focusing on the value of the artmaking process, there is a danger that we de-emphasise the artworks and the artistic competence that brings them to life. Doing so risks participants being denied the possibility to explore and develop their artistry altogether.

This is what happened to Craig, a former academic in his early sixties whose life and career came to a halt when he suffered a major stroke, as a consequent of which he lost most of his speech and mobility. I learnt that Craig's social life had suffered significantly after his stroke. The aphasia caused by the stroke meant that he struggled to keep in conversation with his friends and family. The people around Craig had also found it awkward and perhaps inconvenient to speak slower, in simpler sentences, and to give Craig the time and space to express himself.

It was Jenny, his wife, who encouraged Craig to go to art classes. Jenny had never seen Craig draw or paint before. Much to her surprise, she found out that Craig had an affinity for visual arts. His paintings were intricate: he worked with small brushes, letting the different shades ink in the brushstrokes bleed into each other, creating a rich texture.

Before Craig joined Project Ability, he had attended a different art workshop for people with disabilities. Craig had spent most of his time there working on a watercolour painting. However, on one occasion, a tutor gave him acrylic painting instead of watercolour. When Jenny called the tutor's attention to the mistake, the tutor said that it did not matter. This response made Jenny very upset.

She explained that acrylic acted different from watercolour, and the mix-up ruined the painting Craig had been working on. When the tutor shrugged off the mistake, she also dismissed Craig's artwork, artistry, and the possibility of engaging with Craig as someone who had preferences and aspirations, artistic or otherwise. In attributing value solely to the process of artmaking, there is a risk of neglecting the potential that participants can develop artistic capacities and grow as artists. In worst cases, it denies participants the recognition as artists.

The tutors at the Project Ability workshops *do* care about the end product. They go to lengths to ensure that the art is technically and aesthetically well-executed: they make sure, with painstaking attention, that the clay is not too thick, that canvases are thoroughly primed, or that the oil paint is dry in between sessions. Some of these are tedious, time-consuming, and not necessarily the most enjoyable aspects of artmaking. All this illustrates that for the tutors, the value of engaging with the participants surpasses simply facilitating an enjoyable artmaking process. In fact, it demonstrates that the tutors recognise a distinct type of artistry that participants have.

An idiosyncratic artistry

That distinct type of artistry that the tutors recognise is not obvious at first, certainly not for the uninitiated. When I first started volunteering at the workshops, despite my best efforts, I struggled to see many of the participants as artists. I use this section to reflect on how I came to recognise and appreciate the participants' artistry. I will then discuss how the recognition of this artistry contributes to the debate on the value of engaging with people with learning disabilities.

The first participant I ever assisted as a volunteer was a blind woman. Tutor Rory asked me to set up a canvas while he mixed paints for her. From the corner of my eye, I caught a glimpse of the emerald green, mustard yellow, and steely blue acrylics. I understood that painting had a sensorial character, and slapping thick acrylic on a canvas with broad strokes was a fun and satisfying thing to do. However, the attention Rory spent on making sure the colours were right and that the canvas was properly primed did not strike me as necessary.

I was not the only one who experienced such confusion.

The tutors told me stories about support workers who did not understand how to facilitate participants' artmaking. For instance, there was a support worker who drew outlines and asked participants to colour them in, which the tutors perceived as patronising. I also heard about a support worker who drew a local football club's logo on their client's painting, thus disrespecting not only the participant's work but also the studio's. In most cases, however, tensions stemmed from support workers who exerted overt control over the artmaking process. They tended to do so out of the assumption that the participant did not have the capacity to do art "the right way".

I witnessed these tensions come to surface during an outreach programme I attended with tutor Rory and participant Joshua (which I discussed in chapter four). Each week the three of us went on a road trip to a community centre in the outskirts of Dundee, a small city on the east coast, famous for allegedly being the sunniest region in Scotland. Dundee, despite its lively grassroots arts and music community, has very little art provision for people with learning disabilities. The eight-weeks-long outreach was a pilot for setting up a longer-term local workshop series.

Ella was one of the local participants, a middle aged woman with mild learning disabilities, a broad smile, and pixie blond hair. Ella was also a dog lover. One of projects she undertook at the outreach was a large collage: using colourful, semi-transparent papers, Ella traced the outlines of small photographs of different breeds, then cut around the figures, and glued them together on a heavy paper. Ella's drawings were remarkable. Her outlines did not follow the photographs she used as references. Instead, her dogs had eerie proportions, and expressive, anthropomorphic faces.

Ella attended one of the workshops with her support worker, Grace, a jovial, middle aged woman. Grace seemed invested in Ella's work, and kept a close eye on Ella's drawings, instructing her to follow the lines closely when tracing outlines. At the end of the workshop, Grace remarked to tutor Rory that Ella did not have the attention to detail to do these drawings right.

Rory disagreed. In response, he pulled out Ella's drawings from the previous week and showed Grace that although some of the dogs did not look like the original picture – some hardly looked like dogs – *that* was what made them unique. The ones Ella made under Grace's supervision looked like an outline-filter on Photoshop. Ella's own drawings, on the contrary, were unexpected and had so much more character to them.

Originality, quirkiness, charm, and the ability to surprise were among the most cited reasons for appreciating someone's work. Trained artists who frequented the studio, including tutors, volunteers, and resident artists often spoke about the quirky elements of participants' works that made the art so charismatic and instantly recognisable. For instance, anything with small repeated patterns concentrated in a small part of the canvas would be Aysha's work. Or: confident, unbroken, broad lines depicting jovial figures were indicative of Amir's paintings. Alternatively: Wes Anderson-like pastel colours in ornament graphite outlines were most defining features of Rhona's artwork.

Some of these stylistic idiosyncrasies derive from participants' sensorial preferences for techniques, materials, and colours, which they develop over time by trying out different ways of making art. But some of them are extensions of their learning impairment. For instance, Gerard, one of the elderly participants who often dresses in colourful shirts reminiscent of summer beach holidays is well known for his lively, fluid non-figurative paintings. Gerard's paintings have a beautiful serene quality and spontaneity of ink patches with complementary colours coming together.

Gerard has limited mobility in is hands and wrists. He can only hold a brush in a slightly tilted way; he struggles with tools that require specific angles and pressures, like fountainpens or roller brushes. He also has very little verbal language, so it is usually up to the staff and volunteers to prepare him the papers, brushes, and paints. Gerard seems to be happy drawing with whatever material is presented to him. He usually grabs the brush closest to him and seemingly does not look at the paint pot he dips his brush in. He then paints the same corner of the paper – the one he can reach with his hand – until a tutor or volunteer either moves the paper for him, or asks him if he thinks the painting is done (which means *they* think it is at the edge of being overworked), to which he drops his brush and makes a sound that sounds like he says "done".

Arguably, part of what lends Gerard's works their balanced character is the tutors' and volunteers' ability to select the paper, colours, and materials for Gerard. However, it is the way Gerard moves his wrists with sudden, tight, forceful movements – indicative of the restricted mobility he has in his hands – that make the brush strokes bold and striking. Gerard's impairments, learning and physical, enable his artistry rather than limit it.

Two of Gerard's exhibited paintings exhibited in the studio gallery. Photos by TTP.

Similar to Gerard, a participant's lack of ability to translate two-dimensional shapes into three-dimensional clay models may result in a sculpture of a rabbit that looks like an adult cartoon high on psychoactive substances; unawareness of the rules of glazing can create a clay tile that resembles one of H.R. Giger's nightmarish visions; or the inability trace lines can transform Degas's painting into an expressionist piece of work. The limits posed by impairment can translate into a recognisable artistic style.

The opposite can also happen. Participants can take longer to develop a style, which the staff sometimes attribute to their high levels of technical mastery. Glynn, a former house painter in his early fifties is one of these participants. Glynn has grey hair, a gregarious presence, and a walking stick to assist him. Unlike the majority of the participants in the workshop, he does not have learning disabilities. He started attending the workshops seven years ago when he suffered a serious stroke, as a result of which he lost mobility to the right – the dominant – side of his body. The stroke had a major impact on his speech. The staff members told me that when he had first started coming to Project Ability, he could not talk. By the time I met him, albeit slow in verbal articulation and comprehension, he was able to have conversations. Glynn taught himself to paint with his left hand. Over the years, he developed such dexterity and technical mastery that he became a minor sensation in the local newspaper.

Glynn is well versed in most techniques, from oils to acrylics to pastels. Like most participants, he uses photographs as references. Unlike most participants, Glynn can recreate these photographs almost perfectly. Although his skills are much admired, some staff members told me they are now working together with Glynn to help him develop his own style. One of the staff members explained, Glynn's ability to copy other artists' works makes him a bit of a "forger": stylistically, there is little in his paintings that are his own. This sets him apart from most other participants, most of whom radically reinterpret their photographic references while recreating them.

The unique, spontaneous qualities of participants' work is admired partly because trained artists struggle to reproduce them. I asked Flora, a recent art school graduate and painter by training why that was. She said, "In art school, it's always in the back of your mind that your work might be graded, or you're going to have to explain yourself, explain your process, justify why you've done something, show people your research. I think that really hurts your practice," she said.

Flora's sentiment reflects the tradition of *outsider art* (or *art brut*, as it was originally called). The concept was first articulated by painter and sculptor Jean Dubuffet in 1948 to describe to art made by artists without any formal training. Dubuffet saw these artists as original, raw, untainted alternative to academic art at the time, which was weighed down by unnecessary and arbitrary rules. Outsider art has lost some its novelty in the decades since, as its value has been widely acknowledged by academic art institutions as well as the art market (Maclagan, 2010). However, for people with disabilities, outsider art has opened up new venues of recognition, via acknowledgement as legitimate artists, reclaim their identity from the medical establishment, question the socially sanctioned standards for 'normality', and provided new venues for communication in artistic practice and in special education (Wexler and Derby, 2015). Because proponents of outsider art saw creative value in art created beyond the establishment, it inevitably developed an affinity for art made at the margins of society: prisons, asylums, and mental hospital.

Art made by people with disabilities was heavily represented in the genre. Many of the Project Ability artists share a history with the outsider art movement as former residents of long-stay institutions. There are also elements of outsider art in the way Project Ability appreciates its participants' art. The originality, quirk, and unexpected qualities in participants' artwork are similar to what Dubuffet saw in the works of untrained artists.

However, the staff do not identify with the practice nor ethos of outsider art. This is partly because of the current state of outsider art: once a fringe and radical movement, outsider art is now widely acknowledged, recognised, and valued by the mainstream. Perhaps most indicative of this is that several volunteers I spoke to regarded themselves outsider artists – despite their art school training. "Anybody can be an outsider artist," Lesley, the director said. She did not seem to attribute much descriptive value to the term. "It's very fashionable," she said with a shrug.

Another reason why outsider art does not quite fit with the studio is that outsider art locates value in the artistic unintelligibility stemming from the social exclusion of outsider artists (Maclagan, 2010), which echoed pre-existent, romanticised, and highly problematic associations of creativity with vulnerability, and mental illness in particular (Cardinal, 2009; Parr, 2011; Wexler and Derby, 2015). Although the workshops work with their participants' impairments to develop their artistic style, it does not romanticise participants' disabilities.

Instead of locating the value of the artworks in its technical mastery or ability to represent the artists' inner world, tutors emphasise the surprising, quirky charismatic, unexpected, unique, and recognisable elements in the participants' style. Tutors often take the time to take in the artworks and articulate what they like to support workers, other staff members, or to the participants themselves. They point at the colour combinations, the patterns, placement, and lines they find striking. They speak about famous artists whose work they are reminded of: contemporary neo-expressionist artists, such as Jean Michel Basquiat and Cy Twombly are recurring names.

Vocalising appreciation for someone's artwork has a pedagogical quality. It serves to explain to outsiders – like support workers, family members, or visitors – why the artworks hold an artistic value. Tutor Rory remarked that some support workers did not know how to appreciate the participants' art because a lot of it looked like messy paint. "But a lot of famous art is just messy paint," Rory said. "It's the energy and spontaneity that we're trying to channel."

The practice of vocalising appreciation was a way in which tutors rendered themselves open to the artistry of participants. Staff worked to reframe the idiosyncratic elements of participants work as not a result of impairment but as an extension of their artistic style. For instance, Gerard's solo exhibition at the studio gallery made no mention of Gerard's limited mobility in his hands that limit the ways in which he can apply brushstrokes to his canvas. Instead, the information pamphlets emphasised his unique style comprising a balance of delicate line work and heavy brushstrokes, artistic confidence, and ability to work across multiple mediums and adapt materials to suit his style.

These practices of appreciation not only enable staff to admire the participants' art but also trains them to see the artistry, and open themselves to the possibility to be touched by participants as artists. I was similarly encouraged to spend time looking at participants' works this way: to speak about what I found aesthetically pleasing, funny, surprising about them, or what they reminded me of. Some of them evoked admiration because they looked striking. Others made me laugh by their wit and humour, intentional or not. Following my initial bewilderment, eventually, I found myself becoming affected by these artworks.

///

The examples I cited, as well as my journey of learning to see the artistry of and appreciate the artworks of the participants reveal a number of things about the value of art in the workshops. The tutors valued helping participants not (only) because they demonstrated technical competence or conceptual intent, or because they perceived art to be an enjoyable, therapeutic activity in itself, regardless of output. Instead, the tutors recognised a form of idiosyncratic artistry in the participants' works, one whose value lay in its ability to be unexpected, quirky, and charismatic. This kind of artistry was supported not by helping participants overcome the limitations of their impairments; rather, it was developed as an extension of participants' learning disabilities.

More importantly, participants' idiosyncratic artistry is not immediately obvious to an uninitiated observer. Instead, the ability to recognise and appreciate is a capacity that is cultivated by *actively* seeking and highlighting the unexpected elements of the work. This is not to say that the value of the participants' artwork lies completely in the eyes of the tutors. Instead, what I aimed to demonstrate with these examples is that the value of art is an active, relational achievement, as it requires the beholder to sensitise themselves the artworks aesthetic and affective value.

A different form of agency

How do the ethnographic examples on the artistry and value link to broader question on valuable engagement? Going back to the debate around the debate around the relationship between rational agency and valuable engagement, so far, I have examined the value of facilitating artmaking in relation the two opposite positions: 1) one which argues that engagement with people with learning disabilities is valuable because, with support, they are capable of developing the same capacities associated with rational agency, and 2) one that considers rational agency irrelevant to the value of engagement. While I am sympathetic with both positions, I observed that neither provide a complete picture of tutor-participant engagement.

Anthropologist Patrick McKearney (2018a) observed similar limitations when he examined carer interactions with people with significant learning disabilities. Working as a caregiver in a group home, McKearney noted that the carers often told each other stories about participants in which they emphasised the residents' emotional sensitivity and ability to evoke emotional responses from their caregivers. McKearney, having undergone training as a carer himself, noted that these stories served to sensitise carers to the ways they could recognise residents as agents, and subsequently become open to be affected by them. The carers did not deny residents' agency on the basis of the argument that agency was not necessary for people to be treated with justice and dignity. Yet, neither did they imbue the residents with rational agency. Instead, carers engaged with the residents as "unruly, immediate, disruptive, embodied and charismatic" agents (p.56).

The idea that agency can be other than rational is helpful. Rational agency locates one's capacity for action – comprising the capacity to engage in valuable social relations and make moral decision – in one's ability to be rational: to reason and act with intent in accordance with one's deliberation. However, McKearney's (2018a) account as well as my ethnographic examples make the case for decoupling agency from rationality. The residents who McKearney (2018a) worked with affected their care-givers not by the exercising the capacities associated with rational agency, i.e. by their reasoning skills, intent, or moral action. Similarly, neither did (most of) the participants at Project Ability participants impress with their technical or conceptual mastery. In both cases, residents and participants demonstrated agency, but in neither cases was their agency perceived and appreciated as *rational*.

The interaction between tutors and participants reveals that tutors recognise a distinct form of agency participants. Tutors do not equate participants' artistic abilities with the abilities of trained artists who have technical and conceptual mastery. They do not operate under the assumption that given adequate support, participants at the workshops will be able to produce artwork that is just like the art made by artists without learning disabilities. Instead of cognitive competence, this kind of (artistic) agency manifests as one's ability to experience and sensorial and affective pleasures: to experience these pleasures when making art, and to evoke such pleasures in those observing the art.

Supporting participants to exert such agency means providing them with the personal and material necessities to explore their sensorial preferences, to encourage their confidence with materials and colour, and enable them to experience pleasure. This is in line with

Kittay's (1999) argument that development for people with significant learning disabilities should concentrate on relational, affective, and sensorial capacities. Yet, I differ from Kittay in that I am interested in how these capacities enable agency. Kittay (1999) is little concerned with exploring the agentive possibilities of these capacities because her central argument is that valuable interaction does not need agency. However, the ethnographic examples from the workshops suggest the opposite: that the ability to experience and evoke pleasure and emotions can contribute to one's capacity for action. In this case of Project Ability, this means creating art and growing as artists, making an impact on other artists' work, and evoking appreciation and affect from audiences.

There is a rich body of scholarship which examines pleasure as an enabler of agency. Writers in this field examined the various ways in which dancing (Driessen, 2018), self-care (Pols, 2006), and eating (Vogel and Mol, 2014) can produce sociality, preferences, sense of self, and a sense of achievement. However, their primary focus are the benefits of engaging in the *process* of these activities; they rarely discuss the qualities of the said activity – i.e. the dance, the cleanliness, food – itself.

Similarly, the literature on learning disabilities and the arts in service provision does not discuss the qualities of the artistic outputs. Visual arts, music, and theatre performed by people with learning disabilities is almost exclusively discussed in the context of art therapy and service provision, both of which locate the value of art in the artistic process. These analytical frameworks examine art in relation to its potential to promote sociality and belonging (Hall, 2013; Venn et al., 1993), mental health and wellbeing (Heenan, 2006), perception and self-expression (Wexler, 2012), to reclaim the meaning and experience of disability (Ware, 2011).

Often neglected are the qualities of the artistic medium – including the people, ideas, and materials – that are an essential part of this. Hall (2013) suggests, the physicality and sensoriality of the materials generate emotional and bodily engagement. "People with learning disabilities are often constrained in their daily lives by sociocultural expectations of behaviour and appearance;" Hall (2013) writes, "in the private and free space and open process of devising," meaning collaborative artmaking, "bodily and mental creativity can be expressed and emotions explored away from the judging gaze of the majority society" (p.251). The artists that Hall (2013) spoke to (disabled and non-disabled alike) all felt that the embodied character of their art allowed them to be safe, spontaneous, and unhinged. Hall (2013) subsequently concludes that by it is by investing in the creative work and the artistry that enables learning disabled artists to engage in practices of belonging: of gifting and receiving the artwork or performance. In his interviews, the staff members tell Hall (2013) what they see in the artworks: the "human hand", the "energy", the palpable "love of creating" (p.253). These elements echo how the tutors at Project Ability perceive the participants' artworks. However, Hall does examine the cultivation of artistry and appreciation further than this, as his interest lies in the relationships that giving and receiving art creates.

Notably, Hall (2013) is one of the few writers who makes the art central to analysing the benefits of the artistic process. The literature on learning disabilities art in the context of art therapy and service provision considers the artistic product secondary to the benefits that its making brings.

I contribute to these bodies of scholarship by approaching value and appreciation as practice. The ethnographic examples I cited reveal that appreciating the artworks takes work: it is an ongoing practice of training one's attention to the details in the artwork that convey the energy and spontaneity that non-disabled artists working with learning disabled artists take note of. Focusing solely on the value and appreciation of the process misses a fundamental element of value: that it is investment and care about the end product that enables participants' artistic agency and enables engagement with them as artists. This kind of engagement comprises not only the technical aspects of artmaking but also a commitment to recognise the participants' idiosyncratic, surprising style and spontaneous energy.

Conclusion

What makes one valuable to the lives of others is a central preoccupation of citizenship theories in that they seek to describe how we live with others as a collective, and what makes a collective more than the sum of individuals (Lazar, 2013). In contractarian theories, the value of engaging with fellow citizens is conceived in terms of mutual advantage (discussed in chapter one), which relies on one's ability to act with rational agency (Nussbaum, 2006). Liberal theories place value in one's ability to reason, deliberate, and act with intent, as these are the capacities that enable citizens to consent to and uphold the social contract. The same theories often denied people with learning disabilities rational agency, thus excluding them from venues of social participation through which they could become a valuable part of society.

The learning disability scholarship has traditionally resisted this exclusion by either setting out to prove that with support, people with learning disabilities could develop rational agency too; or by dismissing the importance of rational agency altogether. In this chapter, I explored an alternative ways in which engaging with people with (significant) learning disabilities could valuable beyond the notion of rational agency. I did so through examining why tutors found helping participants make art valuable. I contended that neither of the two major approaches in the learning disability scholarship provided a complete answer. The tutors did not see (most) participants as artists who could develop the same technical and conceptual competence as non-disabled artists, nor did they dismiss the importance of artistry altogether in favour of foregrounding the benefits of the artistic process alone. Instead, I observed that the tutors recognised participants as idiosyncratic, charismatic, and quirky artists, the value of whose art lay in their ability to surprise and affect those who viewed it. I further observed that the tutors actively learnt and taught others to appreciate the participants' art and to recognise their artistry by vocalising what they liked about the art and seeking out the quirky elements they liked. These practices sensitised them to aesthetic and affective value of the artwork.

Examining art and other creative practices provides answers to the larger question of why any of us should engage with people with learning disabilities? A key message to take away from this is that even if people with learning disabilities are not perceived as rational agents, they have the capacity to act upon others by evoking appreciation, surprise, affection, and enjoyment. And to be able to recognise their charisma, we need to put in the work to sensitive ourselves to it, render ourselves vulnerable and appreciative of it.

Therein lies two lessons for citizenship. Although I have discussed at length in this thesis how the social contract is exclusive of people with learning disabilities, it is worth noting that its narrow view of personhood can limit the way we understand all social exchanges, not only ones with people with learning disabilities. Evoking appreciation, surprise, affection, enjoyment are forms of agency that anyone can develop or already possesses: recognising it more explicitly can contribute more inclusive understandings of citizenship. The second lesson is this: the citizenship of people with learning disabilities is a relational achievement. For them to become citizens, it is not enough that they learn to inhabit the ideals of citizenship, but it is essential that non-disabled people also undertake a similar learning to recognise the values that engaging with people with learning disabilities brings.

Chapter eight:

The citizenship of people with learning disabilities

Introduction

I started this thesis by asking what citizenship means for people with learning disabilities in their everyday lives, and how they can be supported by those who work with and care for them. I set out to explore these questions with the goals of, firstly, to document positive practices of support, and secondly, to articulate more inclusive conceptualisations of citizenship that take into account people with learning disabilities as a diverse group of individuals who require specific social arrangements to accommodate their impairments. In my enquiry, I departed from rights-based approaches to citizenship. Instead, I regarded citizenship as an essentially contested and polyvalent concept, which could be ethnographically derived from everyday practice. In framing my approach to citizenship, I partly drew on philosopher Martha Nussbaum's (2006, 2009) capabilities approach. Specifically, I focused on the notion that a just society promotes conditions that allows individuals to live a life of dignity, and provides affirmative measures for humans to develop, flourish, and engage with others to the best of their capacities. This helped me foreground positive interventions and atypical social arrangements, and led to examine what should happen once the social minimum – such as civil, political, and economic rights – are granted. Secondly, to frame citizenship as a set of practices, I followed anthropologist Aihwa Ong's (1996) observation that individuals became citizens by the dual process of "self-making and being made" (p.737). Subsequently, I examined how people with learning disabilities and those who worked with them navigated, negotiated, and rearticulated liberal ideals of citizenship, which have been dominating social policy and service provision discourses.

As I discussed in my **first chapter**, the challenge and urgency of the task lies in that learning disabilities question the very foundations of the way we understand citizenship. The problem of learning impairment challenges common liberal Western political philosophy and its narratives about how and why we live together as a society: it highlights the contradictions in the tale these theories tell about humans, as rational individuals, coming together and cooperating in pursuit of mutual advantage.

I have argued that liberal ideas are fundamentally exclusive of people with learning disabilities. Yet, their understanding of personhood and participation frame the way society engages with and relates to people with learning disabilities, from policy, to service provision, to personal support. These ideas are present in the way institutional prioritises employment, financial independence, and autonomy over emotional and social life. In addition, they often provided justification for the privatisation and funding withdrawal from the social care sector. All this contributes to the social exclusion, isolation, discrimination that are part of the day-to-day existence of many individuals with learning disabilities. As long as social policy and service provision uncritically deploy liberal understandings of citizenship, they will struggle to address the enduring social inequalities and injustices people with continue to experience. Taking seriously the contention that people with learning disabilities are citizens requires rethinking what citizenship entails beyond being a buzzword in policy publications.

At the same time, what has hopefully become apparent from this thesis is that liberal ideals of citizenship are not simply exclusive and oppressive. On the contrary, individuals also demonstrate tremendous agency in manipulating, negotiating, navigating, and strategically deploying various meanings of citizenship. They do so to claim rights, pursue their personal aspirations, and to engage with others and in activities they hold valuable. Enacting citizenship is thus an ongoing process, which takes a lot of work on the part of individuals with learning disabilities and those who work with them. This means that advocating for their citizenship requires the recognition *and* support of these practices, in addition to upholding and enforcing legal rights.

I had two goals when presenting my ethnographic material. The first one was to examine what liberal ideals of citizenship meant in practice, and simultaneously demonstrate that it was possible to help people with learning disabilities to make choices (**chapter four**), to become independent (**chapter five**), to be social (**chapter six**), and to be recognised as valuable to the lives of others (**chapter seven**). The practicalities of such support are important not only because they provide a know-how for care provision, but also because they represent various forms of ethical engagement with people whose inner lives, desires, and aspirations are often brushed off, and whose historical mistreatment continues to present day.

My second goal was to demonstrate that a different, more inclusive understandings of citizenship was possible. Past ideologies, such as deinstitutionalisation, normalisation, the social model, independent living, and personalisation have all shaped the ways in which the social position (and hence the citizenship) of people with learning disabilities was imagined. Since their conception, these theories have been extensively critiqued and revised. Yet, learning disability scholars Johnson and Walmsley (2010) lament, some of the constructive criticism has raised such negative reactions, which seemed to have stifled the development of new ideas. I discussed this in **chapter two**, where I argued that the lack of theorisation on learning disabilities resulted in disability studies and activism glossing over the specific needs of people with learning disabilities, especially of those with significant impairments. This has been partially responsible for the lack of imagination in learning disability policy and service provision, leading to the regurgitation of the same debates around autonomy and independence.

I took upon the anthropological task to move beyond these tired debates: as anthropologist Tim Ingold (2017b) writes, anthropology is, after all, a "critical inquiry into the conditions and possibilities of human life in the one world we all inhabit" (p.22). In order to focus on the "possibilities of human life", I drew on Kulick and Rydström's (2015) suggestion to approach learning disability as a productive condition that creates new understandings of agency, personhood, relationships.

I explored these questions by observing the way people with learning disabilities make art. Artmaking reveals much about citizenship: it requires engaging with concepts that imbue citizenship narratives, such as (artistic) choice-making and community membership. It demands us to reflect on what being independent and responsible means, especially when the activities carry an element of risk. It finally asks: what is the value of any of these activities?

I discussed these in my ethnographic chapters. I dedicated chapter four and five to explore the way leaning disabled citizens can practice self-determination. In **chapter four**, I looked at the ways participants were helped to make choices in the art workshop. I argued that because participants did not always know what they wanted to do, and often had difficulties verbally articulating their desires, the tutors looked for sensorial cues to help them explore different options and develop preferences. **Chapter five** I dedicated to exploring the idea of independence, and what it meant to support someone in the age of risk management. I argued that independence inevitably carried risks that could be either minimised by removing the individual from the environment, or by increasing support to ensure that individuals could safely navigate it. I observed that while the workshop opted for the latter, many participants experienced the former approach to risk management in other areas of their lives.

In the second half of the thesis, I turned my attention to the relational aspects of citizenship. In **chapter six**, I discussed the diversity of social lives. I demonstrated that although many participants may not have seemed like they were engaging with the social environment, they were often social in a quiet, unconventional, blink-and-you-miss-it way. Finally, in **chapter seven** I asked why the tutors (and the organisation) cared about the participants' artworks, and what their care revealed about the value of engaging with people with learning disabilities. I argued that the tutors recognised the participants as idiosyncratic artists whose recognisable style was an extension of their learning impairment.

In this final chapter, I want to return to my initial questions of citizenship: how is it lived, what support does it require, and what new articulation of citizenship does it reveal if any? Following a methodological reflection, I will explore these questions through three overarching themes that emerged from the ethnographic material. These themes are: 1) citizenship as (self-)cultivation, 2) the sensorial aspects of citizenship, and 3) the material conditions of citizenship. Once I unpacked these three themes, I will discuss what all this means for the citizenship of people with learning disabilities.

A methodological reflection

Social research with people with learning disabilities has predominantly involved so-called inclusive research, a method that engages people with learning disabilities as co-researchers. I did not undertake inclusive research; instead, I conducted a long-term ethnography and participant observation. I approached fieldwork as a form of cultural apprenticeship: a process whereby I immersed myself in the world of the participants, systematically questioned my pre-existent assumptions, and acquired new skills and perceptions through engaging with, responding to, and undertaking collaborative action with the people in the field (Jenkins, 1994).

I started fieldwork as a complete outsider. Prior to joining the Project Ability workshops, I had very little experience in interacting with people with learning disabilities, and I did not know much about artmaking outside of the occasional hobbyist's venture into life drawing. I came to this project as someone who completed a graduate degree in medical anthropology and was interested in theories of citizenship and embodiment. For me, learning disabilities had been first and foremost a concept through which I could explore questions about the margins of belonging and the possibilities of mobilisation – the workshops radically shifted my priorities and perspective in this respect.

At the beginning of the fieldwork, I felt a sense of disjuncture and displacement – a common sentiment for anthropologists as they enter the participants' world as novices (Blasco and Wardle, 2006). I was pushed out of the comfort of academia, and was dropped into an environment where I found the interactions impenetrable, and the activities far beyond my skillset. As I developed familiarity with the people in the workshop, I went from being a complete outsider to being accepted by the Project Ability community. As part of this transformation, I became familiar with a wide range of artistic techniques, which enabled me to work more closely with the participants as volunteer-researcher. As part of this process, I came to further appreciate life within the workshops. I recognised the level of skill, attention, patience, and empathy that the tutors and participants demonstrated towards each other. I also learnt to recognise the artistry of the participants. I developed close relationships with them and became deeply invested in their wellbeing. By the end of the fieldwork, people with learning disabilities ceased to be a topic of purely intellectual interest for me; they shaped and fuelled my sense of justice.

I also developed further appreciation for Project Ability as a service provider. The standard mode of knowledge production in which anthropology tends to operate is critique and judgement, which goes hand in hand with the analytical imperative to deconstruct and contextualise practices that anthropologists observe (Jenkins, 1994; McKearney, 2019). However, not only did Project Ability's treatment of people with learning disabilities stand up to my anthropological scrutiny; I found myself humbled by the level of skill, experience, and labour that the organisation demonstrated in engaging with its service users.

The learning process I undertook as a kind of apprentice was a series of trial and error, throughout which I made mistakes in my role as a volunteer. For instance, I overwhelmed participants with options because I had thought it helped their choice-making; I suggested artmaking techniques that did not consider their impairments; I handed them the wrong art material because I did not listen carefully enough to what they had wanted. As much as I was mortified at these mistakes at the time, they had a methodological value. They highlighted the discrepancy between my pre-existent assumptions about things such as choice, friendship, and value, and the way these were understood and practiced by participants. Such anthropological engagement is a long-term undertaking: it takes time to get to know people. It also takes time to unlearn preconceptions about them, and become open to new ways of knowing.

My fieldwork presented me with ethical challenges that required me to continuously reflect on my roles as researcher and volunteer. In my methods chapter, I wrote that I opted for obtaining individual verbal consent for participant observation, which I did by asking participants and their support workers if I could sit with them. However, upon reflection, some participants may have consented because they perceived me as a volunteer, rather as a researcher conducting participant observation. In fact, some of the participants continued to refer to me as a volunteer, despite me identifying myself and regularly reminding participants about my role as a researcher. In retrospect, instead of verbally explaining my research to the participants and their support workers, I should have prepared an easy-read version of my research proposal, and formally consulted them prior to my fieldwork – this would have better ensured that the participants were informed about my research and about my role. At the time, I was concerned about being intrusive and taking up too much of their time by talking about my research. I was keenly aware that participants paid for their attendance, and that for many of them, being at Project Ability was the highlight of their week. However, my concern may have interfered with their ability to give informed consent.

To help me navigate the ethical complexities resulting from the multiple roles I held as researcher, volunteer, and inevitably, friend, I followed the principle of "do no harm" (American Anthropologial Association, 2012; Association of Social Anthropologists of the UK and and the Commonwealth (ASA), 2011). A subsequent ethical conundrum I faced when presenting my ethnographic material was the risk of breaching internal confidentiality (Kaiser, 2009; Tolich, 2004). I addressed this by I carefully considering the possible negative impacts that my thesis could have on people if their identities were revealed from my descriptions. Because of this, I decided not to include information that I felt could breach individuals' trust, or would present a person in an undignified manner, even if this meant that I had fewer ethnographic examples to work with.

I argued in my methods chapter that although ethnography and participant observation were not inclusive by the standards of inclusive research, they were an ethical and collaborative way of engaging people with learning disabilities in research. The knowledge I acquired during my fieldwork was produced collaboratively with those I encountered and engaged with. I did so *not* by inviting them into the field of academia, but by me entering the spaces of their ordinary lives (Kleinman, 1999). I became privy to their knowledge by having been present with them, responding to them, and undertaking activities with them. The insights I gained were not only "propositions about the world", but also "skills of perception, and capacities of judgement that develop in the course of direct, practical, and sensuous engagement" with the surrounding social and physical environment (Ingold, 2014: 387). It was an ethical form of engagement because, instead of expecting participants to become quasi-researchers, it required me to adapt my research activities to work around individuals' needs and interests.

By the standards of inclusive research, I was not inclusive. A resultant drawback was that the topic of my thesis might not have born correspondence with what people with learning disabilities found relevant to their everyday lives. I set the research topic and agenda in consultation with other academics and healthcare professionals; however, I did not ask people with learning disabilities (and those who worked with them) about their research priorities.

During my fieldwork, I found that participants had little interest in discussing my thesis with me; they were more interested in talking about art, politics, and the films they saw over the weekend. It may also reflect the gap between what I found interesting as a doctoral researcher and what they held important in their everyday lives. In retrospect, having involved people with learning disabilities from the outset of the research would have helped me formulate, translate, present my research questions in a way that better aligned with the interests of my participants. To partially rectify this, during my fieldwork, I had ongoing conversations about my research questions and the emerging themes with the people at the workshops. Their insights and interests helped me shape the arguments presented in my ethnographic chapters.

However, diverting from inclusive research afforded me a couple of methodological advantages. First of all, conducting an ethnography and participant observation allowed me to seek out and apply other forms on inclusion in research. By entering the world of participants, I took part in the activities they held valuable, adapted to their pace of working, and learnt about the stakes they held in their everyday lives. By doing so, I was able to recognise and reflect on forms of engagement, interaction, and value that I would have not noticed and appreciated otherwise. In the process, I continuously reflected on my positionality, and used my misconceptions and mistakes as ethnographic material that held epistemological value. In short, my methods allowed me to produce insights I could have not gained with employing shorter-term and less participatory forms of qualitative research.

What transpired from the methodological approach I took is that the inclusivity of the research has to derive from ethical engagement and the obligation to respond to participants in a genuine and human manner. This involved listening to them, understanding their aspirations and desires, and connect with them in a truthful and human manner.

Citizenship and self-cultivation

In this thesis, I approached citizenship as an essentially contested concept that emerged and could be ethnographically derived from everyday practice. As opposed to rights-based approaches that use Marshall's (1950) definition of citizenship-as-status as starting point, the practice-based framework allowed me to study citizenship from the "bottom-up". I approached citizenship as a dual process of "self-making" and "being made", which recognised its dynamic nature, and people's ability to manipulate its meaning and deployment for their own ends (Ong, 1996).

In social policy and service provision, the citizenship for people with learning disabilities revolve around the ideals of choice-making, independence, sociality, and social contributions. In the past – prior to deinstitutionalisation and the emergence of disability rights – people with learning disabilities were seen as lacking the capacity to achieve these ideals. Subsequent rights-based perspectives focused on inadequacies in the social, political, and material provisions that prevented people from making claims. A practice-based approach complements these rights-based perspectives by highlighting that ideals of citizenship are cultivated capabilities that develop with time and practice. Having social, political, and material rights are a necessary but insufficient condition of citizenship. In addition to being guaranteed rights, people with learning disabilities become citizens by continuously engaging in acts of citizenship. This engagement helps people develop preferences, imagine further possibilities, and thus foster broader aspirations.

Note that the ways in which these ideals of citizenship are practiced in the workshops are different from the way they are understood in social policy. First of all, in the workshops, the "success" of these activities is not determined by their outcome, but by their sustainability and ability to enable further engagement and activity. Citizenship is not accomplished when individuals make a choice, meet a friend, or sell a painting; rather, it is an ongoing process that necessitates institutional support and materials by which they can continue to develop the capabilities associated with citizenship. This is because each act of citizenship enables further acts of citizenship: the more one makes a choice or participates in social life, the better one becomes at choice-making and socialising.

Whereas the rights-based approaches conceptualise citizenship as a status, citizenship-as-practice is interested in the mechanism by which individuals are transformed into citizens. Such a practice-based approach has been recognised in republican traditions of Western political philosophy. As opposed to the liberal narratives that envision political life as a competition between individuals, republicanism offers a counter-narrative in which citizenship is a collective endeavour to pursue the "good life". These elements can be found in Aristotle's early accounts of citizenship, in which he argued that it was this collective undertaking that transformed an individual into a citizen (Beckett, 2006: 25). Such foregrounding of collective praxis makes republican narratives an alluring alternative to the individualism of liberalism. However, much like liberal theories, republican narratives also do not discuss how people with learning disabilities could participate in citizenship practices (Carey, 2009a).

Supporting citizenship practices involves more than ensuring that material conditions for citizenship are provided (e.g. options for choice-making, people they can socialise with, and venues in which they can be responsible and contributing members of society). Support also entails nourishing the inner lives of people by helping them develop preferences and aspirations through dialogue and persuasion. As I discussed in my introduction chapter, this presents a set of difficulties when inner lives seem incomprehensible or impenetrable by the standards of Western liberal philosophy.

Unexpectedly, anthropologists working in the field of ethics of Islam in the Middle East offer some theoretical directions. A rich body of this anthropological literature has been preoccupied with understanding why individuals partook in practices that contradicted Western liberal ideals of a “good life”. This confusion is most apparent in the way Muslim women in the Middle East are framed, Saba Mahmood (2001, 2005) observes. The subject of Mahmood’s seminal ethnography are Egyptian women who participate in the mosque movement, which formed as part of a larger wave of the 1970s Islamic Revival. As part of their daily practice, women of the mosque movement women undergo strict religious education to cultivate modesty. They read Islamic scripts, participate in lectures, and organise meetings to teach each other about Islam. Their self-cultivation carries a significant embodied dimension: they train their emotions and bodily comportment to align with ideals of modesty.

The mosque movement enabled women to enter and take on public roles within formerly male-dominated field of religious institutions. Yet, Western observers were perplexed that these women seemed to willingly engage in practices that reinforced their subjugation. Mahmood (2001) argues that this confusion derives from the way Western political philosophy understands action and agency in terms of oppression and resistance. For Western observers, there are two ways individuals can act in relation to power: one can render themselves subservient to power, and hence be oppressed by it; or they can resist it. “What is seldom problematized in such an analysis is the universality of the desire – central for liberal and progressive thought, and presupposed by the concept of resistance it authorizes – to be free from relations of subordination and, for women, from structures of male domination,” Mahmood (2001: 206) writes. This dichotomous understanding of agency makes Western liberal philosophy ill-equipped to explain why women intentionally participate in Islamic practices, apart from circular and patronising explanations that label their actions false consciousness and internalised oppression.

Seeking an alternative framework to make sense of the mosque movement, Mahmood (2001) draws on the concept of habitus as embodied pedagogy: “a conscious effort at reorienting desires, brought about by the concordance of inward motives, outward action, inclination, and emotional states through the repeated practice of virtuous deeds” (p. 215). Whereas the liberal framework sees women veiling, practicing patience, and denying themselves mundane pleasures as a form of reinforcing patriarchal norms and gendered submission, Mahmood suggests that these acts are “technologies of the self” (Foucault, 1976), which imbue women with a different modality of agency, and enable them to inhabit the world as virtuous subjects. She likens this mode of subjectivation to the way virtuoso pianists master their instrument by rendering themselves under strict regimes of practice: the more the pianist is acquainted with the musical rules and scales, they more he or she will be able to improvise.

Self-cultivation is an influential and enduring analytical framework in the anthropology of Islam and Middle Eastern ethics. Scholars have drawn on it to problematise Western interventionism (Abu-Lughod, 2002; Hirschkind and Mahmood, 2002), and examine a wide variety of everyday practices, such as veiling (Crăciun, 2017), dreaming (Mittermaier, 2011), or listening (Hirschkind, 2006). Self-cultivation provides a productive theoretical ground for this thesis, not least because the desires and aspirations of people with learning disabilities – much like that of the women in the mosque movement – pose a similar challenge to Western liberal philosophy and the oppression-resistance dichotomy prominent in disability activism. It is further helpful for explaining the process of becoming citizens: much like it unveils the practices by which Muslim women come to be virtuous, self-cultivation helps document the acts by which people with learning disabilities come to be citizens. Self-cultivation provides a theoretical framework for the question of: if we recognise people with learning disabilities as citizens, how do we engage with them as citizens?

A notable example for applying self-cultivation as a framework to understand engagement with learning disabilities is anthropologist McKearney's (2018a) ethnography on carers working in group homes housing people with significant learning disabilities, whose works I have cited in my previous chapters. Taking theoretical inspiration from anthropologists of the Middle East, McKearney frames the carers' interaction with the residents as a form of self-cultivation. Carers in these care homes tell each other stories in which the residents – people with significant learning disabilities – are portrayed as charismatic and emotional agents who have the capability to surprise those around them. McKearney argues that these stories act as form of training through which carers taught themselves to relate to the residents as agentive individuals. Drawing on McKearney (2018a), I similarly drew on the notion of self-cultivation to frame the process by which the Project Ability tutors and volunteers learnt to appreciate participants' artistry, and rendered themselves to be affected by the artworks.

I wrote in my introduction that the anthropological literature on citizenship-as-practice predominantly focuses on organised collective action that redress the relationship between the state and individuals. Citizenship as self-cultivation complements these anthropological accounts by calling attention to the smaller, less visible practices that focus on less so the relationship with the state, and more on interactions between individuals. The lens of self-cultivation reveals the mechanism by which small, everyday interactions constitute citizens and citizenship. It opens the space for enquiries on how the capacities that make someone a citizen can be acquired. The ethnographic examples I cited should make it clear that one's capacity for action – to make art, be with people, or make choices – is achieved by undergoing said action.

However, while the self-cultivation scholarship primarily focuses on the individual's intentionality, my fieldwork highlighted that cultivating citizenship is a relational and tentative achievement. Firstly, Mahmood's ethnography focuses on an individual's cultivation of the self; she is less concerned with how such cultivation manifests and is constitutive of one's engagement with others. The women in Mahmood's ethnography may partake in group lectures and seek each other's advice, their journey is ultimately an individual undertaking. The art workshops however demonstrate that such self-cultivation is undertaken in relationship with other. The tutors cultivate appreciation by making art together with the participants, and the participants cultivate their artistic and social capabilities with the help of the tutors and support workers. Ultimately, both processes of self-cultivation are conditional to the support relationship.

Secondly, the women of the Mosque movement work towards clearly defined ideals of modesty with intention. They are "success stories" (Schielke, 2009: 36) that have little space to acknowledge the indeterminacy and fluidity of their desires and aspirations. On the other hand, the workshops demonstrate that developing the capacity to act is a process of trial and error, rather than a straightforward pedagogical process that has clear goals from the outset. Participants are encouraged to try new things; some take such encouragement more readily than others. Not all of the suggestions take to the participants' liking, but those that do, generate further possibilities for participants to partake in activities and engage in relationships that they value.

This is not to say that artmaking in the workshops is a directionless and haphazard process, whereby options of all sorts are thrown at people to see what sticks. On the contrary: much of it hinges upon the careful and close attention of those who work with people with learning disabilities, who ensure that these capacities can be nourished and explored. Recall tutor Eilidh, who, by watching the quiet and introverted Scott taking joy in picking dried paint deducted that he would enjoy drypoint etching; or support worker Helen, who observed the selectively mute Stewart's amusement at other people's conversations, and thus inferred that

Stewart enjoys being around people, despite appearing disengaged; or tutor Rory, who looked for the idiosyncrasies in the participants' works, and went out of his way to explain to others why these unique qualities made the artworks one of their kind. It is by these ongoing efforts that people with disabilities were helped to become citizens.

There is a lot of learning that social policy and service provision can distil from these observations. Thinking of citizenship as a form of self-cultivation calls for a relational and practice-oriented approach to supporting the citizenship of people with learning disabilities. It asks policymakers to take note of the everyday acts and relationships that make individuals into citizens, and provide the support needed so that people's engagement in these practices and relationships can be sustained. My ethnographic examples highlight how artistic activities and building creative capacity are a vehicle through which people with learning disabilities can become citizens. Obviously, more opportunities for people to make art with organisations like Project Ability would be welcome. However, more broadly speaking, engagement with others in activities that one deems valuable can help people with learning disabilities cultivate capabilities associated with citizenship. A shift of emphasis in service provision from personal goal setting to the value of collective engagement would be helpful. People with learning disabilities need venues in which they can pursue various activities and engage with others; they need support services that focus on helping them explore and develop their preferences, without a pressure to achieve goals; and they need supportive relationships with people with whom they can undertake such activities.

Citizenship and sensorial attunement

The relationship between people with learning disabilities and those who support them emerged as a second overarching theme of this thesis. One question stood out in particular: how did support workers, care givers, and tutors understand the desires of the people who had significant impairments and a limited capacity to express themselves with verbal language of assistive technologies.

I observed in my ethnographic chapters that the body of people with limited verbal language played a central role in interactions between participants and social care and workshop staff members. This was apparent in the way tutors offered participants options, suggested new techniques, and helped participants make artistic choices, based on their observations of the participants' sensorial preferences. It is documented by the way support workers seemed to be attuned with the participants' mood, and could tell if they were bored or engaged by their silence or posture. This kind of silent, embodied attention also underlay the nonverbal sociality of participants who enjoyed and appreciated one another's company without saying a word.

In the medical and psychiatric literature, preoccupation with non-verbal interactions has predominantly revolved around so-called augmentative and alternative communication. This comprises communication technologies that assist individuals with limited speech, ranging from simplified language and gestural communication, to visual aids, to speech generating devices. The medical and psychiatric discussion is generally concerned with the effectiveness of and preferences for different technologies a variety of social and clinical contexts (Chinn, 2017; Gevarter et al., 2013; Hong et al., 2016; van der Meer et al., 2011). There is also a rich body of literature evaluating interventions to teach communications skills to individuals – children, in particular – with significant learning disabilities (Akamoglu and Meadan, 2018; Hatton, 1998; Hong et al., 2016; Neely et al., 2018). These studies and technologies are undisputedly useful in aiding interaction for people with significant learning disabilities. Yet, it is notable that at the workshops, tutors and support workers did not use assistive technologies apart from sign language. Instead, the tutors often spoke about developing an embodied connection with the participants through long-term sustained engagement, which was the primary – albeit not exclusive – aid for their engagement.

Surprisingly, the ways in which the body can facilitate communication is little discussed in social research on learning disabilities; the body is generally reserved for the medical literature where it is regarded as an object of clinical enquiry, which passively endures comorbidities. While embodiment is a prominent lens of analysis in disability studies, it is predominantly applied to the examination of lived experiences of physical impairment. This gives little direction regarding non-verbal engagement with people with limited means to self-expression.

An example of research that analyses how care workers interact with people with significant learning disabilities is Kulick and Rydström's (2015) ethnography on disability and sex. During his ethnographic fieldwork at a Danish group home, anthropologist Don Kulick (in Kulick and Rydström, 2015: 193–195) met Rasmus, a man who had restricted mobility and whose verbal language consisted of one-syllable words. Kulick and Rydström note that for most of the uninitiated, the noises that Rasmus makes would seem unintelligible. That is why they were surprised to find that the staff managed to discern that Rasmus preferred to have sex with men. Kulick and Rydström recount the process by which both parties were able to understand and discuss these preferences: first, Rasmus's carers noticed that he took little interest in women. Then, a sexual advisor spoke to Rasmus to confirm these observations, leading to a social worker helping him find out what exactly Rasmus's preferences for a sexual partner were.

Getting to this point took much "time, patience, alertness, and empathy," Kulick and Rydström later reflected on the episode (p. 193). Although the staff working with Rasmus were able to interpret his sounds and worked out a method by which they could follow up his answers with yes/no questions, they did not learn about Rasmus's preferences using an assisted communication strategy with which Rasmus could declare his sexual identity. They learnt about it because they paid attention to him and pursued the cues he gave them: they sensitised and attuned themselves to the Rasmus's bodily, sensorial, and tactile preferences.

Phenomenological literature may shed light on the nature of this type of engagement. Unlike the medical literature, which considers the body a passive object of study, the phenomenologist's starting point is that the body is an active subject that provides an "existential ground" through which sociality is experienced and practiced (Csordas, 1990). In his seminal essay, Csordas (1994) argues for "culturally mediated ways of attending to and with one's body in the surroundings that include the embodied presence of others" (p.138). Attention, he writes, is not purely a cognitive and disembodied act, but requires bodily ways of engagement.

An example for what this means in practice is anthropologist Jason Throop's writing on traditional bonesetting on the island of Yap in Micronesia. Throop (2012) takes a phenomenological lens to examining embodied forms of understanding between healer and patient. Lani, a healer Throop spent time with is generally recognised as an exceptional healer in the Yapese community. As a bonesetter, she has developed a sensorial familiarity with the joints, muscles, and bones of the body; instead of X-rays and medical tests, she uses her tactility to tell if something is wrong. Lani told Throop that her ability to diagnose and heal a patient is conditional to the patient feeling the pain: Lani works out what is happening to the patient's body by touching and massaging the pained tissue. However, Throop observes that Lani is particularly perceptive of people's emotional states; this is significant for her therapeutic practice, as a misplaced touch could cause further injuries. Even with less expressive patients, Throop writes, Lani could tell how much pain they were feeling from minuscule changes in muscle tension.

What Throop observed between Lani and her patients resonates with the interactions I observed at the workshops. The way tutors and support workers understood participants' seemingly fleeting and indiscernible body language is indicative of an embodied form of attention. Throop (2012) writes that these forms of understanding "complement and yet importantly extend what are at times the often overly intellectualist, emotional, or discursive views of empathy that are prevalent in contemporary philosophical and social theories" (p. 424).

If embodied experiences mediate social relationships, it does not take a big leap to examine the way in which they shape the rules of belonging that constitute citizenship. In much of disability studies, embodied citizenship is discussed inasmuch as it relates to the ways bodily difference excludes people from participation, such as access to employment and education. These are important works from a social justice perspective. However, in predominantly framing embodied citizenship in terms of what is being done to the bodies of disabled people, there is a risk of framing bodies as passive objects onto which oppressive structures – disablist policies, language, imagination – are inscribed (Bacchi and Beasley, 2002). As feminist scholars Bacchi and Beasley (2002) argue that contrary to bodies being simply a blank canvas that reflect social structures, embodied experiences of the everyday life simultaneously shape and are being shaped by individuals' self and sociality. In line with the phenomenological tradition, examining embodied citizenship is must not be limited to the study of how citizenship excludes certain bodies; it also needs to explore how embodied experiences make citizen subjectivities.

Although it has been long recognised that bodies and sociality are co-constitutive (see Bourdieu, 1977; Howes, 2010), the anthropological scholarship has only recently started to explore it in relation to the concept of citizenship. In their edited book, Trnka et al. (2013) display a wide range of ways in which communities are constituted through the cultivation of sensorial practice in relation to, for example, taste (Newcomb, 2013), dance (Hughes-Freeland, 2013), and sound (Booth, 2013).

For instance, Rachel Newcomb (2013) discusses they ways in which the post-2000s economic liberalisation changed the sensorial modes in which Moroccan people engaged with their food, thereby the way Moroccan citizenship and identity were formed. Newcomb argues, economic liberalisation created the citizen-consumer via fundamentally changing diets, eating schedules, and grocery shopping habits. This also changed people's sensory experience of food: the introduction of ready-made meals to Moroccan cuisine, while sanitised supermarkets replaced olfactory overload of traditional food markets. Newcomb's work highlights how facets of citizenship are mediated by the senses: the construction of the citizen predicates upon the naturalisation of certain ways of sensing, tasting, smelling.

These sensorial aspects of the citizenship of individuals with significant learning disabilities often go unacknowledged in favour of cognitivised, abstract, and disembodied formulations of citizenship. In the art workshops, embodied forms of attention, empathy, and connection provide a language by which the tutors, support workers, and participants interact with each other. The tutors and support workers rely on this type of embodied understanding to help participants make choices, make art, and socialise.

These are more than just strategies tutors and support workers employ to help participants make art. They are the basic mechanism by which participants are supported to practice the ideals of citizenship. This approach to the body is different from that in pre-existent medical and psychological literature, where bodies are seen as passive objects onto which social and health inequalities inscribe themselves (as ill health, comorbidities, and impairment). When the embodied basis of interactions are foregrounded, the bodies of people with learning disabilities transform into an active subject that makes individuals into citizens.

Examining and documenting the existence and cultivation of sensorial citizenship therefore provides an alternative to current exclusive narratives of what makes a citizen.

These observations give a clear outline of the qualities that make a good care and support worker: someone who recognises different forms of communication, is perceptive to sensory cues, and has the attention, patience, and sensitivity to interact with care-recipients with an embodied language. These qualities need to be recognised and nurtured, as they can be taught and learned. Although most people I met at the workshops engaged with people with learning disabilities with a sensorial attentiveness which they learnt on the job, social policy and service provision could provide more formalised training and support for those who are new to the field.

The material conditions of citizenship

This kind of personal support is contingent on the relationship between care provider and recipient, the space for experimentation and indeterminacy, and material resources. However, social care provision not only falls short by failing to provide adequate time, materials, and space for care-relationships to develop (Needham, 2014); the principle under which social care is organised – personalisation and austerity – is fundamentally unprepared to meet these needs.

The spending cuts created working conditions that prevented carers and care recipients from being able to establish a close and personal working relationship. The cuts resulted in staff shortages and increased workloads for support workers, which meant they had to take on caring responsibilities for multiple people in a day. Subsequently, they were afforded reduced time that they could spend with individual care recipients (Brimblecombe et al., 2018). Both care workers and families of care recipient have raised concerns with the subsequent decrease in the quality of care (Malli et al., 2018).

At the same time, paid care work was deskilled and devalued: there is little training for people entering support work. Those who provide care do so on low wages, and their labour is considered replaceable (UNISON, 2018). This means that care recipients do not have continuity of care and may be assigned a different person to help them with their daily activities without much notice. The hours of support care recipients are entitled to have also been reduced, placing additional time and emotional pressures on unpaid carers, many of whom faced difficulties balancing their care responsibilities and their employment (Brimblecombe et al., 2018). The language of choice, control, and independence in the personalisation agenda offers little guidance for such a resource-poor context: policy documents do not discuss the care provider-recipient relationship.

The same applies to the working conditions of staff employed at third sector service providers like Project Ability. Unlike many similar services in Scotland, Project Ability's art workshops survived austerity. However, despite a growth in their attendance – due to cuts to other services – staffing did not increase: the same number of tutors continue to run the workshop, while number of attendants doubled in size. At the time of my fieldwork, the tutors had not received a pay raise for fifteen years. Because they were employed as freelancers, they did not receive income from Project Ability when the workshops went on their monthly breaks. To compensate for the unreliable salary, many of them juggled several freelance projects simultaneously, and some of them were considering the possibility of finding more stable employment.

When service provision is underfunded and overstretched, there is little space for carers and care recipients to experiment and explore by taking part in different activities. Public services that provide leisure activities for people with learning disabilities – such as the art workshops of Project Ability – are oversubscribed (Walker and Hayton, 2017). This means that there are hardly any options for individuals with learning disabilities who want to pursue one activity, let alone enough for them to alternate between different programmes the way participants in the Project Ability workshop are encouraged to experiment and explore with different artmaking techniques. This kind of experimentation is further discouraged when care recipients are expected to set goals to develop their knowledge, skills, and self-management. Their care plans are set up to systematically pursue these goals in a cost-efficient manner.

Although at the time of my fieldwork, Project Ability successfully renewed its core funding for their main workshops for an extra five years, many of their extracurricular activities have been either cut or significantly shortened due to the lack of resources. For instance, the walking group that took participants around the city's art galleries and heritage sites had to cease due to lack of funding.

Ultimately, recognising and supporting the citizenship of people with learning disabilities requires a better redistribution of resources. There is a difference to be made here between citizenship-as-recognition and citizenship-as-redistribution, a conceptual distinction coined by Fraser and Honneth (2003). Arguably, the citizenship of people with learning disabilities has been widely recognised: it is generally accepted that they are citizens, have rights, and should be treated with dignity and respect. However, to be able to live the dignified life as citizens, people with learning disabilities also require extensive affirmative measures, which rely on a more equal redistribution of resources. This comprises more support staff, whose labour should be valued more with higher wages and better work conditions. More resources need to be spent on support hours: this would help people with learning disabilities and those who work them spend more time with each other. This in turn enables better communication and support. People with learning disabilities also need more options for spaces of friendship and belonging, in addition to the activities aimed at improving skills and employability.

Besides spending more on social care, the economistic logic of public services need to be rethought. Current services are geared towards efficient delivery, which means that they are often required to demonstrate clear goals, timeframe, and efficient delivery. However, not all activities lend themselves to quantifiable outcomes, such as artmaking in Project Ability, where participants are not expected to meet clearly defined goals within any set timeframes. Efficiency means that there is no wasted time and materials in delivering an end result: but waste is not in a vocabulary of the workshops. Participants do not have to account for how they spend their time in the workshop, and how they use the materials. Their enjoyment with the artmaking is valued equally, even though for some participants it may take months – sometimes years – to demonstrate that they are engaged. Because the workshops escape the economistic logic of social care delivery, they enable a space where people with learning disabilities can be supported to engage in activities that cultivate their citizenship.

Ultimately, the issue with a scarcely funded care sector propped up by an economistic logic is that it frames dignified treatment of people with learning disabilities and the working conditions of people employed in the care sector as a zero-sum game. There is an insidious assumption behind the funding cuts which claims that because there are limited resources, one needs to choose between the interests of people with learning disabilities and care workers: the money can only either go to fund services, or improve working conditions. This is a false dichotomy that advocates of disability rights must not fall for. Firstly, because as Project Ability demonstrates, it is untrue: the more that the labour of care providers are recognised and valued, the better they are able to provide improved services for people with learning disabilities. Secondly and more importantly, better treatment for one group cannot be achieved at the expense of another. Justice has to be built by expanding solidarity between people; otherwise it is not justice at all.

What does this mean for the citizenship and learning disabilities?

I opened this thesis by observing that for much of the learning disability scholarship, policy, and service provision, citizenship has been predominantly understood as a status that granted people to political, civil, and social rights. In this thesis, I departed from these accounts and examined citizenship as practice. In this final section, I will reflect on what a practice-based approach says about the citizenship of people with learning disabilities, and discuss the key messages for future research and social policy.

In my first chapter I wrote that even though ideals of liberal citizenship disregard the interests of people with learning disabilities, an anthropological examination has the potential to highlight how these ideals guide everyday practices, are constitutive of desires and aspirations, and may therefore be emancipatory despite their philosophically exclusive origins. The ethnographic examples I cited in this thesis clearly illustrate that citizenship is a valuable tool for addressing issues of inequalities and injustices, and for examining and advocating for better practices regarding engagement with people with learning disabilities. Citizenship-as-practice reveals how these ideals are lived: how they manifest in relationships and routines, what conundrums they pose in everyday situations, and how people negotiate and resolve these conundrums. Not only does citizenship as an analytical tool reveal discrepancies in equality and justice, but it also foregrounds the everyday strategies people employ to mitigate these, which, in turn, can generate policy action. The relative novelty of practice-based approaches to citizenship in learning disabilities research means that there is still much untapped emancipatory steam left in the concept for future research and advocacy to explore.

Secondly, citizenship-as-practice produces new takes on old philosophical debates, understandings of ethical engagement, and examples of best practice. A practice-based approach moves the focus of citizenship theories beyond individuals' basic entitlements, as it seeks to envision what life could be like once those entitlements are granted. Rights guarantee what Nussbaum (2006) refers to as a social minimum: a threshold provision under which it is not possible to live a dignified life. However, rights say little about what happens once one reaches this social minimum. A rights-based approach may help uncover what is wrong with the provision of justice; a practice-based approach can help generate discussions around what kind of society we want to build. This thesis argued that the practices around citizenship could help individuals with learning disabilities flourish: to explore their desires, develop their preferences, and pursue their aspirations. Being a citizen not only means that individuals have the right to not suffer or die prematurely; there is room in there for play, imagination, and affection (Nussbaum, 2006). Approaching citizenship this way not only provides directions on the sort of engagement that would support individuals to flourish, but it also argues that such engagement should be the fundamental organising principle of society.

My thesis focuses on the way one organisation helps people flourish. Although I used my observations to reflect on broader assumptions about justice, equality, agency, and personhood, much can be learnt by taking this anthropological lens elsewhere. I discussed artmaking, but there is a question of how the observations on citizenship manifest other in other learning disability services and organisation; in families, employment, education; with regards to housing, healthcare, or parenting. How is citizenship lived, negotiated, facilitated, and hindered in these contexts?

I have emphasised the importance of Project Ability providing a space where people with learning disabilities could exist without being pressured, judged, harassed, or disciplined. Besides being a shelter, the studio also served as a space of friendship and positive social encounters, exploration, self-development, and care. The studio’s microcosm offered an alternative to managerial and economistic social relations. The question is, can the features that make Project Ability an exemplary service be applied to other organisations? Could these features be taken up outside of service provision, to non-segregated spaces, in order to make “mainstream” society more welcoming for people with learning disabilities? What would such a space look like, what kind of sociality would it enable, and what kind of institutional and material conditions would that require?

Finally, I examined the nature of the support relationship between the art tutors, support workers, and the participants, and highlighted how they are essential to the citizenship of people with learning disabilities. Future research could examine how these support relationships could be extrapolated to wider society. The way participants in Project Ability are treated exemplify what treating people with learning disabilities as citizens truly means: it is not only defined by the recognition that people with learning disabilities are capable individuals, but also by the ability to listen to and interact with them based on their capacity of self-expression, and by the willingness to render oneself vulnerable to and appreciative. These abilities are not only relevant for people working in care provision, but serve with lessons for us all on how to ethically engage with one another.

This thesis could potentially contribute to improving policy and practice in relation to social care and support of people with significant learning disabilities. First of all, the findings highlight the importance of increasing public spending and providing more funding for services. The atypical social arrangements that people with learning disabilities require to practice citizenship relies upon the services of organisations like Project Ability, who need funding for art materials, staff, and studio space. In addition, more funding is needed to improve the working conditions of service providers – in this case, freelance art tutors and support workers. I also hoped to demonstrate the centrality of spaces like the Project Ability art studio and the importance of the infrastructure that people with learning disabilities rely on to get there. Affordable and accessible public transport and safer streets are a necessary condition of the citizenship of people with learning disabilities; therefore, it is crucial to put in place policies that improve and maintain this infrastructure. Finally, as part of the aim of this thesis, I highlighted exemplary practice that support people with learning disabilities to become citizens. I specifically focused on the non-verbal, sensorial modes of attention, communication, and care tutors and support workers demonstrated towards the participants. These qualities should be better recognised and supported in social care services for instance by providing formal training to new entries. All this could contribute improved services and better treatment for people with learning disabilities.

Conclusion

In this final chapter, I presented the overarching themes that emerged from the ethnographic material. I observed that citizenship was a process rather than a status; that it was mediated by embodied relationships as opposed to abstract and cognitivised rules of belonging; and that the recognition of citizenship was conditional to a more equal redistribution of resources. I then discussed what these observations said about the citizenship of people with learning disabilities, and reflected on the possibilities of future research based on these findings.

I hope to have conveyed three overall messages with this thesis. The first is the merit of anthropological, practice-based approaches for examining abstract, taken-for-granted concepts, and for outlining new visions of social life. If anything, this ethnography should have made the case for how practice-based approaches could enrich epistemological debates and intellectual projects by grounding them in everyday life, and thus revealing the sociality and agency that emerge in their wake. Secondly, I hope to have demonstrated the methodological possibilities of ethnographic research and long-term participant observation with people with learning disabilities, especially with individuals with significant impairments. Conversely, I hope to have illustrated how researching with people with learning disabilities could challenge and further develop the principles of the ethnographic method.

Finally, my aim with this thesis was to contribute to a so far limited body of scholarship that sits at the intersection of anthropology and learning disability studies. I hope that this work illustrated how marrying the two fields could generate productive conversations. Embracing an anthropological lens of analysis could infuse the field of learning disability studies with new theoretical and methodological directions; in exchange, anthropological interest in learning disabilities can contribute to anthropology recognising further forms of equality, justice, agency, and personhood.

Such recognition is humbling. It highlights the expanse of each individual's potential, and it makes visible the work that goes into responding to and realising such potential. More importantly, it underlines our obligation to engage; this engagement is what citizenship is made of.

References

Abbott D and Marriott A (2013) Money, finance and the personalisation agenda for people with learning disabilities in the UK: some emerging issues. *British Journal of Learning Disabilities* 41(2): 106–113. DOI: 10.1111/j.1468-3156.2012.00728.x.

Abu-Lughod L (2002) Do Muslim Women Really Need Saving? Anthropological Reflections on Cultural Relativism and Its Others. *American Anthropologist* 104(3): 783–790. DOI: 10.1525/aa.2002.104.3.783.

Akamoglu Y and Meadan H (2018) Parent-Implemented Language and Communication Interventions for Children with Developmental Delays and Disabilities: a Scoping Review. *Review Journal of Autism and Developmental Disorders* 5(3): 294–309. DOI: 10.1007/s40489-018-0140-x.

Aldridge J (2007) Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability & Society* 22(1): 1–17. DOI: 10.1080/09687590601056006.

Alexandra P, Angela H and Ali A (2018) Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities* 31(5): 643–658. DOI: 10.1111/jar.12432.

American Anthropologial Association (2012) AAA Statement on Ethics. Available at: https://www.americananthro.org/LearnAndTeach/Content.aspx?ItemNumber=22869&navItemNumber=652 (accessed 6 January 2021).

American Psychiatric Association (2013) DSM-5 Intellectual Disability Fact Sheet. American Psychiatric Association. Available at: http://dsm5.org/psychiatrists/practice/dsm/educational-resources/dsm-5-fact-sheets.

Angrosino MV (2004) Participant Observation and Research on Intellectual Disabilities. In: Emerson E, Hatton C, Thompson T, et al. (eds) *The International Handbook of Applied Research in Intellectual Disabilities*. John Wiley & Sons Ltd, pp. 161–177. DOI: 10.1002/9780470713198.ch7.

Association of Social Anthropologists of the UK and and the Commonwealth (ASA) (2011) Ethical Guidelines for good research practice. Available at: https://www.theasa.org/downloads/ASA%20ethics%20guidelines%202011.pdf (accessed 6 January 2021).

Atkinson D and Williams F (1990) *Know Me As I Am*. 1st ed. edition. Milton Keynes: Hodder Education.

Atkinson D, McCarthy M and Walmsley J (eds) (2000) *Good Times, Bad Times: Women with Learning Difficulties Telling Their Stories*. Birmingham: BILD Publications.

Bacchi CL and Beasley C (2002) Citizen bodies: is embodied citizenship a contradiction in terms? *Critical Social Policy* 22(2). SAGE Publications Ltd: 324–352. DOI: 10.1177/02610183020220020801.

Baines D and Cunningham I (2015) Care work in the context of austerity. *Competition & Change* 19(3): 183–193. DOI: 10.1177/1024529415580263.

Bank-Mikkelsen NE (1969) A Metropolitan Area in Denmark: Copenhagen: Danish National Service for the Mentally Retarded. In: Kugel RB and Wolfensberger W (eds) *Changing Patterns in Residential Services for the Mentally Retarded*. President's Committee on Mental Retardation, pp. 229–245.

Barfoot M (2009) The 1815 Act to Regulate Madhouses in Scotland: A Reinterpretation. *Medical History* 53(1): 57–76.

Bartlett P and Wright D (eds) (1999) *Outside the Walls of the Asylum: The History of Care in the Community 1750-2000*. A&C Black.

Bates K, Goodley D and Runswick-Cole K (2017) Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity. *Disability & Society* 32(2): 160–175. DOI: 10.1080/09687599.2017.1281105.

Bates P and Davis FA (2004) Social capital, social inclusion and services for people with learning disabilities. *Disability & Society* 19(3): 195–207. DOI: 10.1080/0968759042000204202.

Beckett AE (2006) *Citizenship and Vulnerability: Disability and Issues of Social and Political Engagement*. Houndsmill, Basingstoke: Palgrave Macmillan.

Bennet D and Morris I (1982) Deinstitutionsalition in the United Kingdom. *International Journal of Mental Health* 11(4): 5–23.

Bentley S, Nicholls R, Price M, et al. (2011) 'Our Journey Through Time': an oral history project carried out by young people with learning disabilities. *British Journal of Learning Disabilities* 39(4): 302–305. DOI: 10.1111/j.1468-3156.2010.00668.x.

Biehl JG (2005) *Vita: Life in a Zone of Social Abandonment*. University of California Press.

Biehl JG (2007) *Will to Live: AIDS Therapies and the Politics of Survival*. Princeton University Press.

Bigby C and Frawley P (2010) Reflections on doing inclusive research in the “Making Life Good in the Community” study. *Journal of Intellectual & Developmental Disability* 35(2): 53–61. DOI: 10.3109/13668251003716425.

Bigby C and Fyffe C (2009) Position statement on housing and support for people with severe or profound intellectual disability. *Journal of Intellectual & Developmental Disability* 34(1). Taylor & Francis: 96–100. DOI: 10.1080/13668250802676020.

Bigby C and Wiesel I (2011) Encounter as a dimension of social inclusion for people with intellectual disability: Beyond and between community presence and participation. *Journal of Intellectual & Developmental Disability* 36(4): 263–267. DOI: 10.3109/13668250.2011.619166.

Bigby C and Wiesel I (2015) Mediating Community Participation: Practice of Support Workers in Initiating, Facilitating or Disrupting Encounters between People with and without Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 28(4): 307–318. DOI: 10.1111/jar.12140.

Bigby C and Wiesel I (2018) Using the concept of encounter to further the social inclusion of people with intellectual disabilities: what has been learned? *Research and Practice in Intellectual and Developmental Disabilities* 0(0): 1–13. DOI: 10.1080/23297018.2018.1528174.

Bigby C, Frawley P and Ramcharan P (2014) Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 27(1): 3–12. DOI: 10.1111/jar.12083.

Bigby C, Bould E and Beadle-Brown J (2017) Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual & Developmental Disability* 42(4): 309–319. DOI: 10.3109/13668250.2016.1253051.

Björnsdóttir K, Stefánsdóttir GV and Stefánsdóttir Á (2015) ‘It’s my life’: Autonomy and people with intellectual disabilities. *Journal of Intellectual Disabilities* 19(1): 5–21. DOI: 10.1177/1744629514564691.

Blackburn C (2009) Differentiating indigenous citizenship: Seeking multiplicity in rights, identity, and sovereignty in Canada. *American Ethnologist* 36(1): 66–78. DOI: 10.1111/j.1548-1425.2008.01103.x.

Blasco PG y and Wardle H (2006) *How to Read Ethnography*. 1st edition. Abingdon England ; New York: Routledge.

Blunt C, Blyth C, Chapman R, et al. (2012) Editorial. *British Journal of Learning Disabilities* 40(2): 83–84. DOI: 10.1111/j.1468-3156.2012.00748.x.

Bogdan R and Taylor SJ (1982) *Inside Out: The Social Meaning of Mental Retardation*. University of Toronto Press.

Booth GD (2013) Gender, Nationalism, and Sound: Outgrowing ‘Mother India’. In: Trnka S, Dureau C, and Park J (eds) *Senses and Citizenships: Embodying Political Life*. Routledge, pp. 136–158.

Bourdieu P (1977) *Outline of a Theory of Practice* (tran. R Nice). Cambridge: Cambridge University Press.

Bourdieu P (1980) *The Logic of Practice* (tran. R Nice). Cambridge: Polity Press.

Boxall K and Ralph S (2011) Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities* 39(3): 173–180. DOI: 10.1111/j.1468-3156.2010.00645.x.

Brimblecombe N, Pickard L, King D, et al. (2018) Barriers to Receipt of Social Care Services for Working Carers and the People They Care For in Times of Austerity. *Journal of Social Policy* 47(2): 215–233. DOI: 10.1017/S0047279417000277.

Brindle D (2011) Remploy factories for disabled workers could all close. *The Guardian*, 11 July. Available at: https://www.theguardian.com/society/2011/jul/11/remploy-factories-could-close (accessed 6 December 2019).

Buccitelli AB (2016) Digital Ethnography: Anthropology, Narrative, and New Media. *Journal of American Folklore* 129(511). Columbus: American Folklore Society, Inc.: 100–101.

Burke A, McMillan J, Cummins L, et al. (2003) Setting up participatory research: a discussion of the initial stages. *British Journal of Learning Disabilities* 31(2): 65–69. DOI: 10.1046/j.1468-3156.2003.00183.x.

Burton M and Kagan C (2006) Decoding Valuing People. *Disability & Society* 21(4): 299–313. DOI: 10.1080/09687590600679899.

Butler J (2016) Rethinking vulnerability and resistance. In: Butler J, Gambetti Z, and Sabsay L (eds) *Vulnerability in Resistance*. Durham: Duke University Press, pp. 12–27.

Cameron D (2009) The age of austerity. Available at: http://conservative-speeches.sayit.mysociety.org/speech/601367 (accessed 6 December 2019).

Cameron L and Murphy J (2007) Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities* 35(2): 113–120. DOI: 10.1111/j.1468-3156.2006.00404.x.

Campbell F (2009) *Contours of Ableism: The Production of Disability and Abledness*. Springer.

Cardinal R (2009) Outsider Art and the autistic creator. *Philosophical Transactions of the Royal Society B: Biological Sciences* 364(1522): 1459–1466. DOI: 10.1098/rstb.2008.0325.

Carey A (2009a) *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America*. Philadelphia: Temple University Press.

Carey A (2009b) The Feebleminded versus the Nation 1900 –1930s. In: *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America*. Philadelphia: Temple University Press, pp. 52–82.

Carlson L and Kittay EF (2010) Introduction: Rethinking Philosophical Presumptions in Light of Cognitive Disability. In: Carlson L and Kittay EF (eds) *Cognitive Disability and Its Challenge to Moral Philosophy*. Wiley-Blackwell, pp. 1–28.

Chaplin E, Paschos D, O'Hara J, et al. (2010) Mental ill-health and care pathways in adults with intellectual disability across different residential types. *Research in Developmental Disabilities* 31(2): 458–463. DOI: 10.1016/j.ridd.2009.10.015.

Chapman R (2014) An Exploration of the Self-Advocacy Support Role Through Collaborative Research: 'There Should Never be a Them and Us'. *Journal of Applied Research in Intellectual Disabilities* 27(1): 44–53. DOI: 10.1111/jar.12084.

Chappell AL, Goodley D and Lawthom R (2001) Making connections: the relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities* 29(2): 45–50. DOI: 10.1046/j.1468-3156.2001.00084.x.

Chinn D (2017) Review of Interventions to Enhance the Health Communication of People With Intellectual Disabilities: A Communicative Health Literacy Perspective. *Journal of Applied Research in Intellectual Disabilities* 30(2): 345–359. DOI: 10.1111/jar.12246.

Christensen K (2010) Caring about independent lives. *Disability & Society* 25(2): 241–252. DOI: 10.1080/09687590903537562.

Christensen K (2012) Towards sustainable hybrid relationships in cash-for-care systems. *Disability & Society* 27(3): 399–412. DOI: 10.1080/09687599.2012.654990.

Clegg J and Bigby C (2017) Debates about dedifferentiation: twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group. *Research and Practice in Intellectual and Developmental Disabilities* 4(1): 80–97. DOI: 10.1080/23297018.2017.1309987.

Clegg J, Murphy E, Almack K, et al. (2007) Tensions Around Inclusion: Reframing the Moral Horizon. *Journal of Applied Research in Intellectual Disabilities* 21(1): 81–94. DOI: 10.1111/j.1468-3148.2007.00371.x.

Clement T and Bigby C (2009) Breaking Out of a Distinct Social Space: Reflections on Supporting Community Participation for People with Severe and Profound Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities* 22(3): 264–275. DOI: 10.1111/j.1468-3148.2008.00458.x.

Cohen MN (2002) An anthropologist looks at 'race' and IQ testing. In: Fish JM (ed.) *Race and Intelligence: Separating Science From Myth*. London: Routledge, pp. 201–223.

Collinson P (2019) Life expectancy falls by six months in biggest drop in UK forecasts. *The Guardian*, 7 March. Available at: https://www.theguardian.com/society/2019/mar/07/life-expectancy-slumps-by-five-months (accessed 6 December 2019).

Concannon L (2005) *Planning For Life: Involving Adults with Learning Disabilities in Service Planning*. Routledge.

Cooper M and Atkinson D (n.d.) Mabel's story | Social History of Learning Disability. Available at: http://www.open.ac.uk/health-and-social-care/research/shld/resources-and-publications/life-stories/mabels-story (accessed 31 July 2020).

Crăciun M (2017) Aesthetics, ethics and fashionable veiling: a debate in contemporary Turkey. *World Art* 7(2). Routledge: 329–352. DOI: 10.1080/21500894.2017.1339732.

Crow L (1996) Including all our lives: renewing the social model of disability. In: Barned C and Mercer G (eds) *Exploring the Divide*. Leeds: The Disability Press, pp. 55–72.

Csordas TJ (1990) Embodiment as a Paradigm for Anthropology. *Ethos* 18(1): 5–47.

Csordas TJ (1994) *Embodiment and Experience: The Existential Ground of Culture and Self*. Cambridge University Press.

Culham A and Nind M (2003) Deconstructing normalisation: clearing the way for inclusion. *Journal of Intellectual & Developmental Disability* 28(1): 65–78. DOI: 10.1080/1366825031000086902.

Cunningham I and James P (2014) Public Service Outsourcing and its Employment Implications in an Era of Austerity: The Case of British Social Care. *Competition & Change* 18(1): 1–19. DOI: 10.1179/1024529413Z.00000000045.

Davis J (2000) Disability Studies as Ethnographic Research and Text: Research strategies and roles for promoting social change? *Disability & Society* 15(2): 191–206. DOI: 10.1080/09687590025621.

Davy L (2015) Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory. *Hypatia* 30(1): 132–148. DOI: 10.1111/hypa.12119.

Department of Health (2001) *Valuing people A new strategy for learning disability for the 21st century: a white paper*. White paper. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf.

Department of Health and Social Care (2000) No Secrets: guidance on protecting vulnerable adults in care.

Department of Health and Social Security (1969) *Report on Ely Hospital*. Cmnd 3975. Available at: https://www.sochealth.co.uk/national-health-service/democracy-involvement-and-accountability-in-health/complaints-regulation-and-enquries/report-of-the-committee-of-inquiry-into-allegations-of-ill-treatment-of-patients-and-other-irregularities-at-the-ely-hospital-cardiff-1969/ (accessed 22 August 2020).

Dexter LA (1962) On the Politics and Sociology of Stupidity in Our Society. *Social Problems* 9(3). [Oxford University Press, Society for the Study of Social Problems]: 221–228. DOI: 10.2307/799232.

Di Lorito C, Bosco A, Birt L, et al. (2017) Co-research with adults with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities*. DOI: 10.1111/jar.12435.

Driessen A (2018) Pleasure and Dementia: On Becoming an Appreciating Subject. *The Cambridge Journal of Anthropology* 36(1): 23–39. DOI: 10.3167/cja.2018.360103.

Duffy S (2013) *A fair society? How the cuts target disabled people*. The Centre for Welfare Reform.

Duffy S (2017) The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities* 4(1): 26–34. DOI: 10.1080/23297018.2017.1292147.

Duggan C and Linehan C (2013) The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature. *British Journal of Learning Disabilities* 41(3): 199–207. DOI: 10.1111/bld.12040.

Ecks S (2005) Pharmaceutical Citizenship: Antidepressant Marketing and the Promise of Demarginalization in India. *Anthropology & Medicine* 12(3): 239–254. DOI: 10.1080/13648470500291360.

Edgerton RB (1967) *The Cloak of Competence*. Berkeley: University of California Press.

Edgerton RB (1993) *The Cloak of Competence, Revised and Updated Edition*. University of California Press.

Ellis C (1995) EMOTIONAL AND ETHICAL QUAGMIRES IN RETURNING TO THE FIELD. *Journal of Contemporary Ethnography* 24(1). SAGE Publications Inc: 68–98. DOI: 10.1177/089124195024001003.

Emerson E (2007) Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 13(2): 107–113. DOI: 10.1002/mrdd.20144.

Emerson E and Baines S (2011) Health inequalities and people with learning disabilities in the UK. *Tizard Learning Disability Review* 16(1): 42–48. DOI: 10.5042/tldr.2011.0008.

Emerson E and Einfeld SL (2011) *Challenging Behaviour*. Cambridge University Press.

Emerson E and Hatton C (1998) Residential Provision for People with Intellectual Disabilities in England, Wales and Scotland. *Journal of Applied Research in Intellectual Disabilities* 11(1): 1–14. DOI: 10.1111/j.1468-3148.1998.tb00030.x.

Emerson E and Roulstone A (2014) Developing an Evidence Base for Violent and Disablist Hate Crime in Britain: Findings From the Life Opportunities Survey. *Journal of Interpersonal Violence* 29(17): 3086–3104. DOI: 10.1177/0886260514534524.

Erevelles N (2011) (Im)material citizens: cognitive disability, race, and the politics of citizenship. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*: 147-+.

Estroff (1985) *Making It Crazy: An Ethnography of Psychiatric Clients in an American Community*. New Ed edition. Berkeley, CA: University of California Press.

Evans-Pritchard EE (1940) *The Nuer: A Description of the Modes of Livelihood and Political Institutions of a Nilotic People*. New e. edition. New York: OUP USA.

FAQ - Self-directed Support (2018). Available at: http://www.selfdirectedsupportscotland.org.uk/faq (accessed 4 December 2018).

Fassin D (2007) *When Bodies Remember: Experiences and Politics of AIDS in South Africa*. University of California Press.

Fassin D (2012) *Humanitarian Reason: A Moral History of the Present*. University of California Press.

Feldman I (2007) Difficult Distinctions: Refugee Law, Humanitarian Practice, and Political Identification in Gaza. *Cultural Anthropology* 22(1): 129–169.

Ferguson I (2007) Increasing User Choice or Privatizing Risk? The Antinomies of Personalization. *The British Journal of Social Work* 37(3): 387–403. DOI: 10.1093/bjsw/bcm016.

Ferguson I (2012) Personalisation, social justice and social work: a reply to Simon Duffy. *Journal of Social Work Practice* 26(1): 55–73. DOI: 10.1080/02650533.2011.623771.

Finkelstein V (1980) *Attitudes and Disabled People : Issues for Discussion*. World Rehabilitation Fund. Available at: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-attitudes.pdf.

Flood S, Bennett D, Melsome M, et al. (2012) Becoming a researcher. *British Journal of Learning Disabilities* 41(4): 288–295. DOI: 10.1111/j.1468-3156.2012.00756.x.

Forrester-Jones R, Carpenter J, Coolen-Schrijner P, et al. (2006) The Social Networks of People with Intellectual Disability Living in the Community 12 Years after Resettlement from Long-Stay Hospitals. *Journal of Applied Research in Intellectual Disabilities* 19(4): 285–295. DOI: 10.1111/j.1468-3148.2006.00263.x.

Foucault M (1961) *Madness and Civilization: A History of Insanity in the Age of Reason* (tran. R Howard). New York: Pantheon Books.

Foucault M (1976) *The History of Sexuality: An Introduction* (tran. R Hurley). New York: Pantheon Books.

Francis LP and Silvers A (2010) Thinking About the Good: Reconfiguring Liberal Metaphysics (or Not) for People with Cognitive Disabilities. In: Kittay EF and Carlson L (eds) *Cognitive Disability and Its Challenge to Moral Philosophy*. Wiley-Blackwell, pp. 237–260.

Frankena TK, Naaldenberg J, Cardol M, et al. (2015) Active involvement of people with intellectual disabilities in health research – A structured literature review. *Research in Developmental Disabilities* 45–46(Supplement C): 271–283. DOI: 10.1016/j.ridd.2015.08.004.

Fraser N (2013) *Fortunes of Feminism: From State-Managed Capitalism to Neoliberal Crisis*. Verso Books.

Fraser N and Honneth A (2003) *Redistribution Or Recognition?: A Political-Philosophical Exchange*. Verso.

Frawley P and Bigby C (2011) Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual & Developmental Disability* 36(1): 27–38. DOI: 10.3109/13668250.2010.549465.

Fyson R and Cromby J (2013) Human rights and intellectual disabilities in an era of 'choice'. *Journal of Intellectual Disability Research* 57(12): 1164–1172. DOI: 10.1111/j.1365-2788.2012.01641.x.

Fyson R and Fox L (2014) Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning. *Disability & Society* 29(2). Routledge: 239–254. DOI: 10.1080/09687599.2013.776491.

Fyson R and Kitson D (2010) Human Rights and Social Wrongs: Issues in Safeguarding Adults with Learning Disabilities. *Practice* 22(5). Routledge: 309–320. DOI: 10.1080/09503153.2010.517831.

Fyson R, McBride G and Myers B (2004) Progress on Participation? Self-Advocate Involvement in Learning Disability Partnership Boards. *Tizard Learning Disability Review* 9(3). Emerald Group Publishing Limited: 27–36. DOI: 10.1108/13595474200400025.

Gallie WB (1956) IX.—Essentially Contested Concepts. *Proceedings of the Aristotelian Society* 56(1). Wiley-Blackwell: 167–198. DOI: 10.1093/aristotelian/56.1.167.

Genova ND (2013) Spectacles of migrant 'illegality': the scene of exclusion, the obscene of inclusion. *Ethnic and Racial Studies* 36(7): 1180–1198. DOI: 10.1080/01419870.2013.783710.

Gentleman A (2019) Austerity has fuelled racial inequality in the UK, says UN expert. *The Guardian*, 14 June. Available at: https://www.theguardian.com/business/2019/jun/14/austerity-has-fuelled-racial-inequality-in-the-uk-says-un-expert (accessed 6 December 2019).

Gevarter C, O'Reilly MF, Rojeski L, et al. (2013) Comparing communication systems for individuals with developmental disabilities: A review of single-case research studies. *Research in Developmental Disabilities* 34(12): 4415–4432. DOI: 10.1016/j.ridd.2013.09.017.

Gibbon S (2006) *Breast Cancer Genes and the Gendering of Knowledge: Science and Citizenship in the Cultural Context of the 'New' Genetics*. Palgrave Macmillan UK.

Gilbert T (2004) Citizenship: locating people with intellectual disabilities (ID). *Journal of Intellectual Disability Research* 48: 482–482.

Gilmore L and Cuskelly M (2014) Vulnerability to Loneliness in People with Intellectual Disability: An Explanatory Model. *Journal of Policy and Practice in Intellectual Disabilities* 11(3): 192–199. DOI: 10.1111/jppi.12089.

Ginn J (2013) Austerity and Inequality. Exploring the Impact of Cuts in the UK by Gender and Age. *Research on Ageing and Social Policy* 1(1): 28–53. DOI: 10.4471/rasp.2013.02.

Ginsburg F and Rapp R (2013) Entangled ethnography: Imagining a future for young adults with learning disabilities. *Social Science & Medicine* 99: 187–193. DOI: 10.1016/j.socscimed.2013.11.015.

Ginsburg F and Rapp R (2018) Cognitive Disability: Towards an Ethics of Possibility. *The Cambridge Journal of Anthropology* 36(1): 113–119. DOI: 10.3167/cja.2018.360109.

Goffman E (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Garden City: Anchor Books.

Goodley D (1996) Tales of Hidden Lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society* 11(3): 333–348. DOI: 10.1080/09687599627642.

Goodley D (1999) Disability Research and the “Researcher Template”: Reflections on Grounded Subjectivity in Ethnographic Research. *Qualitative Inquiry* 5(1): 24–46. DOI: 10.1177/107780049900500102.

Goodley D (2001) ‘Learning Difficulties’, the Social Model of Disability and Impairment: Challenging epistemologies. *Disability & Society* 16(2): 207–231. DOI: 10.1080/09687590120035816.

Goodley D (2009) Bringing the Psyche back into Disability Studies: The Case of the Body with/out Organs. *Journal of Literary & Cultural Disability Studies* 3(3): 257–272. DOI: 10.1353/jlc.0.0021.

Goodley D (2010) *Disability Studies: An Interdisciplinary Introduction*. SAGE.

Goodley D (2014) *Dis/Ability Studies: Theorising Disablism and Ableism*. Routledge.

Goodley D and Rapley M (2001) How do you understand ‘learning difficulties’? Towards a social theory of impairment. *Mental Retardation* 39(3): 229–232. DOI: 10.1352/0047-6765(2001)039<0229:HDYULD>2.0.CO;2.

Goodley D and Roets G (2008) The (be)comings and goings of ‘developmental disabilities’: the cultural politics of ‘impairment’. *Discourse: Studies in the Cultural Politics of Education* 29(2): 239–255. DOI: 10.1080/01596300801966971.

Goodley D and Runswick-Cole K (2016) Becoming dishuman: thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education* 37(1): 1–15. DOI: 10.1080/01596306.2014.930021.

Guardian Editorial (2018) The Guardian view on disability and the arts: time for change | Editorial. *The Guardian*, 3 December. Available at: https://www.theguardian.com/commentisfree/2018/dec/03/the-guardian-view-on-disability-and-the-arts-time-for-change (accessed 4 March 2020).

Hadley B and McDonald D (2018) *The Routledge Handbook of Disability Arts, Culture, and Media*. Routledge.

Hale CR (2005) Neoliberal Multiculturalism: The Remaking of Cultural Rights and Racial Dominance in Central America. *Political and Legal Anthropology Review* 28(1): 10–28.

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

Hall E (2010) Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research* 54: 48–57. DOI: 10.1111/j.1365-2788.2009.01237.x.

Hall E (2011) Shopping for support: personalisation and the new spaces and relations of commodified care for people with learning disabilities. *Social & Cultural Geography* 12(6): 589–603. DOI: 10.1080/14649365.2011.601236.

Hall E (2013) Making and Gifting Belonging: Creative Arts and People with Learning Disabilities. *Environment and Planning A* 45(2): 244–262. DOI: 10.1068/a44629.

Hall E and Kearns R (2001) Making space for the ‘intellectual’ in geographies of disability. *Health & Place* 7(3): 237–246. DOI: 10.1016/S1353-8292(01)00007-7.

Hall E and McGarrol S (2013) Progressive localism for an ethics of care: Local Area Co-ordination with people with learning disabilities. *Social & Cultural Geography* 14(6): 689–709. DOI: 10.1080/14649365.2013.803290.

Hamilton LG, Mesa S, Hayward E, et al. (2017) ‘There’s a lot of places I’d like to go and things I’d like to do’: the daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom. *Disability & Society* 32(3): 287–307. DOI: 10.1080/09687599.2017.1294049.

Hammersley M (2018) What is ethnography? Can it survive? Should it? *Ethnography and Education* 13(1): 1–17. DOI: 10.1080/17457823.2017.1298458.

Harding SG (2004) Introduction. In: *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. London: Routledge, pp. 1–16.

Harris M (1976) History and Significance of the Emic/Etic Distinction. *Annual Review of Anthropology* 5. Annual Reviews: 329–350.

Hatton C (1998) Pragmatic language skills in people with intellectual disabilities: A review. *Journal of Intellectual & Developmental Disability* 23(1): 79–100. DOI: 10.1080/13668259800033601.

Hazelton M (2005) Mental health reform, citizenship and human rights in four countries. *Health Sociology Review* 14(3): 230–241. DOI: 10.5172/hesr.14.3.230.

Heenan D (2006) Art as therapy: an effective way of promoting positive mental health? *Disability & Society* 21(2): 179–191. DOI: 10.1080/09687590500498143.

Helm T (2019) Austerity to blame for 130,000 ‘preventable’ UK deaths – report. *The Observer*, 1 June. Available at: https://www.theguardian.com/politics/2019/jun/01/perfect-storm-austerity-behind-130000-deaths-uk-ippr-report (accessed 6 December 2019).

Hilsenrath J, Ng S and Paletta D (2008) Worst Crisis Since ’30s, With No End Yet in Sight. *Wall Street Journal*, 18 September. Available at: http://www.wsj.com/articles/SB122169431617549947 (accessed 14 June 2017).

Hirschkind C (2006) *The Ethical Soundscape: Cassette Sermons and Islamic Counterpublics*. Columbia University Press.

Hirschkind C and Mahmood S (2002) Feminism, the Taliban, and Politics of Counter-Insurgency. *Anthropological Quarterly* 75(2). The George Washington University Institute for Ethnographic Research: 339–354.

Hobbes T (1651) *Leviathan: Or, The Matter, Forme, & Power of a Common-Wealth Ecclesiasticall and Civill*. Andrew Crooke.

Hong ER, Ganz JB, Neely L, et al. (2016) A Meta-Analytic Review of Family-Implemented Social and Communication Interventions for Individuals with Developmental Disabilities. *Review Journal of Autism and Developmental Disorders* 3(2): 125–136. DOI: 10.1007/s40489-016-0071-3.

Howell S (2017) Two or three things I love about ethnography. *HAU: Journal of Ethnographic Theory* 7(1): 15–20. DOI: 10.14318/hau7.1.004.

Howes D (2010) *Sensual Relations: Engaging the Senses in Culture and Social Theory*. University of Michigan Press.

Hudson B and Henwood M (2002) The NHS and social care: the final countdown? *Policy & Politics* 30(2): 153–166. DOI: 10.1332/0305573022501610.

Hughes B and Paterson K (1997) The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment. *Disability & Society* 12(3): 325–340. DOI: 10.1080/09687599727209.

Hughes-Freeland F (2013) Embodied Perception and the Invention of the Citizen: Javanese Dance in the Indonesian State. In: Trnka S, Dureau C, and Park J (eds) *Senses and Citizenships: Embodying Political Life*. Routledge, pp. 1–32.

Hunt N (1967) *The World of Nigel Hunt: The Diary of a Mongoloid Youth*. New York: Darwen Finlayson.

Ingold T (2014) That’s enough about ethnography! *HAU: Journal of Ethnographic Theory* 4(1): 383–395. DOI: 10.14318/hau4.1.021.

Ingold T (2017a) *Anthropology and/as Education*. Routledge.

Ingold T (2017b) Anthropology contra ethnography. *HAU: Journal of Ethnographic Theory* 7(1): 21–26. DOI: 10.14318/hau7.1.005.

Ingstad B and Whyte SR (2007) *Disability in Local and Global Worlds*. University of California Press.

Jenkins T (1994) Fieldwork and the Perception of Everyday Life. *Man* 29(2). [Wiley, Royal Anthropological Institute of Great Britain and Ireland]: 433–455. DOI: 10.2307/2804481.

Johannes A, Belden-Charles G and Serminj J (2017) Ongoing voices of isolation and marginalisation of people with intellectual disabilities supported in different kinds of programs: the “cocoon of impossibility”. *Research and Practice in Intellectual and Developmental Disabilities* 4(1): 42–53. DOI: 10.1080/23297018.2017.1309986.

Johnson K and Walmsley J (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. Jessica Kingsley Publishers.

Johnson K and Walmsley W (2010) *People with Intellectual Disabilities: Towards a Good Life?* Policy Press.

Johnson K, Walmsley J and Wolfe M (2010) *People with Intellectual Disabilities: Towards a Good Life?* Policy Press.

Jones K (1960) *Mental Health and Social Policy, 1845-1959*. Routledge.

Jones K (2006) *Making of Social Policy in Britain: From the Poor Law to the New Labor, Third Edition*. New Brunswick: Bloomsbury Publishing.

Jones K and Fowles AJ (2008) Total institutions. In: Johnson J and DeSouza C (eds) *Understanding Health and Social Care: An Introductory Reader*. New York: SAGE Publications.

Juris JS (2007) Practicing Militant Ethnography with the Movement for Global Resistance in Barcelona. In: Shukaitis S, Graeber D, and Biddle E (eds) *Constituent Imagination: Militant Investigations//Collective Theorization*. AK Press.

Kaiser K (2009) Protecting Respondent Confidentiality in Qualitative Research. *Qualitative Health Research* 19(11). SAGE Publications Inc: 1632–1641. DOI: 10.1177/1049732309350879.

Kalofonos IA (2010) ‘All I eat is ARVs’: the paradox of AIDS treatment interventions in central Mozambique. *Medical Anthropology Quarterly* 24(3): 363–380.

Kamstra A, Putten AAJ van der and Vlaskamp C (2015) The Structure of Informal Social Networks of Persons with Profound Intellectual and Multiple Disabilities. *Journal of Applied Research in Intellectual Disabilities* 28(3): 249–256. DOI: 10.1111/jar.12134.

Kingsley P (2018) In Britain, Even Children Are Feeling the Effects of Austerity. *The New York Times*, 26 September. Available at: https://www.nytimes.com/2018/09/26/world/europe/uk-austerity-child-poverty.html (accessed 6 December 2019).

Kittay EF (1999) *Love’s Labor: Essays on Women, Equality, and Dependency*. Psychology Press.

Kittay EF (2005) At the Margins of Moral Personhood. *Ethics* 116(1): 100–131. DOI: 10.1086/454366.

Kittay EF (2010) The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield. In: Kittay EF and Carlson L (eds) *Cognitive Disability and Its Challenge to Moral Philosophy*. Wiley-Blackwell, pp. 393–413.

Kleinman A (1999) Moral Experience and Ethical Reflection: Can Ethnography Reconcile Them? A Quandary for ‘The New Bioethics’. *Daedalus* 128(4): 69–97.

Kottak C (2014) *Anthropology: Appreciating Human Diversity*. 16th edition. New York: McGraw-Hill Education.

Krahn GL and Fox MH (2014) Health Disparities of Adults with Intellectual Disabilities: What Do We Know? What Do We Do? *Journal of applied research in intellectual disabilities : JARID* 27(5): 431–446. DOI: 10.1111/jar.12067.

Kramer JM, Kramer JC, García-Iriarte E, et al. (2011) Following Through to the End: The Use of Inclusive Strategies to Analyse and Interpret Data in Participatory Action Research with Individuals with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 24(3): 263–273. DOI: 10.1111/j.1468-3148.2010.00602.x.

Kulick D and Rydström J (2015) *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. Duke University Press.

Kymlicka W (1996) *Multicultural Citizenship: A Liberal Theory of Minority Rights*. Clarendon Press.

Langan M (1990) Community care in the 1990s: the community care White Paper: ‘Caring for People’. *Critical Social Policy* 10(29): 58–70. DOI: 10.1177/026101839001002904.

Langness LL and Levine HG (1986) *Culture and Retardation: Life Histories of Mildly Mentally Retarded Persons in American Society*. Springer Science & Business Media.

Lazar S (2004) Education for Credit: Development as Citizenship Project in Bolivia. *Critique of Anthropology* 24(3): 301–319. DOI: 10.1177/0308275X04045423.

Lazar S (2013) Introduction. In: *The Anthropology of Citizenship: A Reader*. Wiley-Blackwell, pp. 1–22.

Lister R (1997) *Citizenship: Feminist Perspectives*. NYU Press.

Littlewood R and Lipsedge M (1997) *Aliens and Alienists: Ethnic Minorities and Psychiatry*. Psychology Press.

Long V (2017) ‘Heading up a blind alley’? Scottish psychiatric hospitals in the era of deinstitutionalization. *History of Psychiatry* 28(1): 115–128. DOI: 10.1177/0957154X16673025.

Luhrmann TM (2000) *Of Two Minds: The Growing Disorder in American Psychiatry*. 1st edition. New York: Alfred A. Knopf.

Lukose R (2005) Empty Citizenship: Protesting Politics in the Era of Globalization. *Cultural Anthropology* 20(4): 506–533. DOI: 10.1525/can.2005.20.4.506.

Lymbery M (2010) A new vision for adult social care? Continuities and change in the care of older people. *Critical Social Policy* 30(1): 5–26. DOI: 10.1177/0261018309350806.

M. van Alphen L, Anton JMD, Bart HM van den B, et al. (2010) People with intellectual disability as neighbours: Towards understanding the mundane aspects of social integration. *Journal of Community & Applied Social Psychology* 20(5): 347–362. DOI: 10.1002/casp.1042.

Mackay K (2017) The UK policy context for safeguarding adults: Rights-based v public protection? In: MacIntyre G, Stewart A, and McCusker P (eds) *Safeguarding Adults: Key Themes and Issues*. Macmillan Education UK, pp. 35–52.

Mackenzie C and Stoljar N (2000) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford University Press.

Maclagan D (2010) *Outsider Art: From the Margins to the Marketplace*. Reaktion Books.

Mahmood S (2001) Feminist Theory, Embodiment, and the Docile Agent: Some Reflections on the Egyptian Islamic Revival. *Cultural Anthropology* 16(2): 202–236.

Mahmood S (2005) *Politics of Piety: The Islamic Revival and the Feminist Subject*. Princeton University Press.

Malinowski B (1922) *Argonauts of the Western Pacific: An Account of Native Enterprise and Adventure in the Archipelagoes of Melanesian New Guinea, Enhanced Edition*. Waveland Press.

Malli MA, Sams L, Forrester-Jones R, et al. (2018) Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature. *Disability & Society* 33(9): 1412–1435. DOI: 10.1080/09687599.2018.1497950.

Manning C (2010) 'My memory’s back!’ Inclusive learning disability research using ethics, oral history and digital storytelling. *British Journal of Learning Disabilities* 38(3): 160–167. DOI: 10.1111/j.1468-3156.2009.00567.x.

Manthrope J, Walsh M, Alaszewski A, et al. (1997) Issues of Risk Practice and Welfare in Learning Disability Services. *Disability & Society* 12(1): 69–82. DOI: 10.1080/09687599727470.

Marcus GE (1995) Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography. *Annual Review of Anthropology* 24(1): 95–117. DOI: 10.1146/annurev.an.24.100195.000523.

Marshall TH (1950) *Citizenship and Social Class and Other Essays*. Cambridge: Cambridge University Press.

Martin E (2009) *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton, NJ: Princeton University Press.

Mason P, Timms K, Hayburn T, et al. (2013) How Do People Described as having a Learning Disability Make Sense of Friendship? *Journal of Applied Research in Intellectual Disabilities* 26(2): 108–118. DOI: 10.1111/jar.12001.

McCarthy M (1999) *Sexuality and Women with Learning Disabilities*. Jessica Kingsley Publishers.

McClintock K, Hall S and Oliver C (2003) Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research* 47(6): 405–416. DOI: 10.1046/j.1365-2788.2003.00517.x.

McKearney P (2018a) Receiving the Gift of Cognitive Disability: Recognizing Agency in the Limits of the Rational Subject. *The Cambridge Journal of Anthropology* 36(1): 40–60. DOI: 10.3167/cja.2018.360104.

McKearney P (2018b) The Weight of Living: Autonomy, Care, and Responsibility for the Self. *Journal of Disability & Religion* 22(3): 266–282. DOI: 10.1080/23312521.2018.1483219.

McKearney P (2019) The Ability to Judge: Critique and Surprise in Theology, Anthropology, and L'Arche. *Ethnos* 0(0). Routledge: 1–17. DOI: 10.1080/00141844.2019.1640261.

McKearney P and Zoanni T (2018) Introduction: For an Anthropology of Cognitive Disability. *The Cambridge Journal of Anthropology* 36(1): 1–22. DOI: 10.3167/cja.2018.360102.

McMahan J (1996) Cognitive Disability, Misfortune, and Justice. *Philosophy & Public Affairs* 25(1): 3–35. DOI: 10.1111/j.1088-4963.1996.tb00074.x.

McMahan J (2010) Cognitive Disability and Cognitive Enhancement. In: Kittay EF and Carlson L (eds) *Cognitive Disability and Its Challenge to Moral Philosophy*. Wiley-Blackwell, pp. 345–368.

Melling K, Beyer S and Kilsby M (2011) Supported employment for people with learning disabilities in the UK: the last 15 years. *Tizard Learning Disability Review* 16(2). Available at: https://www.researchgate.net/profile/Stephen_Beyer/publication/239781591_Supported_employment_for_people_with_learning_disabilities_in_the_UK_The_last_15_years/links/0c96053b57fc2aa27d000000/Supported-employment-for-people-with-learning-disabilities-in-the-UK-The-last-15-years.pdf.

Mencap (2004) *PMLD Network Partnership Board survey 2004*. London. Available at: https://www.choiceforum.org/docs/pmld_survey_2004.pdf.

Mencap (2016) *About profound and multiple learning disabilities*. Available at: https://www.mencap.org.uk/sites/default/files/2016-11/PMLD%20factsheet%20about%20profound%20and%20multiple%20learning%20disabilities.pdf.

Mercer JR (1973) *Labeling the Mentally Retarded: Clinical and Social System Perspectives on Mental Retardation*. University of California Press.

Merleau-Ponty M (1945) *Phenomenology of Perception*. Routledge.

Mietola R, Miettinen S and Vehmas S (2017) Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology* 20(3): 263–274. DOI: 10.1080/13645579.2017.1287872.

Mittermaier A (2011) *Dreams That Matter: Egyptian Landscapes of the Imagination*. University of California Press.

Mol A (2008) *The Logic of Care: Health and the Problem of Patient Choice*. Routledge.

Morris J (1991) *Pride Against Prejudice: Transforming Attitudes to Disability: A Personal Politics of Disability*. London: The Women’s Press.

Mouffe C (1992) Democratic citizenship and the question of identity. In: Mouffe C (ed.) *Dimensions of Radical Democracy: Pluralism, Citizenship, Community*. London: Verso, p. 253.

Mueller B (2019) What Is Austerity and How Has It Affected British Society? *The New York Times*, 24 February. Available at: https://www.nytimes.com/2019/02/24/world/europe/britain-austerity-may-budget.html (accessed 6 December 2019).

Nakamura K (2013) *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan*. Cornell University Press.

National Council for Civil Liberties (1951) *50,000 Outside the Law: An Examination of the Treatment of Those Certified as Mentally Defective*. National Council for Civil Liberties.

Needham C (2012) *What is happening to day centre services? Voices from frontline staff*. UNISON. Available at: https://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/2012/what-is-happening-to-day-centre-services-Unison-report.pdf (accessed 6 December 2019).

Needham C (2014) Personalization: From day centres to community hubs? *Critical Social Policy* 34(1): 90–108. DOI: 10.1177/0261018313483492.

Neely L, Garcia E, Bankston B, et al. (2018) Generalization and maintenance of functional communication training for individuals with developmental disabilities: A systematic and quality review. *Research in Developmental Disabilities* 79: 116–129. DOI: 10.1016/j.ridd.2018.02.002.

Newcomb R (2013) Modern Citizens, Modern Food: Taste and the Rise of the Moroccan Citizen-Consumer. In: Trnka S, Dureau C, and Park J (eds) *Senses and Citizenships: Embodying Political Life*. Routledge, pp. 99–119.

Nguyen V-K (2007) Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship. In: Ong A and Collier SJ (eds) *Global Assemblages*. Blackwell Publishing Ltd, pp. 124–144. DOI: 10.1002/9780470696569.ch8.

Nguyen V-K (2010) *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Duke University Press.

NICE (2015) Overview | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges | Guidance | NICE. Available at: https://www.nice.org.uk/guidance/ng11 (accessed 2 September 2019).

Nind M (2008) *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. Working Paper, November. National Centre for Research Methods. Available at: http://eprints.ncrm.ac.uk/491/ (accessed 6 October 2017).

Nind M (2011) Participatory data analysis: a step too far? *Qualitative Research* 11(4): 349–363. DOI: 10.1177/1468794111404310.

Nind M (2014) *What Is Inclusive Research?* A&C Black.

Nind M (2016) Towards a second generation of inclusive research. In: Buchner T, Koenig O, and Schuppener S (eds) *Inklusive Forschung. Gemeinsam Mit Menschen Mit Lernschwierigkeiten Forschen.*, pp. 186–198.

Northway R (2000) Ending Participatory Research? *Journal of Learning Disabilities* 4(1): 27–36. DOI: 10.1177/146900470000400102.

Nussbaum M (2006) *Frontiers of Justice: Disability, Nationality, Species Membership*. Harvard University Press.

Nussbaum M (2009) The Capabilities of People with Cognitive Disabilities. *Metaphilosophy* 40(3–4): 331–351. DOI: 10.1111/j.1467-9973.2009.01606.x.

O'Brien P, McConkey R and García-Iriarte E (2013) Co-researching with People who Have Intellectual Disabilities: Insights From a National Survey. *Journal of Applied Research in Intellectual Disabilities* 27(1): 65–75. DOI: 10.1111/jar.12074.

O'Leary L, Cooper S-A and Hughes-McCormack L (2018) Early death and causes of death of people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities* 31(3): 325–342. DOI: 10.1111/jar.12417.

Oliver M (1990) *Politics Of Disablement*. Macmillan International Higher Education.

Oliver M (1992) Changing the Social Relations of Research Production? *Disability, Handicap & Society* 7(2): 101–114. DOI: 10.1080/02674649266780141.

Oliver M (1999) Capitalism, Disability and Ideology: A Materialist Critique of the Normalization Principle. In: Flynn RJ and Lemay R (eds) *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. University of Ottawa Press, pp. 163–174.

Ong A (1996) Cultural Citizenship as Subject-Making: Immigrants Negotiate Racial and Cultural Boundaries in the United States [and Comments and Reply]. *Current Anthropology* 37(5): 737–762.

Ootes S, Pols AJ, Tonkens EH, et al. (2010) Bridging boundaries: the concept of 'citizenship' as a boundary object in mental healthcare. *Medische Antropologie* 22. Available at: http://dare.uva.nl/search?metis.record.id=346586 (accessed 9 January 2017).

Ootes STC (2012) *Being in Place: Citizenship in Long-Term Mental Healthcare (PhD Thesis)*. University of Amsterdam. Available at: https://dare.uva.nl/search?identifier=8a7ca9ce-7df1-4c8c-945e-4348be76adea.

Ootes STC, Pols AJ, Tonkens EH, et al. (2013) Where is the citizen? Comparing civic spaces in long-term mental healthcare. *Health & Place* 22: 11–18. DOI: 10.1016/j.healthplace.2013.02.008.

Parker-Jenkins M (2018) Problematising ethnography and case study: reflections on using ethnographic techniques and researcher positioning. *Ethnography and Education* 13(1): 18–33. DOI: 10.1080/17457823.2016.1253028.

Parr H (2011) *Mental Health and Social Space: Towards Inclusionary Geographies?* John Wiley & Sons.

Paterson K and Hughes B (1999) Disability Studies and Phenomenology: The carnal politics of everyday life. *Disability & Society* 14(5): 597–610. DOI: 10.1080/09687599925966.

Pearson C (2000) Money talks? Competing discourses in the implementation of direct payments. *Critical Social Policy* 20(4): 459–477. DOI: 10.1177/026101830002000403.

Pearson C (2004) Keeping the cash under control: what's the problem with direct payments in Scotland? *Disability & Society* 19(1): 3–14. DOI: 10.1080/0968759032000155596.

Pearson C (2012) Independent Living. In: Watson N, Roulstone A, and Thomas C (eds) *Routledge Handbook of Disability Studies (Hardback) - Routledge*. London and New York: Routledge, pp. 240–252. Available at: https://www.routledge.com/Routledge-Handbook-of-Disability-Studies/Watson-Roulstone-Thomas/p/book/9780415574006 (accessed 1 December 2016).

Pearson C and Ridley J (2016) Is Personalization the Right Plan at the Wrong Time? Re-thinking Cash-for-Care in an Age of Austerity. *Social Policy & Administration*: n/a-n/a. DOI: 10.1111/spol.12216.

Pearson C, Brunner R, Porter T, et al. (2020) Personalisation and the Promise of Independent Living: Where Now for Cash, Care and Control for Disability Organisations Across the UK? *Scandinavian Journal of Disability Research* 22(1). 1. Stockholm University Press: 285–295. DOI: 10.16993/sjdr.742.

Peirano MGS (1998) WHEN ANTHROPOLOGY IS AT HOME: The Different Contexts of a Single Discipline. *Annual Review of Anthropology* 27(1): 105–128. DOI: 10.1146/annurev.anthro.27.1.105.

People First (2017) Our values. Available at: http://peoplefirstltd.com/about-us/our-values/ (accessed 26 June 2017).

Petryna A (2003) *Life Exposed: Biological Citizens after Chernobyl*. REV-Revised. Princeton University Press. Available at: http://www.jstor.org/stable/j.ctt1r2fhh (accessed 3 March 2017).

Petryna A (2004) Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations. *Osiris* 19: 250–265.

Pink S (2011) Multimodality, multisensoriality and ethnographic knowing: social semiotics and the phenomenology of perception. *Qualitative Research* 11(3): 261–276. DOI: 10.1177/1468794111399835.

Pink S, Horst H, Postill J, et al. (2015) *Digital Ethnography: Principles and Practice*. 1st edition. Los Angeles: SAGE Publications Ltd.

Pols J (2006) Washing the citizen: washing, cleanliness and citizenship in mental health care. *Culture, Medicine and Psychiatry* 30(1): 77–104. DOI: 10.1007/s11013-006-9009-z.

Pols J (2016) Analyzing Social Spaces: Relational Citizenship for Patients Leaving Mental Health Care Institutions. *Medical Anthropology* 35(2): 177–192. DOI: 10.1080/01459740.2015.1101101.

Power A (2013) Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. *Social Science & Medicine* 88: 68–75. DOI: 10.1016/j.socscimed.2013.04.008.

Power A (2016) Disability, (auto)mobility and austerity: shrinking horizons and spaces of refuge. *Disability & Society* 31(2): 280–284. DOI: 10.1080/09687599.2016.1145385.

Power A and Bartlett R (2015) Self-building safe havens in a post-service landscape: how adults with learning disabilities are reclaiming the welcoming communities agenda. *Social & Cultural Geography*. Available at: https://eprints.soton.ac.uk/374205/ (accessed 14 June 2017).

Power A and Bartlett R (2019) Ageing with a learning disability: Care and support in the context of austerity. *Social Science & Medicine* 231. ‘Hopeful adaptation’ in health geographies: Seeking health and wellbeing in times of adversity: 55–61. DOI: 10.1016/j.socscimed.2018.03.028.

Power A, Bartlett R and Hall E (2016) Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity. *Journal of Intellectual Disabilities* 20(2): 183–193. DOI: 10.1177/1744629516634561.

Priestley M, Jolly D, Pearson C, et al. (2007) Direct Payments and Disabled People in the UK: Supply, Demand and Devolution. *The British Journal of Social Work* 37(7): 1189–1204. DOI: 10.1093/bjsw/bcl063.

Rabeharisoa V (2003) The struggle against neuromuscular diseases in France and the emergence of the 'partnership model' of patient organisation. *Social Science & Medicine (1982)* 57(11): 2127–2136.

Rabinow P (1996) Artificiality and enlightenment: from socio-biology to biosociality. In: *Essays on the Anthropology of Reason*. Princeton University Press.

Race D, Boxall K and Carson I (2005) Towards a dialogue for practice: reconciling Social Role Valorization and the Social Model of Disability. *Disability & Society* 20(5): 507–521. DOI: 10.1080/09687590500156196.

Rawls J (1971) *A Theory of Justice*. Cambridge, Massachusetts: Harvard University Press.

Rawls J (1993) *Political Liberalism*. Columbia University Press.

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

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

Riddell S, Pearson C, Jolly D, et al. (2005) The Development of Direct Payments in the UK: Implications for Social Justice. *Social Policy and Society* 4(1): 75–85. DOI: 10.1017/S1474746404002209.

Rivett G (1998) Powell's Water Tower Speech. Available at: http://www.nhshistory.net/watertower.html (accessed 5 December 2019).

Robertson J, Emerson E, Hatton C, et al. (2007) Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities. *Journal of Intellectual Disability Research* 51(3): 232–243. DOI: 10.1111/j.1365-2788.2006.00864.x.

Roets G and Goodley D (2008) Disability, Citizenship and Uncivilized Society: The smooth and nomadic qualities of self-advocacy. *Disability Studies Quarterly* 28(4). Available at: http://dsq-sds.org/article/view/131 (accessed 22 November 2016).

Rorty R (1991) *Objectivity, Relativism, and Truth: Philosophical Papers*. Cambridge: Cambridge University Press. DOI: 10.1017/CBO9781139173643.

Rosaldo R (1994) Cultural Citizenship in San Jose, California. *PoLAR: Political and Legal Anthropology Review* 17(2): 57–64. DOI: 10.1525/pol.1994.17.2.57.

Rose N (2001) The Politics of Life Itself. *Theory, Culture & Society* 18(6): 1–30. DOI: 10.1177/02632760122052020.

Rose N, O’Malley P and Valverde M (2006) Governmentality. *Annual Review of Law and Social Science* 2(1): 83–104. DOI: 10.1146/annurev.lawsocsci.2.081805.105900.

Roulstone A and Morgan H (2009) Neo-Liberal Individualism or Self-Directed Support: Are We All Speaking the Same Language on Modernising Adult Social Care? *Social Policy and Society* 8(3): 333–345. DOI: 10.1017/S1474746409004886.

Schelly D (2008) Problems associated with choice and quality of life for an individual with intellectual disability: a personal assistant’s reflexive ethnography. *Disability & Society* 23(7): 719–732. DOI: 10.1080/09687590802469206.

Scheper-Hughes N (1995) The Primacy of the Ethical: Propositions for a Militant Anthropology. *Current Anthropology* 36(3): 409–440. DOI: 10.1086/204378.

Schielke S (2009) Being good in Ramadan: ambivalence, fragmentation, and the moral self in the lives of young Egyptians. *Journal of the Royal Anthropological Institute* 15(s1): S24–S40. DOI: 10.1111/j.1467-9655.2009.01540.x.

Schrag P and Divoky D (1975) *The Myth of the Hyperactive Child: And Other Means of Child Control*. Pantheon Books.

Scottish Government (2000) The same as you? A review of services for people with learning disabilities. Available at: http://www.gov.scot/resource/doc/1095/0001661.pdf.

Scottish Government (2009) *Personalisation: a shared understanding ; Commissioning for personalisation ; A personalised commissioning approach to support and care services*. Edinburgh: Scottish Government.

Scottish Government (2013a) Social Care (Self-directed Support) (Scotland) Act 2013: statutory guidance. Available at: https://www.gov.scot/publications/statutory-guidance-accompany-social-care-self-directed-support-scotland-act-2013/ (accessed 25 September 2020).

Scottish Government (2013b) The keys to life: Improving the quality of life for people with learning disabilities. Edinburgh. Available at: https://keystolife.info/wp-content/uploads/2014/05/the-keys-to-life-full-version.pdf.

Scottish Government (2017) Independent Living Fund Working Group: report and recommendations - gov.scot. Available at: https://www.gov.scot/publications/independent-living-fund-working-group-report-recommendations/pages/5/ (accessed 22 August 2020).

Scottish Government (2019a) Keys to life: implementation framework and priorities 2019-2021. Available at: https://www.gov.scot/publications/keys-life-unlocking-futures-implementation-framework-priorities-2019-21/pages/0/ (accessed 6 February 2020).

Scottish Government (2019b) *Personalising Realistic Medicine: Chief Medical Officer for Scotland’s Annual Report 2017-2018*. Available at: https://www.gov.scot/publications/personalising-realistic-medicine-chief-medical-officer-scotland-annual-report-2017-2018/ (accessed 6 December 2019).

Scottish Learning Disabilities Observatory (2011) Learning disabilities | Census 2011 Information. Available at: https://www.sldo.ac.uk/census-2011-information/learning-disabilities/ (accessed 6 February 2020).

Scourfield P (2007) Social Care and the Modern Citizen: Client, Consumer, Service User, Manager and Entrepreneur. *The British Journal of Social Work* 37(1): 107–122. DOI: 10.1093/bjsw/bch346.

Sevenhuijsen S (1998) *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality, and Politics*. Psychology Press.

Shah A (2017) Ethnography? Participant observation, a potentially revolutionary praxis. *HAU: Journal of Ethnographic Theory* 7(1): 45–59. DOI: 10.14318/hau7.1.008.

Shakespeare T (2006) *Disability Rights and Wrongs*. Taylor & Francis.

Shakespeare T (2013) *Disability Rights and Wrongs Revisited*. Routledge.

Shore C and Wright S (1999) Audit Culture and Anthropology: Neo-Liberalism in British Higher Education. *The Journal of the Royal Anthropological Institute* 5(4): 557–575. DOI: 10.2307/2661148.

Sieder R (2011) Contested sovereignties: Indigenous law, violence and state effects in postwar Guatemala. *Critique of Anthropology* 31(3): 161–184. DOI: 10.1177/0308275X11409729.

Simmons HG (1978) Explaining Social Policy: The English Mental Deficiency Act of 1913. *Journal of Social History* 11(3): 387–403.

Simplican SC (2019) Behaviors that challenge disability studies. *Disability & Society* 34(9–10). Routledge: 1379–1398. DOI: 10.1080/09687599.2018.1552119.

Singer P (2010) Speciesism and Moral Status. In: Kittay EF and Carlson L (eds) *Cognitive Disability and Its Challenge to Moral Philosophy*. Wiley-Blackwell, pp. 331–344.

Siu LCD (2001) Diasporic Cultural Citizenship: Chineseness and Belonging in Central America. *Social Text* 19(4): 7–28.

Sleeter C (2010) Why Is There Learning Disabilities? A Critical Analysis of the Birth of the Field in Its Social Context. *Disability Studies Quarterly* 30(2). DOI: 10.18061/dsq.v30i2.1261.

Sleeter CE (1986) Learning Disabilities: The Social Construction of a Special Education Category. *Exceptional Children* 53(1): 46–54. DOI: 10.1177/001440298605300105.

Solvang PK (2012) From identity politics to dismodernism? Changes in the social meaning of disability art. *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap* 6(3): 178–187. DOI: 10.1016/j.alter.2012.05.002.

Spain D, Sin J, Linder KB, et al. (2018) Social anxiety in autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders* 52: 51–68. DOI: 10.1016/j.rasd.2018.04.007.

Stalker K (1998) Some Ethical and Methodological Issues in Research with People with Learning Difficulties. *Disability & Society* 13(1): 5–19. DOI: 10.1080/09687599826885.

Stalker K (2012) *Theorizing the Position of People With Learning Difficulties Within Disability Studies*. Routledge Handbooks Online. Available at: https://www.routledgehandbooks.com/doi/10.4324/9780203144114.ch10 (accessed 8 December 2016).

Stalker K and Hunter S (1999) To close or not to close? The future of learning disability hospitals in Scotland. *Critical Social Policy* 19(2): 177–194. DOI: 10.1177/026101839901900203.

Stalker K, MacDonald C, King C, et al. (2015) “We Could Kid On that This is Going to Benefit the Kids but No, This is about Funding”: Cutbacks in Services to Disabled Children and Young People in Scotland. *Child Care in Practice* 21(1): 6–21. DOI: 10.1080/13575279.2014.972341.

Stefánsdóttir G, Björnsdóttir K and Stefánsdóttir Á (2018) Autonomy and People with Intellectual Disabilities Who Require More Intensive Support. *Scandinavian Journal of Disability Research* 20(1). DOI: 10.16993/sjdr.21.

Stewart H (2008) We are in the worst financial crisis since Depression, says IMF. *The Guardian*, 10 April. Available at: https://www.theguardian.com/business/2008/apr/10/useconomy.subprimecrisis.

Strnadová I and Cumming TM (2014) People with Intellectual Disabilities Conducting Research: New Directions for Inclusive Research. *Journal of Applied Research in Intellectual Disabilities* 27(1): 1–2. DOI: 10.1111/jar.12075.

The Herald (2002) Locking away an unhappy history Lennox Castle hospital is about to close its doors for the last time on its controversial past. Available at: https://www.heraldscotland.com/news/12130988.locking-away-an-unhappy-history-lennox-castle-hospital-is-about-to-close-its-doors-for-the-last-time-on-its-controversial-past/ (accessed 6 December 2019).

The Trussell Trust (n.d.) The Trussell Trust - End of Year Stats. Available at: https://www.trusselltrust.org/news-and-blog/latest-stats/end-year-stats/ (accessed 6 December 2019).

Thomas C (1999) *Female Forms: Experiencing and Understanding Disability*. Open University Press.

Thomas C (2007) *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. Macmillan International Higher Education.

Thomson M (1998) Mental Deficiency and the Welfare State. In: *The Problem of Mental Deficiency: Eugenics, Democracy, and Social Policy in Britain, c.1870-1959*. Oxford: Clarendon Press, pp. 270–296. Available at: http://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780198206927.001.0001/acprof-9780198206927-chapter-9 (accessed 1 May 2017).

Throop CJ (2012) On the Varieties of Empathic Experience: Tactility, Mental Opacity, and Pain in Yap. *Medical Anthropology Quarterly* 26(3): 408–430. DOI: 10.1111/j.1548-1387.2012.01225.x.

Ticktin M (2006) Where ethics and politics meet. *American Ethnologist* 33(1): 33–49. DOI: 10.1525/ae.2006.33.1.33.

Timmeren EA van, Schans CP van der, Putten AAJ van der, et al. (2017) Physical health issues in adults with severe or profound intellectual and motor disabilities: a systematic review of cross-sectional studies. *Journal of Intellectual Disability Research* 61(1): 30–49. DOI: 10.1111/jir.12296.

Tolich M (2004) Internal Confidentiality: When Confidentiality Assurances Fail Relational Informants. *Qualitative Sociology* 27(1): 101–106. DOI: 10.1023/B:QUAS.0000015546.20441.4a.

Trnka S, Dureau C and Park J (eds) (2013) *Senses and Citizenships: Embodying Political Life*. Routledge.

Tuffrey-Wijne I and Butler G (2010) Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis. *Health Expectations* 13(2): 174–184. DOI: 10.1111/j.1369-7625.2009.00576.x.

Tuffrey-Wijne I, Giatras N, Goulding L, et al. (2013) *Identifying the Factors Affecting the Implementation of Strategies to Promote a Safer Environment for Patients with Learning Disabilities in NHS Hospitals: A Mixed-Methods Study*. Health Services and Delivery Research. Southampton (UK): NIHR Journals Library. Available at: http://www.ncbi.nlm.nih.gov/books/NBK259489/ (accessed 7 September 2020).

Turner BS (1990) Outline of a Theory of Citizenship. *Sociology* 24(2): 189–217. DOI: 10.1177/0038038590024002002.

UNISON (2018) UNISON evidence to the Low Pay Commission on minimum wage rates for 2019. Available at: https://www.unison.org.uk/content/uploads/2018/06/UNISON-evidence-to-Low-Pay-Commission-2018.pdf.

United Nations (2006) Convention on the Rights of Persons with Disabilities (CRPD) | United Nations Enable. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 6 February 2020).

United Nations (2015) Convention on the Rights of Persons with Disabilities. United Nations. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 24 July 2018).

van der Meer L, Sigafoos J, O'Reilly MF, et al. (2011) Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: A review of the literature. *Research in Developmental Disabilities* 32(5): 1422–1431. DOI: 10.1016/j.ridd.2011.02.003.

Vehmas S and Curtis B (2017) Profound Intellectual Disability and the Bestowment View of Moral Status. *Cambridge Quarterly of Healthcare Ethics* 26(3): 505–516. DOI: 10.1017/S0963180116001183.

Venn ML, Wolery M, Werts MG, et al. (1993) Embedding instruction in art activities to teach preschoolers with disabilities to imitate their peers. *Early Childhood Research Quarterly* 8(3): 277–294. DOI: 10.1016/S0885-2006(05)80068-7.

Verdery K (1998) Transnationalism, Nationalism, Citizenship, and Property: Eastern Europe Since 1989. *American Ethnologist* 25(2): 291–306.

Verdonschot MML, Witte LPD, Reichrath E, et al. (2009) Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research* 53(4): 303–318. DOI: 10.1111/j.1365-2788.2008.01144.x.

Vogel E and Mol A (2014) Enjoy your food: on losing weight and taking pleasure. *Sociology of Health & Illness* 36(2): 305–317. DOI: 10.1111/1467-9566.12116.

Walker CM and Hayton JW (2017) Navigating austerity: balancing ‘desirability with viability’ in a third sector disability sports organisation. *European Sport Management Quarterly* 17(1): 98–116. DOI: 10.1080/16184742.2016.1210190.

Walmsley J (1991) ‘Talking to Top People’: Some Issues Relating to the Citizenship of People with Learning Difficulties. *Disability, Handicap & Society* 6(3): 219–231. DOI: 10.1080/02674649166780261.

Walmsley J (2000) Women and the Mental Deficiency Act of 1913: citizenship, sexuality and regulation. *British Journal of Learning Disabilities* 28(2): 65–70. DOI: 10.1046/j.1468-3156.2000.00042.x.

Walmsley J (2001) Normalisation, Emancipatory Research and Inclusive Research in Learning Disability. *Disability & Society* 16(2): 187–205. DOI: 10.1080/09687590120035807.

Walmsley J (2007) Organisations, Structures and Community Care, 1971–2001: From Care to Citizenship? In: Walmsley J and Welshman J (eds) *Community Care in Perspective*. Palgrave Macmillan UK, pp. 77–96. DOI: 10.1057/9780230596528_3.

Walmsley J and Johnson K (2003a) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. Jessica Kingsley Publishers.

Walmsley J and Johnson K (2003b) Nothing About Us Without Us: Good Times Bad Times. In: *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. Jessica Kingsley Publishers, pp. 95–108.

Walmsley J and Rolph S (2001) The development of community care for people with learning difficulties 1913 to 1946. *Critical Social Policy* 21(1): 59–80. DOI: 10.1177/026101830102100102.

Walmsley J and Welshman J (2006) *Community Care in Perspective Care, Control and Citizenship Introduction* (eds J Welshman and J Walmsley).

Walmsley J, Strnadová I and Johnson K (2017) The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*: 1–6. DOI: 10.1111/jar.12431.

Walters MA, Brown R and Wiedlitzka S (2016) Equality and Human Rights Commission Research report: Causes and motivations of hate crime. Equality and Human Rights Commission.

Wanless D (2006) *Securing Good Care for Older People - Taking a Long-term View*. King's Fund. Available at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/securing-good-care-for-older-people-wanless-2006.pdf.

Ware L (2011) When Art Informs: Inviting Ways to See the Unexpected. *Learning Disability Quarterly* 34(3): 194–202. DOI: 10.1177/0731948711417557.

Watson N (2002) Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and disability. *Disability & Society* 17(5): 509–527. DOI: 10.1080/09687590220148496.

Wehmeyer ML and Bolding N (2001) Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research* 45(5): 371–383. DOI: 10.1046/j.1365-2788.2001.00342.x.

Welshman J (2007) Ideology, Ideas and Care in the Community, 1948–71. In: Walmsley J and Welshman J (eds) *Community Care in Perspective*. Palgrave Macmillan UK, pp. 17–37. DOI: 10.1057/9780230596528_3.

Wexler A (2012) Introduction. In: *Art Education Beyond the Classroom: Pondering the Outsider and Other Sites of Learning*. Springer, pp. xiii–xx.

Wexler A and Derby J (2015) Art in Institutions: The Emergence of (Disabled) Outsiders. *Studies in Art Education* 56(2): 127–141. DOI: 10.1080/00393541.2015.11518956.

Whitaker S (2013) *Intellectual Disability: An Inability to Cope with an Intellectually Demanding World*. Springer.

Williams L and Nind M (1999) Insiders or Outsiders: Normalisation and women with learning difficulties. *Disability & Society* 14(5): 659–672. DOI: 10.1080/09687599926000.

Williams V (1999) Researching Together. *British Journal of Learning Disabilities* 27(2): 48–51. DOI: 10.1111/j.1468-3156.1999.tb00085.x.

Wolfensberger W, Nirje B, Olshansky S, et al. (1972) *The Principle of Normalization In Human Services*. Books: Wolfensberger Collection. Available at: http://digitalcommons.unmc.edu/wolf_books/1.

World Health Organization (2018) *International Classification of Diseases for Mortality and Morbidity Statistics (11th Revision)*. Available at: https://icd.who.int/browse11/l-m/en.

Wright D (1997) Getting Out of the Asylum: Understanding the Confinement of the Insane in the Nineteenth Century. *Social History of Medicine* 10(1): 137–155. DOI: 10.1093/shm/10.1.137.

Wright D (1998) The certification of insanity in nineteenth-century England and Wales. *History of Psychiatry* 9(35): 267–290. DOI: 10.1177/0957154X9800903501.

Wright D (2001) *Mental Disability in Victorian England: The Earlswood Asylum, 1847-1901*. Clarendon Press.

Young IM (1990) *Justice and the Politics of Difference*. Princeton University Press.

Young IM (1995) Mothers, Citizenship, and Independence: A Critique of Pure Family Values. *Ethics* 105(3). University of Chicago Press: 535–556.

Appendices

University of Glasgow

College of Social Sciences

Consent Form

Title of the project: Enacting a citizen: An ethnography of everyday citizenship practices of people with learning disabilities

Name of the researcher: Thu Thuy Phan

1. I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I consent to interviews being audio-recorded and transcribed.

4. I understand that

- the material will be treated as confidential and kept in secure storage at all times
- personal data that links research material to individual participants will be destroyed once the project is complete
- the material may be used in future publications, both print and online
- the anonymised material will be retained in secure storage for use in future academic research
- my identity will not be disclosed in the subsequent research and that I will be referred to by a pseudonym in any publications arising from the research.

5. I understand that the information I give will be kept confidential, subject to legal limitations.

6. I agree to waive my copyright to any data collected as part of this project.

7. I agree to take part in the above study.

Name of Participant	Date	Signature
Researcher	Date	Signature

University of Glasgow

College of Social Sciences

Consent Form

I would like to hear what you think about citizenship for people with learning disabilities and Project Ability.

- You do not have to answer any questions you do not like.
- You can stop talking to me at any time.

Do you want to talk to me about what it is like to be a citizen, and take part in Project Ability and other similar activities?

Please put a circle around your answer.

YES NO

Can I record our chat?

Please put a circle around your answer.

YES NO

Can I tell other people what you think? I will not tell them your name.

Please put a circle around your answer.

YES NO

I understand

- that personal information will be destroyed after the research
- the material will be stored for future research
- the material may be used in future publications.
- I agree to waive my copyright to any data collected as part of this project.

Please put a circle around your answer.

YES NO

Please write your name in the box below.

University of Glasgow

College of Social Sciences

Easy-Read Participant Information Sheet

My name is Thu Thuy Phan, and I'm a researcher at the University of Glasgow.

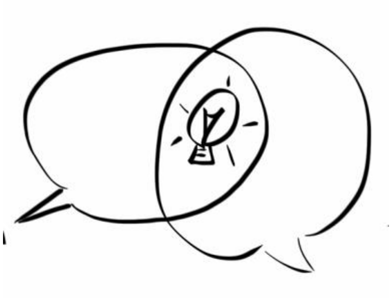
What is this study about?

This study will be finding out what citizenship means for people with learning disabilities. As part of the study, I take part in the Project Ability workshops, and watch how people make art together. Then, I interview people on their experiences of Project Ability and citizenship.

Who can take part in the study?

People who

- ❖ Are aged 18 or over
- ❖ Have a learning disability
- ❖ Are part of Project Ability



What will I do if I take part?

We will meet for an interview.

We will talk about what it's like to do activities with people in Project Ability and outside.

We will meet three or four times. We will talk 20 minutes each time. It could be at your home or somewhere else.

This talk would be audio-recorded.

Do I have to take part?

No. You don’t have to do this study. You can decide if you would like to take part.

Can I change my mind?

Yes, you can change your mind at any time we talk. We will stop talking.

You don’t have to tell me why you want to stop.

What happens to my information?

Your information will be kept safe and private.

What we talk about will be tape recorded.

Then, it will be written down. Your name will not be on it.

If I think you, or someone else is not safe, I will have to tell other people about it.

When the research is finished, I will destroy the tape recordings and the personal information. I have to keep the interview transcripts and observations for 10 years for future research.

Good things about taking part?

Talking about what you like or dislike about your daytime activities will be helpful for others.

Risks when taking part?

Some may feel sad or upset.

Tell me if you feel sad or upset. We can stop. I can support you if you to get more help if you feel very upset.

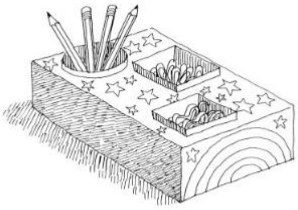
What will you do to the results?

I will write about the results.

I will use the results to write a PhD thesis for the University of Glasgow.

I will use the results to write to a journal so other people can read about it.

We can meet again to talk about the results. I can send you a written copy.



Who is sponsoring this research?

The Scottish Government.

The College of Social Sciences Ethics Committee of University of Glasgow will also check this study. They make sure that the study is run well.

If you would like to know more, you can contact me or my supervisors.

Researcher

Thu Thuy Phan (PhD candidate)

- Email: [Email address removed]
- Telephone: [phone number removed]

Supervisors

Prof Craig Melville

- Email: [Email address removed]
- Telephone: [phone number removed]

Prof Nicholas Watson

- Email: [Email address removed]
- Telephone: [phone number removed]

College of Social
Sciences

Participant Information Sheet – Service user

Title

Enacting a citizen: An ethnography of everyday citizenship practices of people with learning disabilities

PhD research project undertaken by Thu Thuy Phan within the Institute of Health and Wellbeing, University of Glasgow.

Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The goal of this research is to understand the different meanings of citizenship for people with learning disabilities. Using participant observation and face-to-face interviews, I will explore what people with learning disabilities do in their everyday life that can be interpreted as an act of citizenship, and what rights they claim with these acts, if any. I will specifically document 1) the financial and infrastructural conditions of citizenship, 2) experiences of the collectivising and individualising tendencies of citizenship ideals, and finally 3) the communities people with learning disabilities are or desire to be part of.

During the participant observation, I'm attending Project Ability workshops to document how people make art together, and how that creates a sense of belonging. In the second part of the study, I interview people about their experiences of Project Ability and community participation.

The research started in November 2016 and is expected to be completed by 2020. The data collection will take place between 2017 and 2018.

Do I have to take part in the study?

You can decide whether or not to take part. If you decide to take part, you are still free to withdraw at any time, without giving a reason, and any information you have given will not be used in the research.

What will happen to me if I take part?

If you decide that you would like to take part, I will invite you to a series of informal, one-on-one interview to talk about your experiences. The interviews will be semi-structured, which means you will be asked open questions and encouraged to give your opinions. The questions will be about your activities and experiences as a service user.

The interviews can take place in your home, or at a place of your convenience. The interviews will take place over three or four sessions, and will last about 20 minutes each time. I will audio record the interviews to transcribe and analyse them. There may be need for a follow-up interview in case of any recording problems or need for further clarification on any answers you have given.

Will my participation be confidential?

All your personal details will be kept strictly confidential, subject to legal limitations (e.g. the Freedom of Information (Scotland) Act 2002). I will remove all data that could identify you in the transcripts, such as your name or address. All audio-recorded interviews will be kept in password-protected files, and they will only be available to the researcher. I will destroy the audio recording and the original transcript when the research is finished.

- Please note that confidentiality will be maintained as far as it possible, unless during our conversation I hear anything which makes me worried that someone might be in danger of harm, I might have to inform relevant agencies of this.

What will happen to the data of this research?

When the research is finished, I will destroy the audio recordings and the original transcripts. I will also delete the personal information that links your identity to the data. I will keep the anonymised transcripts for any publications beyond this research, for example for journal articles or conference papers. All data will be kept in password protected files and in locked filing cabinets. The university requires all research material to be archived for 10 years after the research is finished. The anonymised transcripts will be kept in the data repository of the University of Glasgow. I will keep the observational material on a password protected PC and store the back up in a locked filing cabinet. Only the transcripts will be available for future re-use.

The results of the research will form the main part the PhD thesis. A copy of the thesis will be kept by the University of Glasgow, and copies can be made available to all the participants on request. The PhD thesis will potentially be used to form the basis of further journal, book, or magazine articles. You will not be identified in any report or publication that stems from this research.

Who is organising and funding this research?

The research is organised by a research team at the Institute of Health and Wellbeing, University of Glasgow as a PhD project. The PhD research project is funded by the Scottish Government.

This project has been considered and approved by the College Research Ethics Committee.

Where can I get more information?

If you would like more information, feel free to contact anyone on the research team:

- Thu Thuy Phan, PhD student, [contact details removed]
- Prof Craig Melville, PhD supervisor, [contact details removed]
- Prof Nicholas Watson, PhD supervisor, [contact details removed]

If you have any complaints, please contact the College of Social Sciences Ethics Officer, Dr Muir Houston, email: Muir.Houston@glasgow.ac.uk

University of Glasgow

College of Social Sciences

Participant Information Sheet – Service provider

Title

Enacting a citizen: An ethnography of everyday citizenship practices of people with learning disabilities

PhD research project undertaken by Thu Thuy Phan within the Institute of Health and Wellbeing, University of Glasgow.

Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The goal of this research is to understand the different meanings of citizenship for people with learning disabilities. Using participant observation and face-to-face interviews, I will explore what people with learning disabilities do in their everyday life that can be interpreted as an act of citizenship, and what rights they claim with these acts, if any. I will specifically document 1) the financial and infrastructural conditions of citizenship, 2) experiences of the collectivising and individualising tendencies of citizenship ideals, and finally 3) the communities people with learning disabilities are or desire to be part of.

During the participant observation, I'm attending Project Ability workshops to document how people make art together, and how that creates a sense of belonging. In the second part of the study, I interview people about their experiences of Project Ability and community participation.

The research started in November 2016 and is expected to be completed in 2019. The data collection will take place between 2017 and 2018.

Do I have to take part in the study?

You can decide whether or not to take part. If you decide to take part, you are still free to withdraw at any time, without giving a reason, and any information you have given will not be used in the research.

What will happen to me if I take part?

If you decide that you would like to take part, I will invite you to an informal, one-on-one interview to talk about your experiences. The interview will be semi-structured, which means you will be asked open questions and encouraged to give your opinions. The questions will be about your activities and experiences as a service provider.

The interview can take place in your home, or at a place of your convenience. The interview will last about one hour. I will audio record the interviews to transcribe and analyse them. There may be need for a follow-up interview in case of any recording problems or need for further clarification on any answers you have given.

Will my participation be confidential?

All your personal details will be kept strictly confidential, subject to legal limitations (e.g. the Freedom of Information (Scotland) Act 2002). I will remove all data that could identify you in the transcripts, such as your name or address. All audio-recorded interviews will be kept in password-protected files, and they will only be available to the researcher. I will destroy the audio recording and the original transcript when the research is finished.

- Please note that confidentiality will be maintained as far as it possible, unless during our conversation I hear anything which makes me worried that someone might be in danger of harm, I might have to inform relevant agencies of this.

What will happen to the data of this research?

When the research is finished, I will destroy the audio recordings and the original transcripts. I will also delete the personal information that links your identity to the data. I will keep the anonymised transcripts for any publications beyond this research, for example for journal articles or conference papers. All data will be kept in password protected files and in locked filing cabinets. The university requires all research material to be archived for 10 years after the research is finished. The anonymised transcripts will be kept in the data repository of the University of Glasgow. I will keep the observational material on a password protected PC and store the back up in a locked filing cabinet. Only the transcripts will be available for future re-use.

The results of the research will form the main part the PhD thesis. A copy of the thesis will be kept by the University of Glasgow, and copies can be made available to all the participants on request. The PhD thesis will potentially be used to form the basis of further journal, book, or magazine articles. You will not be identified in any report or publication that stems from this research.

Who is organising and funding this research?

The research is organised by a research team at the Institute of Health and Wellbeing, University of Glasgow as a PhD project. The PhD research project is funded by the Scottish Government.

This project has been considered and approved by the College Research Ethics Committee.

Where can I get more information?

If you would like more information, feel free to contact anyone on the research team:

- Thu Thuy Phan, PhD student, [contact details removed]
- Prof Craig Melville, PhD supervisor, [contact details removed]
- Prof Nicholas Watson, PhD supervisor, [contact details removed]

If you have any complaints, please contact the College of Social Sciences Ethics Officer, Dr Muir Houston, email: Muir.Houston@glasgow.ac.uk

INTERVIEW GUIDE – SERVICE USERS

My aim with the interview is to compare experiences of policy rhetoric of citizenship with a relational definition of citizenship that may emerge from participating in inclusive spaces. I will explore the kind of communities that services users are part of, or desire and imagine to belong to. The questions will aim to tease out the relationship between (imagined) community participation, the type of inclusive space that hosts this participation, social relationships, and material conditions.

I regard the interview as an inductive tool, where my expectations of what counts as important might not correspond with what the participants hold important for community participation or social membership. Therefore, it has to be flexible enough to allow participants to talk about what they find important. Additionally, I conduct interviews 2 months into the fieldwork, so that I can incorporate the themes that emerge during the initial observations. Therefore, I expect that the rough guide below will change, and that some themes will prove more important than others. Furthermore, I may do repeat or follow-up interviews to track changes in the participants' narratives.

Narrative:
Can you start with telling me a bit about yourself?

Semi-structured interview
Experiences of participating in Project Ability and other third sector organisations
Project Ability

- Can you talk about how you got involved with Project Ability?
- Can you describe what you do when you come to the studio?
- Questions about how often they come, whether they come alone or with support worker, how long have they been involved, etc.
- Questions about what they like/dislike
- Questions about the relationship with the other service users, service providers, volunteers, etc. at Project Ability

Possible membership in other groups: e.g. experiences of day centres, activities at other organisations, hobbies that they may pursue with other voluntary groups, self-advocacy groups

Online communities/forums they might be part of

Experiences outside the third sector: This section aims to probe the policy rhetoric on what makes a citizen, such as independent living, being in paid employment, being off benefits, being part of "mainstream society". Questions about these experiences will pay particular attention to the relational aspects of policy-defined citizenship.

Questions may include the following:
Can you describe what you do on an average day/week?
Can you tell me with whom you spend the most of your time on an average day/week?

Work: sheltered or paid employment, voluntary work

- Can you tell me a little bit about what you do on days you’re not at one of the workshops? Do you work, or do voluntary work? Additional questions about experiences of that
- Relationships with colleagues?
- Ideal work, questions on whether being in paid employment is an aspiration at all

Housing
- Living alone, with family, with other people?
- Relationship with people they live with

On benefit payments

On experiences of social care services

INTERVIEW GUIDE – SERVICE PROVIDER

Narrative:
Can you start with telling me a bit about yourself?

Semi-structured interview
Experiences of participating in Project Ability and other third sector organisations
Project Ability

- Can you talk about how you got involved with Project Ability?
- Can you describe what you do when you come to the studio?
- Questions about how often they come, how long have they been involved, etc.
- Can you describe the people who participate in these workshops? What is the appeal of these workshops, in your view?

Questions about the art created during the workshops:

- Can you talk about how you work with the participants during the workshops?
- What do you think about the art created during these workshops?
- Questions about any exhibitions, purpose of the workshops

Questions about the relationships formed during the workshops:

- Can you talk about who attends these workshops? What is the turnover in attendance?
- Do you keep in touch with people outside the workshops?
- Can you describe the relationship between you and the participants of the workshops?

Can you talk about what you perceive as the benefits of these workshops? Potential drawbacks?
How did these workshops change over time?