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'They care about a lot of folk. They definitely do.': Taking  
an asset-based approach to promote inclusion and support  
adults with intellectual disabilities during the Covid-19  
pandemic

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## Abstract

Asset-based approaches focus on strengths and capabilities as opposed to deficits. Social inclusion is central to asset-based work and what it seeks to achieve. However, social inclusion is often difficult for people with intellectual disabilities to fully realise. This may have particularly been the case during the Covid-19 pandemic. This body of work sought to explore the role an organisation taking an asset-based approach had in the lives of people with intellectual disabilities, both before and during the pandemic. It also explored the impact the pandemic had on the organisation and its members and how they adapted to the pandemic. A focus was placed on how the organisation taking an asset-based approach facilitated social inclusion among members and the role this organisation played in members' lives both before and during the Covid-19 pandemic. A case study design was adopted to address these aims.

The study initially incorporated in-person interviews and observations and a photo-mapping exercise. However, the Covid-19 pandemic and resulting government restrictions prevented data collection. A new study was designed to take these restrictions into account. A case study was carried out with an organisation taking an asset-based approach, dates-n-mates, in Scotland. A single-case embedded design was adopted. Six members of the organisation were interviewed a total of 37 times either online or by telephone in the summer and early autumn of 2020. Each participant was interviewed up to seven times on a fortnightly basis for three months to capture change over time. They were asked about their experiences of the pandemic and their experiences of taking part in the organisation both before and during the pandemic. In addition to the interviews, social media data were collected from the Twitter account held by the organisation from March 2020 to June 2021.

It was found that participants faced a range of difficulties and barriers during the pandemic, but they also showed an ability to adapt. Their individual accounts illustrate some of the challenges people faced during this time and the strategies they employed to cope with this unprecedented situation. Dates-n-mates helped to support members during this time through the dissemination of information and by hosting a wide range of online activities, chats, events, and workshops. The restrictions that were in place during the pandemic meant that individuals were cut off from social connections and revealed the fragility of the support networks of many people with intellectual disabilities. However,

dates-n-mates clearly helped to facilitate the broader social inclusion of members and fostered a sense of belonging within the group both before and during the pandemic, which highlights the importance of organisations like dates-n-mates, particularly during challenging life circumstances.

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## Author's Declaration

“I hereby declare that I am the sole author of this thesis, except where the assistance of others has been acknowledged. It has not been submitted in any form for another degree or professional qualification.”

Lauren Fulton

February 2024

# Chapter 1: Introduction

## 1.1 Aims of thesis

In this thesis, I aim to explain what asset-based approaches are and explore how one organisation taking an asset-based approach supported adults with intellectual disabilities both before and during the Covid-19 pandemic. Asset-based approaches were selected as the focus of this thesis because of their emphasis on assets or strengths as opposed to deficits. This was considered important because there is often a focus on what people with intellectual disabilities cannot do. By taking an asset-based approach, it allowed for an exploration of people's strengths, capabilities, and agency, which are not often explored in the lives of people with intellectual disabilities. In addition, very little work has been carried out to explore the role of organisations taking an asset-based approach in the lives of people with intellectual disabilities. The work undertaken for this thesis aims to add to this literature.

It is particularly noteworthy that this work was carried out in Scotland during the Covid-19 pandemic. At this particular location and time, government guidelines placed restrictions on what people could do and the services they could receive. This was largely due to the social distancing guidelines that were in place that often prevented people from meeting in person. These guidelines shaped both the conduct of the study and participants' lives during the time of this research. The impact this had on the study and participants is commented and reflected on throughout this work.

This thesis begins with a discussion of asset-based approaches and how they are linked to social inclusion. I then briefly outline some common models of disability. Next, I explore the lives of six adults with intellectual disabilities during the pandemic as they engaged with an organisation taking an asset-based approach. Finally, I explain how social inclusion features in the lives of people with intellectual disabilities who are taking part in one organisation that has adopted an asset-based approach.

In the introduction, I discuss key concepts that feature throughout this work: intellectual disability, asset-based approach, social inclusion, belonging, and reciprocity, and I explain how these concepts relate to each other. I also provide a brief overview of the impact of the Covid-19 pandemic. In Chapter 2, I provide a brief overview of some of the major models

or approaches to disability found in the literature. I connect the chosen model of disability, the capabilities framework, to asset-based approaches to help frame the work in this thesis before going on to the more empirical chapters.

In Chapter 3, I detail a qualitative research project that had received a favourable opinion from the research ethics committee prior to the Covid-19 pandemic. It was to focus on the social inclusion and belonging of adults with intellectual disabilities who took part in a programme taking an asset-based approach. Unfortunately, this project could not be carried out due to the pandemic and the resulting government restrictions. However, this study is important to discuss because it illustrates my thinking at that point in the thesis and demonstrates how the knowledge gained through writing the introduction and conducting a systematic review informed the trajectory of the thesis prior to the pandemic.

In the following chapter, Chapter 4, I then briefly introduce the qualitative study that was developed during the early stages of the pandemic. This project was designed rapidly as a replacement for the project presented in Chapter 3 and incorporated qualitative methods that did not necessitate in-person contact. This project deviated substantially from the original project, but the changes were needed to allow for qualitative research to be carried out during the pandemic. It consisted of an embedded case study and utilised remote methods of data collection. The design and methods for this new study are detailed in Chapter 5.

In Chapter 6, I provide context for the case study and embedded cases that will be presented in Chapters 7 and 8. This contextual information includes a timeline of key events during the pandemic and how they relate to actions taken by the programme featured in this work. This chapter helps to provide a deeper understanding of the study results. Chapter 7 presents the results from the case study centred on the programme taking an asset-based approach. This includes a cross-case analysis of participants' experiences of taking part in the programme and a summary of some of the programme's social media communications during the pandemic. I then turn to the embedded cases in Chapter 8. The cases detail the lives of six people taking part in the programme during the pandemic and are presented as six individual accounts.

Next, I share my reflections of conducting interviews remotely during the pandemic in Chapter 9. The strengths and weaknesses of both telephone and online interviews are



discussed. Finally, in Chapter 10, I present my discussion for this body of work. I discuss the findings from the case study and embedded cases in relation to the literature on the Covid-19 pandemic, social inclusion, and asset-based approaches and provide some reflections on the methods used in this study. I also outline the strengths and limitations of this work and make some recommendations for further research.

## **1.2 Definition of intellectual disability**

The work in this thesis is focused on adults with intellectual disabilities. It is recognised that the term ‘learning disability’ is often used in policy and by professionals in the UK and that some people labelled with learning disabilities have expressed a preference for the label ‘learning difficulty’ (Goodley, 2005; Holland, 2011). However, internationally, the term ‘learning disability’ often refers to specific learning difficulties, such as dyslexia, dysgraphia, and dyscalculia (Learning Disability Association of America [LDA], no date), and the term ‘learning difficulty’ is commonly attributed to these specific learning difficulties within the UK (Holland, 2011; Mencap, no date). Therefore, throughout this thesis, the term ‘intellectual disability’ has been adopted. This is not intended to disregard the wishes of people labelled with learning disabilities / difficulties but rather to make clear to an international audience the population that is being referred to in this work.

The label ‘intellectual disability’ is applied to people who experience significant limitations in both intellectual functioning and adaptive behaviour (Schalock et al., 2021). Limitations to adaptive functioning can be grouped in three domains. These domains include: 1) the conceptual domain, which centres on skills in areas such as reading, reasoning, and knowledge; 2) the social domain, which deals with areas such as social judgement, empathy, and communication skills; and 3) the practical domain which concerns work, personal responsibility, and managing finances (American Psychiatric Association [APA], 2013, p .1). In this context, ‘significant limitations’ generally relates to an intelligence quotient (IQ) score or adaptive behaviour score that is two standard deviations below the mean (Schalock et al., 2021). This is equal to an IQ score of around 70 or below (APA, 2013). In addition, the onset of identified difficulties must begin during the developmental period (APA, 2013), which the American Association on Intellectual and Developmental Disabilities (AAIDD) identifies as being before the age of 22 (Schalock et al., 2021).

## 1.3 Asset-based approaches

### 1.3.1 Background

Asset-based approaches have gained increasing attention in recent years and have grown rapidly in popularity, particularly in Scotland (Friedli, 2012). Asset-based work is now being used in numerous local areas and in a wide variety of contexts (Foot, 2012). According to McNeish et al. (2016), the current discourse surrounding asset-based approaches originates in work on community development. Asset-based approaches first gained widespread attention following the 1993 publication of ‘Building Community from the Inside Out: A Path Toward Finding and Mobilizing a Community’s Assets’ by Kretzmann and McKnight, two of the founders of the Asset-Based Community Development Institute at Northwestern University (McKnight, 2017). The impetus behind the creation of asset-based community development was to encourage communities to recognise and take pride in their strengths, while building their confidence and allowing them to steer development initiatives through collaborative relationships with agencies (Foot & Hopkins, 2010).

Within this community development context, asset-based approaches have focused on building more resilient and cohesive communities (Baker, 2014). This is typically achieved through a process of ‘asset identification’ at local levels using tools that have been specifically designed to engage community members, such as asset-mapping (Baker, 2014). Through such community driven exercises, ‘asset-based approaches recognise and build on a combination of the human, social, and physical capital that exists within local communities...[and] acknowledge and build on what people value most’ (Glasgow Centre for Population Health [GCPH], 2012, p. 2). In practice, this is intended to empower and mobilise communities and put their interests and values at the forefront of discussions surrounding local services and policies.

While the specific *asset* terminology has only gained momentum since the publication of Kretzmann and McKnight’s book in 1993, asset-based approaches themselves have been used in practice for some time (McLean et al., 2017). As Friedli (2012) notes, ‘the social values associated with asset-based approaches—celebration of the power of the human spirit, recognition of people’s strengths, resourcefulness and creativity and the empowering

nature of collective action—have a long history and are common features of social movements and traditions of struggle for social justice’ (p. 5).

Asset-based approaches have many things in common and are often synonymous with more established practices that have been widely used, such as: strengths-based approaches, personalisation, local area coordination (LAC), social pedagogy (McNeish et al., 2016), and positive deviance (Durá & Singhal, 2009). In fact, it has been noted that ‘*asset-based approach*’ and ‘*strengths-based approach*’ are frequently used interchangeably (Manchester City Council, 2015). According to Friedli (2012), asset-based approaches draw from positive psychology, the work of Antonovsky on sense of coherence, and health activism, including the disability rights movement. Asset-based approaches, particularly with regard to health and wellbeing, have strong links to salutogenesis, which stems from Antonovsky’s work (Sigerson & Gruer, 2011). Antonovsky’s thinking with regard to salutogenesis was that it was more important to focus on the resources people had to live healthily than to focus on ill-health (Lindström & Eriksson, 2005). According to Harry Burns, Chief Medical Officer for Scotland, ‘salutogenesis essentially underpins an assets approach’ (Assets Alliance Scotland, 2010, p. 3).

Therefore, while the term *asset-based approach* has emerged in recent years, the concept of asset-based work is hardly new. The ‘asset’ language currently employed to describe these approaches is very much situated within the uncertain political and economic climate we find ourselves in today. As Friedli (2012) explains, ‘constructs like *asset-based approaches* emerge and gain currency in specific social, economic, and political contexts and are pressed into service as part of wider ideological conflicts’ (p. 3). In their critique of asset-based approaches, Macleod and Emejulu (2014) reiterate this point, saying that it is not surprising that asset-based approaches have gained currency in recent years because they provide a way to navigate expansive cuts to state spending by shifting the focus away from the state as a provider of social welfare to communities and their abilities to provide for themselves.

### **1.3.2 What is an asset-based approach?**

When talking about asset-based approaches, it is important to make explicit what exactly these encompass (and identify what they *aren’t*) and explain what is meant by ‘assets’. In

essence, asset-based approaches ‘are forms of engagement and relationship building that enable strengths, capacities, and abilities to be identified and developed for positive outcomes’ (GCPH, 2012, p. 6). At its core, asset-based work is about recognising and utilising an individual’s or community’s strengths, capacities, skills, and knowledge, their assets, as opposed to focusing on their deficits and difficulties (Sigerson & Gruer, 2011; Boelman & Russell, 2013; McNeish et al., 2016). According to the Glasgow Centre for Population Health (2011), ‘assets can be described as the collective resources which individuals and communities have at their disposal’ (p. 2). These ‘assets can be social, financial, physical, and environmental’ (McLean & McNeice, 2012, p. 6), and are grouped into one of three levels: individual, community, or organisational (Sigerson & Gruer, 2011). At an individual level, which will be the focus of this thesis, assets include things such as resilience, self-esteem, and a sense of purpose (GCPH, 2011).

An asset-based approach is directly in contrast to a deficits approach, which ‘designs services to fill the gaps and fix the problems’ (GCPH, 2011, p. 5) and places ‘little focus on enhancing the individuals’ strengths and capabilities’ (GCPH, 2011, p. 5). A deficits approach also largely ignores peoples’ experiences, preferences, perspectives, and knowledge (GCPH, 2011). Essentially, when taking an asset-based approach, an attempt is made to rectify the traditional deficit approach by looking at what people *can* do as opposed to focusing on what people *can’t* do. However, in order to make this shift, professionals and councillors need to be willing to share their power (Foot & Hopkins, 2010, p. 12).

When attempting to assess what exactly constitutes an asset-based approach, there is no definitive answer in the literature. Instead of a singular definition, asset-based approaches tend to encompass a certain set of values and principles (Foot & Hopkins 2010; McNeish et al., 2016). Perhaps most importantly, asset-based approaches are inherently ‘person centred,’ which involves ‘working with people as active participants rather than passive recipients of health or social care programmes, in ways which are empowering’ (Sigerson & Gruer, 2011, p. 2). According to Boelman and Russell (2013), ‘social inclusion, opportunity, and control are [...] at the heart of asset-based approaches and the benefits they seek to deliver’ (p. 26). Asset-based approaches should strive to engage individuals who might not typically get involved in projects (GCPH, 2012). It is also desirable that initiatives taking an asset-based approach be long-term and open-ended (Foot & Hopkins, 2010). In addition, asset-based approaches are ‘strongly associated with a non-materialist

position—money does not matter as much as relationships, sense of meaning and belonging, opportunities to contribute, and autonomy’ (Friedli, 2012, p. 4).

Asset-based work also places a strong emphasis on relationships and networks (McLean & McNeice, 2012; McNeish et al., 2016). According to McNeish et al. (2016), ‘working with individuals in isolation from their communities is not fully asset based’ (p. 49). This centrality of relationships and networks to asset-based approaches is made explicit across the literature. In principle, asset-based work must not only strive to attach value to the resources and skills people have and can contribute, but must also ensure that these assets are recognised by and help contribute to their communities. In sum, asset-based approaches can be defined as approaches that are: inclusive; person-centred and strongly committed to giving individuals (or communities) control over projects or initiatives; celebratory of strengths, skills, knowledge, and capacities; and dedicated to increasing opportunities for people to engage in their communities and build relationships.

Using this definition, we can then begin to identify the ways in which the values that underpin asset-based approaches can be employed in asset-based work. When taking an asset-based approach it generally means: starting by identifying what is working rather than identifying problems, working alongside people, helping people identify their strengths, supporting people to make positive changes, building supportive networks, and shifting control over the design and development of services to individuals (McNeish et al., 2016). Asset-based approaches begin by identifying resources through asking questions such as: ‘What makes us strong? What makes us healthy? What factors make us more able to cope in times of stress? What makes this a good place to be?’ (Foot & Hopkins, 2010, p. 8).

Oftentimes, projects encompass the principles and values behind asset-based work without using this term. For instance, it was found by McNeish et al. (2016) that many organisations in Scotland had been taking an asset-based approach to their work for some time but just did not use that term to describe what they were doing. The Glasgow Centre for Population Health (2011) likewise found that asset-based approaches were operating in many places throughout Scotland but often used different terminology to describe their approaches, such as ‘community empowerment’, ‘enablement’ or ‘self-management’.

### 1.3.3 Applications

In recent years, asset terminology has begun to be applied to areas outside of community development. For instance, asset-based approaches now feature prominently in the literature surrounding health and health inequalities (Friedli, 2012). This has been very apparent in Scotland. According to McLean et al. (2017), ‘the Scottish Government has expressed a commitment to reform public services to build on the assets and potential of individuals, families, and communities’ (p. 6). However, despite this growing popularity, a recent literature review conducted by McNeish et al. (2016) did not reveal any written accounts of projects taking an asset-based approach that included people with intellectual disabilities as their primary focus. They further note that asset-based approaches have only recently begun to be applied to work involving people with intellectual disabilities (McNeish et al., 2016).

I conducted my own search of the literature using Scopus in December 2022. I applied the search terms ‘asset based approach’ and ‘disabilit\*’ to abstracts, titles, and keywords. Only eight journal articles were returned, of which only three focused on people with developmental disabilities. No articles focused specifically on people with intellectual disabilities. Seven of the eight articles were published since the time of McNeish et al.’s (2016) literature review. When ‘asset based approach’ was searched alone, 255 journal articles were returned. 139 of these studies had been published in 2017 or later. The vast majority of the research focused on health and health care or education and learning. A considerable number of studies also focused on marginalised groups, community development, aging, or youth. While it is encouraging to see that research is being conducted in this area, it is still extremely sparse in relation to people with disabilities.

### 1.3.4 Lack of evidence

Despite the growing popularity of asset-based approaches, they lack a strong evidence base. Much of the evidence to suggest asset-based approaches have positive outcomes has been anecdotal (Baker, 2014) or is based on case studies (GCPH, 2011; Sigerson & Gruer, 2011; Friedli, 2012), many cases of which were labelled ‘asset-based’ retrospectively (Friedli, 2012). Most of the research that has been conducted on asset-based projects has been small in scale and exploratory in nature (Foot & Hopkins 2010). A lot of the support for asset-based approaches is based on the idea ‘that confidence and self-esteem are

determinants of health and other outcomes' (Friedli 2012, p. 3). But Friedli (2012) goes on to say that there is little evidence that asset-based approaches contribute to greater self-esteem or confidence in local communities or individuals.

According to GCPH (2012), measures need to be developed to establish baselines and track inputs and outputs, outcomes need to be measured in both the short and long term, and the effectiveness and efficiency of a range of interventions need to be compared. However, Foot and Hopkins (2010) mention that there are methodological challenges associated with developing a framework with which to evaluate asset-based approaches. For one, it would require that the goals of asset-based projects be clarified from the outset in order to adequately measure the outcomes (Foot & Hopkins, 2010). This is challenging because many programmes are not developed with the explicit aim of taking an asset-based approach. The term often gets applied to programmes after they are running (Friedli, 2012).

Furthermore, it takes time to begin to see measurable outcomes from asset-based approaches (Foot & Hopkins, 2010). As Foot and Hopkins note: 'it is not a quick fix' (2010, p. 16). In addition, project staff can be short on time, making it difficult to allocate someone to the task of evaluating outcomes. McLean and McNeice (2012) found that staff involved in most asset-based projects were focused primarily on the implementation of the project, so few had established ways to systematically evaluate the project and measure outcomes. However, most staff felt that the projects they worked on were beneficial and some stated that they wished they had employed a system to better monitor and evaluate the outcomes of their projects (McLean & McNeice, 2012).

The lack of an evidence-base for asset-based approaches points strongly for the need of some sort of evaluative framework and suggests that research needs be carried out to assess whether asset-based approaches have positive and measurable impacts on people's lives. In order to continue pushing services to adopt an asset-based approach, it seems essential that these approaches are evaluated in a systematic way to see if they are as beneficial as many claim.

### 1.3.5 Difficulties to employing an asset-based approach

It is important to note that there are certain obstacles that may arise when carrying out asset-based work. For one, funding can be a major issue for projects taking an asset-based approach (McLean & McNeice, 2012). Programmes may cease due to a lack of funding and leave people unable to participate in the activities they enjoy (Boelman & Russell, 2013). In addition, some projects largely depend on the efforts of one committed individual, which could create problems should that person leave their post (McLean & McNeice, 2010).

When focusing on people with intellectual disabilities, practical issues such as transportation and support needs should be considered when determining the accessibility of programmes taking an asset-based approach (McNeish et al., 2016). According to Boelman and Russell (2013), ‘one of the biggest potential barriers to accessing opportunities is the simple ability to reach the destination’ (p. 19). Strict routines, either chosen or imposed, can also limit peoples’ abilities to take advantage of opportunities (Boelman & Russell, 2013).

Stigma may also pose a barrier to asset-based working (Boelman & Russell, 2013). Asset-based approaches require a shift in the way the community views people with intellectual disabilities and in the way people with intellectual disabilities view themselves (McNeish et al., 2016). In addition, there may be further challenges when trying to form social connections for people who have multiple and complex needs (McNeish et al., 2016).

### 1.3.6 Critique

While asset-based approaches are generally framed in a positive light, they are not without critique. According to Friedli (2012), ‘the move from “welfare to well-being” also signals that asset-based approaches are part of efforts to reduce “unaffordable demand,” to achieve public spending cuts and to promote a DIY response to loss of services and loss of benefits’ (p. 8). However, it has been made explicit that asset-based approaches should not be used in place of adequately funded services (GCPH, 2011; McLean & McNeice, 2012).

It has also been argued that by focusing solely on assets, needs and larger structural inequalities get ignored (Friedli, 2012). Although McLean and McNeice (2012) claim that



‘in practice, there is not a simple and clear division between deficit-based approaches and asset-based approaches’ (p. 14). They found that deficits could be addressed in asset-based projects using a model based on developing strengths and resources. This is expanded upon by Bull et al. (2013):

The question is not whether an assets approach is better than a deficits approach, or whether the one should replace the other. An assets approach in development of health for individuals and communities would involve ‘injection’ of resources to meet needs, however with assets, needs and approaches are defined by the individuals or communities in question, in a true participatory manner. Truly participatory approaches are based on the acknowledgement of the presence of assets in the local contexts. (p. 171)

Therefore, when projects are driven by individuals and communities in a truly collaborative way, they can be asset-based while still recognising needs and inequalities. What is important is that these needs and inequalities are defined by the people themselves, and any initiatives to address them are informed by their preferences and utilise their strengths and capabilities.

### **1.3.7 Final remarks**

While the terminology surrounding asset-based approaches is relatively new, the basic values and principles that underpin asset-based work have been in use in a variety of contexts for many decades. At their core, asset-based approaches are inclusive and person-centred, acknowledge and build upon strengths and skills, and emphasise community engagement and strong social networks. They focus on individual and community strengths but need not, and should not, disregard structural inequalities and social injustice. While they are intended to help people and communities to better help themselves, it is important to stress that they cannot be seen as an alternative to adequately funded public services.

Currently, the evidence-base for asset-based approaches is lacking as very few projects have measured participant outcomes. There are also very few studies that have taken an asset-based approach and included people with intellectual disabilities as their focus. There

is a clear need to address these gaps in the literature, particularly given the increasing popularity of asset-based approaches and the push for services to adopt them.

## **1.4 Connection between asset-based approaches and social inclusion**

Social inclusion is central to asset-based approaches and what they aim to achieve (Boelman & Russell, 2013). Asset-based approaches focus on building social networks (McLean & McNeice, 2012), creating opportunities for everyone to contribute to their communities, and developing community members' sense of belonging (Friedli, 2012). They also strive to involve everyone in community building initiatives, including people who do not typically have a voice in their communities (GCPH, 2012). Therefore, asset-based approaches may provide an effective platform from which the social inclusion of people with intellectual disabilities can be increased.

Taking an asset-based approach could also be beneficial when looking at issues surrounding social inclusion, participation, and engagement. While it is important to examine the barriers that prevent people from being included so inequalities may be addressed, it is equally as important to pay attention to the ways in which people have achieved social inclusion and the activities and organisations that have facilitated this process. By looking at what is already working in communities and for individuals, we can gain better insights into the factors that help people feel included. This can provide useful information about the types of programmes and ways of working that could increase social inclusion more broadly for people with intellectual disabilities.

Asset-based approaches also have the potential to identify new ways of working by valuing the knowledge and skills of everyone in the community. This is important because as Power (2013) noted following an interview with a service manager: 'more successful outcomes can emerge where individuals and families work closely together in identifying novel solutions to support' (p. 73). By valuing the insights people with intellectual disabilities have with regard to social inclusion, we may be able to reveal strategies that can help others become more included in their communities.

## **1.5 Social inclusion**

### **1.5.1 Background**

Research has shown that while people with intellectual disabilities have gained a greater physical presence in their communities in recent decades, they have not necessarily experienced increases in community participation or formed meaningful relationships with other members of their communities (Clement & Bigby, 2009). This is an important distinction to make because social inclusion does not occur merely through an individual's physical presence in the community (Abbott & McConkey, 2006); it requires participation and engagement as well (Cobigo et al., 2012).

From within the disability community, inclusion represents the idea that all people feel welcomed, valued, and incorporated into society (D'Eloia & Price, 2018). However, it has been found that many people with disabilities feel disconnected from their communities beyond the service settings they frequent, saying that they had few friendships and experienced feelings of marginalisation (Milner & Kelly, 2009).

In addition, inclusion often relies upon people with disabilities to conform to the cultural roles that tend to be defined by those without disabilities (D'Eloia & Price, 2018).

According to Robinson and Notara (2015), the 'responsibility for inclusion is often set largely at the feet of people with disability and their families; they are expected to behave in a "normal" fashion, to gain employment; to engage in mainstream community activities' (p. 726). Under current conceptualisations of inclusion, individuals with intellectual disabilities are expected to take certain steps in order to access mainstream society (E. Hall, 2010), and as Bates and Davis (2004) caution, 'individuals who do not engage may be blamed for their situation' (p. 202).

### **1.5.2 Initiatives to increase social inclusion**

Social inclusion initiatives have tended to be narrow in scope, focusing largely on economic or other typically socially valued activities (Abbott & McConkey, 2006), such as employment (Brown et al., 2015; Cobigo et al., 2012; E. Hall, 2004; E. Hall, 2005) and independent living (E. Hall, 2004; E. Hall, 2005). While these aims have been found to agree with what people with mild to moderate intellectual disabilities want for their lives

(Hamilton et al., 2017), and employment has been found to have the potential to increase inclusion for people with intellectual disabilities (Lysaght et al., 2017), this limited view of social inclusion is problematic for a number of reasons. For one, focusing on economic activity overlooks the other ways people can contribute to their communities (Brown et al., 2015) and makes invisible the voluntary contributions people with disabilities and their families do make (Chenoweth & Stehlik, 2004). It also generally requires that people with intellectual disabilities conform to mainstream societal norms in terms of behaviour, appearance, and social location (E. Hall, 2004).

Even when paid employment is obtained, it does not necessarily mean that the individual will achieve social inclusion, and independent living can, in some instances, lead to even greater feelings of isolation and exclusion (E. Hall, 2005). In addition, as E. Hall (2004) writes, ‘for many, experiences of exclusion and rejection continue within “inclusive” spaces’ (p. 302), which creates a situation whereby people ‘are in a “double-bind” of marginalisation, experiencing exclusion *from* and abjection and discrimination *within* the very social spaces that are the key markers of social inclusion policy’ (E. Hall, 2005, p. 110; emphasis in the original).

Lysaght et al. (2017) found that many people with intellectual and developmental disabilities who had obtained waged community-based work found themselves excluded from the social activities their co-workers took part in or had very little contact with other workers within the workplace itself, which led to levels of loneliness similar to those who were unemployed. They also found that people who worked in segregated settings developed a strong sense of belonging and were more likely to establish bonds with co-workers that extended beyond the workplace (Lysaght et al., 2017). This does not mean that efforts should not be made to help people with intellectual disabilities find employment in mainstream settings. However, options should be available to people with intellectual disabilities to decide where and how they would like to work so opportunities can be provided for people to experience the type of employment that is meaningful to them.

A focus on employment and independent living also disregards the experiences of those who may find these goals challenging to achieve. According to Clegg et al. (2008), ‘framing inclusion in terms of productivity and contribution, rather than self-fulfilment or quality of life, certainly has little relevance to most people with severe intellectual

disability' (p. 81). In addition, there are many people who cannot participate in or do not want to pursue dominant pathways to social inclusion but still want to feel they belong (E. Hall, 2010). People with severe and profound intellectual disabilities, for instance, may find it particularly challenging to secure employment (Brown et al., 2015). As Bates et al. (2017) state, 'paid work is tantalisingly held up as the object of desire but remains obstinately out of reach for many people with learning disabilities' (p. 163). According to Anderson and Bigby (2017), using employment as the primary approach to increase social inclusion 'seems to seal the exclusionary fate of those unable to participate for a range of reasons' (p. 109). Furthermore, having such limited views of what constitutes social inclusion can lead 'to moralistic judgement if people reject or cannot achieve the dominant norms' (Cobigo et al., 2012, p. 79).

This is not to say that we should not continue to advocate for inclusive workplaces and supported employment. Work helps people feel they can participate in society and allows for the creation of identities that challenge the literature that positions people with intellectual disabilities as passive subjects (Bates et al., 2017). It can also provide people with income, status, and relationships (Bates & Davis, 2004), as well as an environment in which to feel known and accepted by members of the community (Lysaght et al., 2017). Furthermore, both voluntary and paid work have been reported to provide a sense of belonging to people with intellectual and developmental disabilities (Lysaght et al., 2017), and many people with intellectual disabilities have expressed a desire to obtain employment (Hamilton et al., 2017). It is clear that work does have the potential to provide a powerful platform from which people with intellectual disabilities can forge relationships and create meaningful identities that may disrupt common conceptualisations of people with intellectual disabilities as dependent.

However, while employment has the capacity to build relationships, increase community participation, and lead to positive self-identities, it is important to recognise that less than 10% of people with intellectual disabilities in the UK occupy paid positions (Bates et al., 2017). Low employment figures have persisted despite the approaches aimed at increasing the employment of people with intellectual disabilities (Anderson & Bigby, 2017; Lysaght et al., 2017). While they are not mutually exclusive, voluntary work, involvement in the arts (Hall & Wilton, 2011), self-advocacy groups (Anderson & Bigby, 2017), and providing care for others (Strnadová et al., 2018) present alternatives to paid employment. For one, it has been found that people with intellectual disabilities appreciated the

business-like nature of self-advocacy groups and adopted the position of ‘worker’, while recognising the social value placed on this role (Anderson & Bigby, 2017).

We must help people access valued social roles within society while simultaneously working to reimagine what being valued in society means. Pathways to mainstream employment and independent living must be made available to those who would like to pursue them. However, alternatives should be made available for people who cannot or do not aspire to these goals. The conceptualisation of social inclusion clearly needs to expand beyond notions of employment and independent living if it is ever to truly be inclusive.

### **1.5.3 Defining social inclusion**

Further compounding issues surrounding attempts to increase social inclusion is the fact that social inclusion is difficult to define and can take on many different meanings (Bates & Davis, 2004; Cobigo et al., 2012; Neely-Barnes & Elswick, 2016; Strnadová et al., 2018). In the context of disability, social inclusion has typically been defined in relation to participation in community-based activities and having social networks (Abbott & McConkey, 2006). However, when reading the social inclusion literature, it does not take long to discover that a wide range of definitions have been used. In addition, a large number of interrelated terms have simultaneously been equated with, distanced from, or described as components of social inclusion.

There have been some attempts to create more concrete and comprehensive definitions of social inclusion. For instance, in their review of the literature, Cobigo et al. (2012) found that when defined in relation to people with intellectual and developmental disabilities, social inclusion could be defined as:

- (1) a series of complex interactions between environmental factors and personal characteristics that provide opportunities to
- (2) access public goods and services,
- (3) experience valued and expected social roles of one’s choosing based on his / her age, gender and culture,
- (4) be recognized as a competent individual and trusted to perform social roles in the community, and
- (5) belonging to a social network within which one receives and contributes support. (p. 82)

Through her qualitative meta-analysis, S.A. Hall (2009a) found social inclusion for young adults with intellectual disabilities to encompass: 1) being involved in activities, 2) maintaining reciprocal relationships, and 3) having a sense of belonging.

Simplican et al. (2015), developed a model of social inclusion in an attempt to provide a clearer conceptualisation of the term. According to the authors, their ‘model separates the definition of social inclusion from the processes that may produce social inclusion as well as the subjective feelings that may result from inclusion’ (p. 22). They proposed that social inclusion is made up of two primary domains, interpersonal relationships and community participation, that are interrelated and contain categories to capture the ‘structural and functional components of social inclusion’ (Simplican et al., 2015, p. 22). This model was notably different from the definition provided above because it sought to separate social inclusion from the processes that may give rise to it and the feelings, such as belonging, that may arise from it.

However, in some respects, these attempts at defining social inclusion have introduced additional ambiguities. They ask us to seek definitions for terms such as belonging and community participation, which themselves are not clearly defined in the literature. In seeking definitions to these underlying concepts, we find that they are further entwined with other nebulous concepts and alternative conceptualisations of social inclusion. This work will not seek to disentangle these concepts or offer alternative definitions. However, there will be a recognition of the importance of belonging and reciprocity in discussions of social inclusion. These concepts take social inclusion beyond physical presence and community participation and signify a deeper level of connection with others.

#### **1.5.4 Belonging and reciprocity**

As is apparent through the definitions of social inclusion provided by Cobigo et al. (2012) and S.A. Hall (2009a), belonging and reciprocity are central to the literature on social inclusion and many conceptualisations of the term. As Brown et al. (2015) stated, social inclusion ‘goes beyond involvement in a range of activities in the community; it encompasses the experiences of reciprocity and feelings of belonging that transform involvement in activities into a meaningful participation’ (p. 95).

After recognising the importance of belonging and reciprocity to social inclusion, Fulton et al. (2021) carried out a systematic review to examine the approaches that had been taken to explore belonging and reciprocity in the lives of people with intellectual disabilities. This work was conducted as part of the first author's PhD research and is presented in Appendix A. It was found that despite the central roles belonging and reciprocity play in social inclusion, they are rarely the primary focus of research and often remain undefined.

#### **1.5.4.1 Belonging**

According to Mahar et al. (2013), 'feeling a sense of belonging to the community has been identified as a core dimension of social inclusion of persons with disabilities' (p. 1027). Social inclusion efforts have largely aimed to build a sense of belonging within the wider community (D'Eloia & Price, 2018). While closely related to social inclusion, belonging differs from most conceptualisations of social inclusion in that it focuses specifically on those activities that provide individuals a sense of fulfilment, connection, or purpose. According to E. Hall (2010), 'to achieve belonging is much more than being socially included (as it is normally envisaged). To belong is to feel attached, to feel valued, and to have a sense of insidership and proximity to 'majority' people, activities, networks, and spaces' (p. 56). For Power (2013) 'belonging is defined as *meaningful* engagement and reciprocal relationships within local neighbourhoods or networks between people with and without disabilities' (p. 69; emphasis in original). Developing a sense of belonging is not dependent upon where people participate in their communities but, rather, how they participate (Milner & Kelly, 2009).

In other words, physical presence does not in itself provide people with a sense of belonging (Björnsdóttir, 2017). Belonging entails a feeling of being 'at home' (Yuval-Davis, 2006). These subjective experiences are important because people with intellectual disabilities may experience exclusion in what appear to be spaces of inclusion (E. Hall, 2005). As Reeves et al. (2023) pointed out, 'Despite having increased opportunities to participate in community life, a sense of belonging is frequently absent in the lives of people labelled with intellectual and developmental disabilities, evidenced, in part, by their qualitative reports of exclusion, discrimination and bullying in community spaces' (p. 318).



Mahar et al. (2013) view belonging as highly context dependent. They note that these relationships must take place within the context of a group to which the individual wants to belong and feels permission to belong. They go on to state that ‘an individual may feel a sense of belonging to more than one relationship, group, system or entity simultaneously with each situation encompassing a sense of belonging that is unique to that relationship’ (Mahar et al., 2013, p. 1029). According to Yuval-Davis (2006), belonging is a dynamic process, and people may belong in many different ways (see p. 199). It is also important to point out that it is not reasonable to expect for any one person to be included in every aspect of society (E. Hall, 2010).

Belonging generally encompasses feelings of connection and caring, and is often referred to as connectedness, attachment, membership, or relatedness (D’Eloia & Price, 2018). According to Antonsich (2010), in order to foster a feeling of belonging, the relationships must be long-lasting, positive, stable, significant, and take place at a frequency that is commensurate with the individual’s needs or desires. People must have the opportunity to participate and share in tradition without a fear of being judged or feeling like a burden to others (D’Eloia & Price, 2018). It also requires that individuals begin to feel that they are not so distant from the rest of society (E. Hall, 2010) and that other members of the community value what they say and expect them to contribute (Milner & Kelly, 2009).

Some have even argued that the concept of belonging should be used in place of social inclusion. However, Simplican et al. (2015) caution that ‘emphasizing the subjective component of social inclusion is important, but replacing social inclusion with a sense of belonging may tell us little about the actual level of involvement of people with disabilities in their communities or their social networks’ (p. 21). While this is a valid concern, it seems unlikely that people would feel a sense of belonging if they were not participating in their communities and interacting with others. In addition, as previously explained, levels of involvement do not necessarily relate to inclusion.

Björnsdóttir (2017), argues that it is important to collect input from people with intellectual disabilities when evaluating whether or not a programme has the capacity to provide a sense of belonging, a viewpoint which research has often overlooked. However, some of the research that has been conducted has found that a sense of belonging may be fostered in programmes designed specifically for people with disabilities. Summer camps, for instance, can provide ‘a supportive environment for these youth to engage in challenging

experiences, take on meaningful roles, learn new skills, identify with peer role models who share similar characteristics, and socially connect with similar others, all of which contributes to a sense of belonging' (D'Eloia & Price, 2018, p. 98). Similarly, Frawley and Bigby (2015) found that people with intellectual disabilities who were members a self-advocacy group gained a sense of belonging through their participation in the group.

People with intellectual disabilities have also mentioned feeling a sense of belonging in relation to having knowledge of the local area in which they live and being within walking distance of local facilities (Barr et al., 2003). The ability to feel a sense of belonging to a specific group, neighbourhood, or community follows on from Antonsich's (2010) notion of 'place-belongingness' in which there is a feeling of being at 'home' or having a sense of 'familiarity, comfort, security, and emotional attachment' (p. 646). It is clear that if provided with an accepting atmosphere and the right circumstances, people with intellectual disabilities can feel a sense of belonging to a range of groups and their local communities. Given the importance of achieving a sense of belonging, it is vital that efforts are made to facilitate this process.

#### **1.5.4.2 Reciprocity**

Another key component to social inclusion is reciprocity, which also features strongly in conceptualisations of belonging. According to Overmars-Marx et al. (2014), 'inclusion is a reciprocal process involving commitment and activity from all parties involved' (p. 269). Mahar et al. (2013) list reciprocity as one of the key principles of belonging, and D'Eloia and Price (2018) assert that reciprocity, along with intimate sharing, is essential to the development of a sense of belonging. Furthermore, Milner and Kelly (2009) found that people with disabilities 'consistently identified reciprocity as an important way to challenge implied dependence' (p. 56).

According to Chenoweth and Stehlik (2003), reciprocity 'is not based on the "immediate return" requirement that is inherent in the business contract but rather on the notion that people provide a support to others based on a general expectation that someone will return the favour at some time in the future' (p. 62). Therefore, it is largely dependent upon mutual feelings of trust (Chenoweth & Stehlik, 2004). However, through their research on the social networks of people with disabilities and their families in Australia, the researchers found that reciprocal relationships were more difficult for people with

disabilities and their families to establish. Unfortunately, at many times people expect more immediate reciprocity, which can be difficult for people with disabilities to provide (Chenoweth & Stehlik, 2004). Furthermore, reciprocity is often lacking in relationships between people with and without disabilities because people with disabilities often have a lower social standing than their nondisabled peers (D'Eloia & Price, 2018). This problem could potentially be addressed if people began to value the range of contributions that others are able to make rather than demanding that the reciprocal action match the original.

In their investigation on how people with intellectual disabilities viewed their accommodations, Barr et al. (2003) found that people often valued having reciprocal relationships within or near their places of residence. People enjoyed being able to help others and felt good when they could undertake tasks that were beneficial to their communities (Barr et al., 2003). Similarly, Lysaght et al. (2017) found that people with intellectual and developmental disabilities liked to be able to help others and got satisfaction from being able to assist co-workers, supervisors, or customers in their workplaces. It is clear that people with intellectual disabilities value opportunities to establish reciprocal relationships and that more should be done to create these opportunities.

## **1.6 Impact of Covid-19 pandemic**

Now that key concepts have been explained, it is time to turn to the context in which much of this work was carried out. On the 11<sup>th</sup> of March 2020, the World Health Organisation declared there was a global pandemic due to the rapid spread of Covid-19, a novel coronavirus that could cause severe illness or even death (Scottish Government, 2022b). This led to governments around the world imposing restrictions on their populations to control the spread of the disease. Scotland, for instance, entered lockdown on the night of the 23<sup>rd</sup> of March 2020, under which people were only permitted to leave home for essential purposes (Scottish Government, 2020i). On the 26<sup>th</sup> of March 2020, it became law for everyone in Scotland to follow social distancing measures to reduce contact between people and stop the spread of Covid-19 (Scottish Government, 2020s). Lockdown and social distancing measures resulted in most people being largely confined to their homes and drastically reduced in-person social interaction. People living in different households were not allowed to mix during lockdown and were only permitted to socialise in person with those they lived with.

Being in lockdown had negative impacts on people's health and wellbeing. Tull et al. (2020), for instance, found that lockdown 'was associated with greater health anxiety, financial worry, and loneliness' (p. 5), and Ammar et al. (2020) reported that life satisfaction decreased. In addition, in a study of older Dutch adults, it was found that participants were more emotionally lonely during the pandemic than they were prior to the pandemic (van Tilburg et al., 2021). Furthermore, through a review of the literature on previous pandemics, Brooks et al. (2020) found that lockdown could cause boredom, frustration, and a sense of isolation.

The pandemic also had severe implications for people's physical health. Most notably, many people became severely ill or died due to Covid-19. The infection and fatality rates were pronounced in people with intellectual disabilities. In Scotland, it was found that adults with intellectual disabilities were almost two times as likely to become infected with Covid-19 and were 2.2 times as likely to have a severe infection resulting in hospitalisation or death than the general population (Henderson et al., 2022). In an international study of electronic medical records, case-fatality was also found to be higher among people with intellectual disabilities of all ages (Sabatello et al., 2020).

Not only did Covid-19 have direct implications for people's health, but the resulting lockdown and social distancing measures also had an impact on people's health by changing the availability of healthcare and the way care was accessed and administered. According to Jesus et al. (2021), the health outcome and healthcare access disparities experienced by people with disabilities were exacerbated during the pandemic. People who relied on caregivers or personal assistants often saw an interruption to care during the pandemic (E. Hall, 2021; Jesus et al., 2021). When these networks of care that often enabled people with disabilities to live independently were disrupted, people's wellbeing and abilities to live independent lives were impacted (E. Hall, 2021). In addition, the information about the pandemic, including how to stay safe and healthy, was not always accessible (Sabatello et al., 2020). For some people with intellectual disabilities, this meant that they did not always understand what was happening, which could cause confusion and stress (Embregts et al., 2022) and increase anxiety (Fudge Schormans et al., 2021). Misinformation about the pandemic could also spread rapidly (Xie et al., 2020) adding to this confusion.

The pandemic and social distancing measures also impacted on people's social lives. Places such as day centres and sheltered workshops were forced to close, which removed opportunities for community participation (Jesus et al., 2021), and most face-to-face contact and community-based activities ceased. However, Tull et al. (2020) reported that there was an increase in social support seeking during the pandemic. In order to socialise with friends and family living in other households, many people took their social interactions online. The use of the internet and social media to stay connected was, perhaps unsurprisingly, found to have increased during lockdown (Ammar et al., 2020). This increase in use was also reported among older adults with intellectual disabilities, many of whom did not use technology prior to the pandemic (McCausland et al., 2021). It was found that taking part in online social groups could help build community, provide structure, and give people the chance to meet others they would not have otherwise met (McFerran et al., 2022). In addition, interacting with close others online, such as friends and family members, was found to be related to an increase in positive affect and social connectedness (Tibbetts et al., 2021). In their study on the impact of Covid-19 on people with mild intellectual disabilities, Embregts et al. (2022) found that some participants felt that using video conferencing platforms was a good way to keep in touch with others during the pandemic.

However, not everyone had adequate access to the internet. For instance, Fudge Schormans et al. (2021) reported that many people with intellectual disabilities were unable to get online because they did not have access to devices, support to learn how to access the internet, or the ability to pay for internet service. McFerran et al. (2022) likewise found that people with intellectual disabilities could struggle to use technology. Members of an online music group with intellectual disabilities often relied on family members or supporters to access the group, which could become a problem if the support was unavailable (McFerran et al., 2022). Even when people had access to appropriate technology and support, socialising over the internet could not replicate in-person interactions. Speaking to people online could feel impersonal (Embregts et al., 2022). Therefore, while online interactions could be important for people to maintain relationships during the pandemic, they did not provide the same level of connection as in-person interactions.

## 1.7 Conclusion

In this chapter, key concepts were defined, such as intellectual disability, asset-based approach, social inclusion, belonging, and reciprocity. This chapter ended by briefly explaining the widespread impact of the Covid-19 pandemic. In the next chapter, key models of and approaches to disability will be outlined and the intersection between asset-based approaches and the chosen approach will be discussed. This will help to frame the work described in the rest of this thesis.

## **Chapter 2: Models of disability**

### **2.1 Introduction**

Over time, disability has been understood in many different ways, and many models of disability have both gained currency and fallen out of favour. In this chapter, I will describe the common models or understandings of disability in the literature and discuss how asset-based approaches intersect with the model of disability adopted in this thesis. This will help to frame this body of work and connect it to the broader literature on disability. I will return to reflect upon the chosen model of disability and its connection to asset-based approaches in the discussion (Chapter 10).

### **2.2 Medical model of disability**

The mid-1800s saw the rise of the medical model of disability in conjunction with significant advances in medical science (Retief & Letšosa, 2018), and by the early 1900s, this was the primary lens through which disability was understood (Brett, 2002). According to Marks (1997), ‘the medical model focuses on individual pathology and attempts to find ways of preventing, curing or (failing these) caring for disabled people’ (p. 86). It rests on the idea that disabled people deviate from what is considered to be ‘normal’ by society (Retief & Letšosa, 2018). It emphasises clinical diagnoses (Brisenden, 1986) and sees disability as a characteristic of a person (Woods & Thomas, 2003) and the source of the problem (Oliver, 2004). The medical model ‘regards disability as an impairment that needs to be treated, cured, fixed, or rehabilitated’ (Degener, 2017, p. 42). When this view of disability as an individual problem is adopted, ‘appropriate assistance is understood either as rehabilitation efforts to enable the individual to overcome the effects of the disability, or medical efforts to find a cure for the individual’ (Areheart, 2008, p. 186).

Before discussing the apparent shortcomings of this viewpoint, it is important to note that there are some perceived benefits of the medical model. Obtaining a medical diagnosis is often a route to access funding of care. Moreover, a focus on specific diagnoses can provide a framework for research, which may offer new insights and ways of providing

help and support (Woods & Thomas, 2003). However, there are longstanding concerns about the medical model.

Writing in 2002, Brett declared that the medical model was inappropriate and outdated. Proponents of this model take the view that disability is a personal tragedy and has led to attitudes that professionals are caring for ‘unfortunate’ individuals (Reindal, 2008, p. 141). When the medical model is accepted by medical professionals, it is thought that ‘aspects of the whole person may be neglected’ (Woods & Thomas, 2003, p. 15). Furthermore, there are concerns that the medical model ‘ignores the sociological and psychological aspects of disability’ (Brisenden, 1986, p. 176) and the environmental factors that shape the degree to which disability is experienced (Marks, 1997). According to Degener (2017), with the medical model, the ‘exclusion of disabled persons from society is regarded as an individual problem and the reasons for exclusion are seen in the impairment’ (p. 42). This leads to an emphasis on trying to change the individual to fit society (Burchardt, 2004).

## **2.3 The rise of the social model of disability**

According to Oliver and Barnes (2012), ‘during the 1970s and 1980s, disabled activists and their organizations in Europe and North America became increasingly vocal in their dismissal of the individual, medicalized understanding of disability’ (p. 164). The Union of the Physically Impaired Against Segregation (UPIAS) was formed in the 1970s and began to challenge the medical model of disability (Woods & Thomas, 2003). It argued that disability should not be understood solely through medical models, which gave power to medical professionals over disabled people’s lives (Berghs et al., 2019). In 1976, UPIAS created the Fundamental Principles of Disability document, which stated that people were disabled by society rather than by their impairments (Oliver & Barnes, 2012). It was this document that sparked the idea behind the social model of disability, which was introduced by Michael Oliver in the early 1980s (Oliver, 2013; Oliver & Barnes, 2012), and became ‘an immediate success in the UK’ (Thomas, 2004b, p. 24).

While the medical model focuses on ‘medical solutions to adjust the individual to fit society, the social model focuses on adjusting the social environment to fit individuals’ (Areheart, 2008, p. 189). Adherents to the social model see restrictions as being externally imposed (Oliver, 2004) and bring attention to physical, social, and economic barriers (Burchardt, 2004). The social model ‘locates disability not in an impaired or



malfunctioning body, but in an excluding and oppressive social environment' (Marks, 1997, p. 88). Therefore, it is not impairment that causes social exclusion, but how people with impairments are responded to by society (Oliver, 2004). Under the social model, disability is viewed as a social construct (Areheart, 2008; Degener, 2016). It has been seen by some as a superior model of disability because it more accurately reflects the experiences of disabled people (Riddle, 2020).

According to Burchardt (2004), 'one important distinction made by all versions of the social model is between impairment and disability' (p. 736). While impairment refers to 'a condition of the body or mind' and 'is an attribute of the individual', disability 'arises from the social, economic, and physical environment in which people with impairments find themselves' and 'is the loss or limitation of opportunities to take part in the life of the community on an equal level with others' (Burchardt, 2004, p. 736). Therefore, proponents of the social model argue that disabled people are an oppressed group, and the model differentiates between impairments that people have and oppression that people face (Shakespeare & Watson, 2002). According to Thomas (2004b), 'the denial of a causal link between impairment and disability' became 'the hallmark of the social model' (p. 25).

Oliver and Barnes (2012) state that 'the importance of the social model of disability is that it has provided disabled people with an alternative understanding of the experience and reality of disability. It has given disabled people a basis on which to organize themselves collectively' (p. 23). The ideas which underpin the social model can be very liberating for disabled people (Shakespeare & Watson, 2002), can lead to improvements in self-esteem (Shakespeare, 2013), and can be empowering and mobilising (Riddle, 2020). The social model created a "'disability = social barriers" soundbite' that could be easily grasped and set against the medical model of disability, which made it well suited to disability politics (Thomas, 2004b, p. 24). According to Berghs et al. (2019), 'the social model had an enormous impact in UK society' (p. 1035). The social model gave rise to the Disability Discrimination Act in 1995 and the Equality Act, which replaced it in 2010, and influenced the United Nations Convention on the Rights of Persons with Disabilities (CRPD; Berghs et al., 2019).

However, the social model has been criticised almost as strongly as the medical model (Degener, 2017). Writing over two decades ago, Shakespeare and Watson (2002) argued that the social model used in the UK had already outlived its usefulness. They believed that

it could not be reformed and that it needed to be cast aside, so we could start anew (Shakespeare & Watson, 2002). One of the most glaring issues with the social model of disability is its bracketing off of impairment (Shakespeare & Watson, 2002). Shakespeare and Watson (2002) contend that the distinction between disability as a social creation and impairment as a bodily difference is unsustainable and that it is impossible to remove all of the barriers faced by people with impairment. Other authors have likewise agreed that the social model is flawed because it fails to recognise the impact of impairment (Thomas, 2004a, p. 577). Degener (2017) points out that the social model has also been criticised for neglecting identity politics, which it does not provide space for because it focuses on power relations rather than personal emancipation. In addition, it can be seen as idealistic (Woods & Thomas, 2003) and introduces the idea of a barrier-free utopia (Shakespeare, 2013). In reality, not all environmental barriers can be removed, and sometimes the accommodations people with different impairments need can be incompatible (Shakespeare, 2013).

However, according to Thomas (2004a), while the ‘adherence to the social model of disability has come to be equated, in the minds of many in the disabled people’s movement and some in disability studies, with the position that impairments and chronic illness do not cause any restrictions on activity’, this ‘is an impoverished version of the early UPIAS understanding of disability’ (p. 579). Degener (2016) further points out that according to the founders and advocates of the social model, this model was never intended to disregard impairment. Oliver (2013) stated that he has remained relaxed about these criticisms. This is because in his view the social model is a tool rather than a theory, and as such, it should be used to bring about social and political change and improve peoples’ lives (Oliver, 2004; 2013).

## **2.4 Human rights model of disability**

According to Degener (2016), the human rights model emerged from the adoption of the CRPD in 2006, despite the fact that this model is never explicitly mentioned in the text (Lawson & Beckett, 2021). Under this model, human rights are viewed as fundamental rights that cannot be gained or taken away (Degener, 2016). Like the social model, the human rights model regards disability as a social construct (Degener, 2016); however, Degener (2016; 2017) argues that the human rights model of disability offers an alternative

to and moves beyond the social model. She puts forth six arguments that detail how the human rights model differs from, and improves upon, the social model of disability:

- 1) 'Where 'the social model merely explains disability, the human rights model encompasses the values for disability policy that acknowledges the human dignity of disabled persons' (Degener, 2016, p. 3).
- 2) 'While the social model supports anti-discrimination policy civil rights reforms, the human rights model of disability is more comprehensive in that it encompasses both sets of human rights, civil and political as well as economic, social and cultural rights' (Degener, 2016, p. 4).
- 3) 'Whereas the social model of disability neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life and early death due to impairment, and dependency, the human rights model of disability acknowledges these life circumstances and demands them to be considered when social justice theories are developed' (Degener, 2016, p. 6).
- 4) 'The social model of disability neglects identity politics as a valuable component of disability policy whereas the human rights model offers room for minority and cultural identification' (Degener, 2016, p. 9).
- 5) 'While the social model of disability is critical of prevention policy, the human rights model offers a basis for assessment when prevention policy can be claimed as human rights protection for disabled persons' (Degener, 2016, p. 11).
- 6) 'Whereas the social model of disability can explain why 2/3 of the one billion disabled persons in this world live in relative poverty, the human rights model offers a roadmap for change' (Degener, 2016, p. 12).

Lawson and Beckett (2021) term Degener's approach to the social and human rights models of disability the 'improvement thesis', where the human rights model is viewed as an improvement upon the social model. The social model is not abandoned entirely but developed further (Degener, 2016). In contrast to this view, Lawson and Beckett (2021) put forth what they call the 'complementarity thesis', where 'the relationship between the

two models is one in which neither can be viewed as an improvement on the other because each has distinctive roles to play' (p. 350). In their view, it is only the first and sixth arguments put forth by Degener that represent key differences between the human rights and social models of disability (Lawson & Beckett, 2021). Ultimately, Lawson and Beckett (2021) view the human rights model as a model of disability policy rather than a model of disability, and therefore, see it as performing a different function than the social model, which allows the two models to complement each other.

## **2.5 A social relational understanding of disability**

The social relational understanding of disability was introduced in the 1970s by Vic Finkelstein and Paul Hunt but received little attention after the success of the social model of disability (Thomas, 2004a). Reindal (2008) argues that the social relational model 'recognises the personal and social effects of reduced function without sliding into an individual approach' (p. 144). Whether reduced function becomes a disability depends on the restrictions imposed by society on top of the impact the reduced function has on the individual (Reindal, 2008). This model distinguishes 'between personal experiences of social restrictions due to the reduced function in a social setting, on the one hand, versus imposed social restrictions in social settings, on the other hand' and gives weight to personal experiences of living with reduced function (Reindal, 2008, p. 144). Therefore, the advocates of the social relational model do not take the view that all restrictions to activity have social causes (Thomas, 2004a). Instead, they see impairments and chronic illness as the direct cause of some restrictions to activity (Thomas, 2004a).

In the social relational model, disability is viewed as a form of social oppression (Thomas, 2004a). This is in contrast to the social model of disability which views disability as restricted activity (Thomas, 2004a). Therefore, according to Thomas (2004a), under a social relational understanding, 'disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed' (p. 580).

Restrictions that are not socially imposed are not viewed as disability (Thomas, 2004a). Such restrictions that arise from impairments have been referred to as 'impairment effects' by Thomas (2004a; 2004b). According to Shakespeare (2013), Thomas's reformulation means that 'only people with impairment who face oppression can be called disabled people' (p. 218).

Thomas (2004b) believes that by moving away from the social model and adopting a social relational understanding of disability, we can move past current arguments about whether impairment causes disability and have ‘a more constructive theoretical engagement with the significance of impairment and impairment effects in the lives of disabled people, while enabling the various dimensions of disability – socially imposed exclusions and disadvantages – to take centre stage’ (Thomas, 2004b, p. 33).

## 2.6 The capabilities framework

The capabilities framework was developed by economists and political philosophers and ‘provides a way of conceptualising the disadvantage experienced by individuals in society, which emphasises the social, economic and environmental barriers to equality’ (Burchardt, 2004, p. 735). The major proponents of this framework have been Amartya Sen and Martha Nussbaum (Burchardt, 2004; Robeyns, 2005). According to Robeyns (2005), ‘the core characteristic of the capability approach is its focus on what people are effectively able to do and to be; that is, on their capabilities’ (p. 94).

This framework has adopted the terms ‘capabilities’ and ‘functionings’. Capabilities are understood to be the opportunities to undertake certain activities or achieve certain states (Burchardt, 2004). Under the approach taken by Sen, ‘capability does not constitute the presence of a physical or a mental ability; rather it is understood as a practical opportunity’ (Mitra, 2006, p. 236). Functionings, on the other hand, are what an individual actually achieves (Mitra, 2006). Therefore, capabilities can be seen as potential functionings (Terzi, 2005). At any given time, there will be a set of functionings which an individual can achieve. This is referred to as the capability set (Burchardt, 2004). According to Burchardt (2004), under the capabilities framework, ‘well-being should be assessed in terms of the capability set of the individual’, or the opportunities that individual has to achieve certain states or do certain things (p. 738). It is not important so much what functionings an individual actually achieves, but what opportunities they have or their freedom of choice when it comes to being or doing things (Burchardt, 2004; Robeyns, 2005). Agency is seen as crucial under the capabilities framework (Trani et al., 2011).

According to Mitra (2006), under the capabilities framework, disability results from a combination of factors, including ‘the nature of the impairment and other personal characteristics’, ‘the resources available to the individual’, and ‘the environment’ (p. 241).

Disability is seen as relational with respect to impairment, social arrangements, and the design of the environment and results in the limitations of capabilities (Terzi, 2005). A person is considered to be disabled if they cannot do or be the things they would like to do or be (Mitra, 2006). According to Trani et al. (2011), what is important is not what people with disabilities have achieved but what they could potentially achieve if barriers were removed and opportunities created. Under the capabilities framework, the focus is shifted from ‘the specificities of the disabling situation to looking at establishing equality in terms of possibilities and choices’ (Trani et al., 2011, p. 148). Similar to the social model of disability, the capabilities framework focuses on the removal of societal barriers as a way to bring about change and reduce disability (Burchardt, 2004). The aims of policies are to expand people’s capability sets, the functionings people can achieve, and people’s freedom (Trani et al., 2011). Asset-based approaches have the potential to help achieve these aims.

## **2.7 The intersection between asset-based approaches and the capabilities framework**

Asset-based approaches are at odds with the medical model of disability. They view ‘citizens and communities as the co-producers of health and well-being, rather than recipients of services’ (Foot & Hopkins, 2010, p. 7). This is directly in contrast to the deficit approach that ‘focuses on the problems, needs and deficiencies’ (Boelman & Russell, 2013, p. 7) and ‘designs services to fill the gaps and fix the problems’ (GCPH, 2011, p. 5), which can be attributed to the medical model.

As discussed in the introduction (Chapter 1), asset-based approaches are ‘about recognising and making the most of people’s strengths’ (Friedli, 2012, p. 3). They involve identifying and utilising the assets individuals and communities possess. According to Boelman and Russell (2013), ‘assets are the skills, resources, knowledge or capacity that exist in individuals or communities, and these can be used to enhance or sustain health and wellbeing’ (p. 7). Assets represent the potential for action or what people can do or be if no societal or environmental barriers prevent them from being used. Therefore, it could be argued that assets can become capabilities when barriers are removed and opportunities are created.

Increasing the capability sets of individuals and communities can be seen as a goal of asset-based approaches. According to Sigerson and Gruer (2011), ‘taking an asset-based

approach involves mobilising the skill and knowledge of individuals and the connections and resources within communities and organisations’ (p.1). It is this ability to mobilise skill and knowledge that is key to both asset-based approaches and the capabilities framework. By putting assets into action, people can achieve functionings or realise what they would like to do or be.

Importantly, agency is central to both asset-based approaches and the capabilities framework. McLean and McNeice (2012) state that ‘central to the assets approach is the idea of people in control of their lives through the development of their capabilities and capacities’ (p. 30). The Glasgow Centre for Population Health (2012) further argues that ‘asset-based approaches respect that sustained positive health and social outcomes will only occur when people and communities have the opportunities and facility to control and manage their own futures’ (p. 4). The capabilities framework likewise stresses that freedom of choice is essential when putting capabilities into practice and achieving functionings.

## **2.8 Conclusion**

In this chapter, I briefly outlined some of the primary approaches to disability in the literature: the medical model, the social model, the human rights model, the social relational understanding, and the capabilities framework. I then described the intersection between asset-based approaches and the approach selected for this work, the capabilities framework. The intention was to frame the work that was undertaken as part of this thesis. I will return to a discussion of the capabilities framework in light of the findings from this body of work in Chapter 10.

In the next chapter, I will outline the original study that I sought to undertake and how the Covid-19 pandemic impacted on those plans. The aim of this project was to explore the benefits of taking part in an organisation taking an asset-based approach.

## **Chapter 3: Initially proposed study**

### **3.1 Introduction**

In the previous chapter, five different models of and approaches to disability were briefly described. The intersection between the capabilities framework and asset-based approaches was then outlined. This helped to frame the study that will be discussed in this thesis. However, before detailing the work that was undertaken, a project that received ethical approval but could not be carried out due to the pandemic will be described in this chapter.

### **3.2 Initial research project proposed prior to the pandemic**

Prior to the Covid-19 pandemic, ethical approval was obtained for a project entitled ‘Assessing the role of asset-based approaches in fostering belonging and facilitating the wider community participation of adults with intellectual disabilities’ through the University of Glasgow College of Medical, Veterinary & Life Sciences Ethics Committee (see Appendix B). This project had been intended to form the foundation of this thesis. It reflected the researcher’s thinking at this stage of the thesis and drew from the insights gained from the systematic review conducted by Fulton et al. (2021). The project combined semi-structured interviews, participant observation, questionnaires, and a photo-mapping exercise to explore how a programme taking an asset-based approach fostered a sense of belonging and facilitated community participation among programme participants. All components of data collection for this research were to be undertaken in person.

The primary aim of this study was to develop a complete picture of participants’ experiences of social inclusion, including levels of community presence and participation and subjective feelings of belonging, and explore how these experiences were related to participation in a programme taking an asset-based approach. This study also aimed to situate experiences of social inclusion within the daily lives of participants.

The study sought to answer the following research questions:



1. Do programmes taking an asset-based approach foster a sense of belonging for participants with intellectual disabilities?
  - 1.1 How is belonging experienced within these groups?
  - 1.2 How is sense of belonging fostered or inhibited through group participation?
  - 1.3 How is sense of belonging related to participants' overall social inclusion in their communities?
  
2. Does participation in a programme taking an asset-based approach help to facilitate participants' wider social inclusion?
  - 1.4 How is overall social inclusion fostered or inhibited through group participation?
  - 1.5 How is social inclusion experienced in the community?
  - 1.6 How does participation affect participants' everyday geographies?

### **3.2.1 Study design and methods**

This study was to be a small-scale, non-clinical study. It was to be exploratory in nature and take a multi-method approach.

#### **3.2.1.1 Pilot study**

A pilot study was to have been conducted prior to the primary study. The pilot phase first required the researcher to form links with programmes taking asset-based approaches in the Glasgow area. This initial phase of the project had begun prior to the pandemic. Relevant gatekeepers were contacted, supplied with information about the study, and asked if they had an interest in being involved in the research and helping with the recruitment of participants. The research sought to involve two community groups in the study from which all participants would be recruited. The small number of groups would allow for each group to be described in detail.

Two groups were approached prior to the pandemic, and the researcher met with each group in person to talk through the details of the study. Each group identified with the principles of asset-based approaches and initially agreed to be involved in the research. Unfortunately, one of the groups, a sporting club for people with intellectual and developmental disabilities, ultimately decided not to participate because not all members were eligible for the study. Contact was maintained with the second group after the onset of the Covid-19 pandemic. This group later agreed to take part in a modified study which will be described in detail in the next chapter and be the focus of this thesis.

Between two and four participants were to have been recruited for the pilot phase of the research. The pilot would have allowed the researcher to receive feedback from participants regarding the research process. This would have helped ensure that interview questions were understood, meaningful, and relevant to participants' lives and experiences. It also would have made sure that any challenges with the photo-mapping exercise were identified.

### **3.2.1.2 Primary study**

After making any necessary changes indicated by the feedback received during the pilot study, recruitment to the full-scale study would have begun. Participants would have been recruited through the two community groups identified during the pilot study.

## **Methods of data collection**

### *Measures*

Three measures were to have been used to capture relevant background information about participants and their levels of community participation. These were going to be administered as follows:

1. Basic demographic data would have been collected from all participants. This would have included: age, gender, living accommodation, current work / education status, socio-economic status, and additional impairments or diagnoses.

2. Index of Community Involvement (Raynes et al., 1989): This collects on the social and community-based activities that individuals engaged in during the previous 4 weeks. A version of this scale was adapted by Perry and Felce (1995) to take into account the frequency of social and community-based activities over that 4-week period. It is this version that would have been used in this study. This scale would have provided a basic understanding of participants' levels of community presence and participation.
3. Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II; Wechsler, 2011): The two-subtest form of the WASI-II would have been used to measure the cognitive ability of participants. The WASI-II has been shown to be both brief and reliable.

### *Semi-structured interviews*

Semi-structured interviews were going to be conducted to gain an understanding of participants' experiences of participating in a group taking an asset-based approach. Participants would have been asked about their sense of belonging and whether group involvement had led to additional opportunities in the wider community. Where a primary participant could not engage in the interview process, the interview would have been conducted with an informant who knew the participant well. Data resulting from interviews would have provided insight into how belonging was experienced within groups taking an asset-based approach and how group participation was related to participants' wider community presence and participation.

### *Observation*

Observations would have been carried out with each of the groups in the places they typically met and would have been recorded using ethnographic-style field notes. An observation schedule would have been used to aid in the collection of all pertinent data. A focus would have been placed on the exchanges that took place between group members and the levels at which group members engaged with the activities of the group. Observations were not to have been conducted as part of the pilot study.

### *Mapping project*

Participants would have been asked to document the community places they frequented on a regular basis and their general movements throughout a typical week using a smartphone (or similar mobile device). They and/or their supporters would have been instructed to take photographs and/or audio-recordings of meaningful or significant places in their daily lives. They would have also been encouraged to record any thoughts or feelings about these places through audio-recordings and/or written notes. The researcher would then have used these geo-located photographs and recordings to create a map for each participant using mapping software.

A follow-up interview would have then taken place with each of the mapping participants. The researcher would have presented the maps to participants, and participants would have been provided with the opportunity to add or remove places on the maps. Participants would have also been asked questions about the places identified on their maps. These interviews would have been audio-recorded with participants' consent. Qualitative data from the notes recorded during the mapping exercise and follow-up interviews would have been linked to the corresponding geographic location on the maps.

This mapping exercise would have provided insight into how programmes taking an asset-based approach may facilitate social inclusion in the wider community. It would have also provided additional context about how social inclusion is experienced by participants by situating their experiences within their daily lives.

In addition to the individual maps, the researcher would have carried out group-level mapping of the two programmes taking part in the study. These maps would have displayed the places where group meetings, practices, competitions, etc. are carried out during the course of the research. These maps would have provided visual comparisons to the individual-level maps and revealed the ways in which the paths of individuals and groups converge and diverge.

### **Data analysis**

Contextual data from measures would have been analysed using simple descriptive statistics in SPSS. Semi-structured interviews with primary participants would have been

analysed using interpretative phenomenological analysis (IPA). Additional informant interviews would have been analysed using thematic analysis as described by Braun and Clarke (2006). IPA was not suitable for the informant interviews because these additional informants would have been asked to report on what they thought someone else's experiences had been.

Data collected during the participatory mapping phase would have been entered into mapping software. Geo-located photographs and audio-recordings would have been used to create maps of participants' daily geographies using ESRI's ArcGIS. Photographs and interviews resulting from this phase would have been analysed using thematic analysis.

Following analysis, datasets would have been discussed in relation to each other to provide a more complete understanding of participants' social inclusion. Semi-structured interviews and observations would have provided an in-depth understanding of how belonging was experienced within the context of the groups. The mapping project and the Index of Community Involvement would have illustrated how inclusion is experienced in participants' wider lives and communities. Taken together, these datasets could have provided an understanding of how belonging to a group may impact on an individual's overall social inclusion.

### **Sample size**

Studies using IPA take a very detailed approach to data analysis, making the analysis process relatively painstaking and time-consuming. For this reason, small sample sizes are used in IPA studies (Smith & Osborn, 2007). For this study, the researcher would have aimed to recruit approximately four to six participants from each group, or eight to twelve participants total, to participate in the semi-structured interviews and the mapping project.

The researcher would have aimed to recruit additional group members, including group facilitators and group members without intellectual disabilities, to take part in observations. This would have allowed for the detailed documentation of a wider range of interactions and events, which would have provided a fuller description of the groups. It would have also provided a more complete picture of the processes that take place that may influence participants' social inclusion and feelings of belonging.

## **Beginning data collection**

The final participant packs for this study were compiled and ready for use in February 2020. Each contained an easy read participant information sheet, consent form, privacy notice, and reply slip. Separate documents were created for additional informants and relatives or guardians. This was to accommodate the needs of potential participants with severe or profound intellectual disabilities who would have difficulty providing informed consent or participating in the semi-structured interviews.

Data collection was to begin with an observation session with the recruited group taking an asset-based approach on Monday the 16<sup>th</sup> of March 2020. Unfortunately, on Sunday the 15<sup>th</sup> of March, the university announced that all in-person research activities were to be suspended due to the escalating situation surrounding Covid-19. All scheduled in-person observation sessions for the project had to be cancelled. By the middle of April, it was apparent that the pandemic would be much longer lasting than just a few weeks. In order to adapt to this new reality, it was decided that the project outlined above would need to be completely redesigned to take the Covid-19 pandemic into account. This would include reimagining the methods of data collection and reconsidering the ability to measure community presence and participation during this time. In the following chapter, the redesigned study is outlined, and it is explained how this study was adapted to take the pandemic and resulting government restrictions into account. This adapted study will be detailed in the remaining chapters.

## **3.3 Conclusion**

In this chapter, a study that was approved by the University of Glasgow MVLS ethics committee was outlined. Unfortunately, due to the Covid-19 pandemic, this study could not proceed. Chapter 4 will briefly explain how the study was adapted to the pandemic and list the research questions that were ultimately pursued for this body of work.

## **Chapter 4: Adapting the research to the pandemic**

In this chapter, a brief explanation of how the research was adapted to the Covid-19 pandemic will be provided. The research questions that were developed to take into account the pandemic are listed, and an overview of the group with which the research was conducted is provided.

During the Covid-19 pandemic, Scotland experienced unprecedented social distancing and lockdown measures, which fundamentally altered how people socialised and participated in their communities. It resulted in the cancellation of all in-person events and meetings which challenged programmes taking an asset-based approach and their members to develop new ways of communicating and interacting. It is important to understand how these changes resulting from the pandemic were experienced by people with intellectual disabilities, and in particular, how they impacted on peoples' feelings of inclusion and belonging. It is also important to explore how programmes taking an asset-based approach attempted to adapt to these circumstances and provide support to their members during this time. Without ongoing support from such programmes, many people with intellectual disabilities may have found themselves isolated during the pandemic.

The following research study sought to explore how one programme taking an asset-based approach in Scotland adjusted to the pandemic and the resulting government restrictions. The aims of the study are outlined below, and the study design and data collection methods will be detailed in Chapter 5. All aspects of this study were designed to be carried out during the pandemic.

### **4.1 Research aims**

The primary aim of this study was to explore participants' experiences of participating in a programme taking an asset-based approach both during and prior to the Covid-19 pandemic. The research explored how the group and its members attempted to adapt to restrictions placed on in-person socialisation and how these changes were experienced over time. A focus was placed on how the pandemic and group participation impacted on participants' feelings of inclusion and belonging.

### 4.1.1 Research questions

This research sought to address the following questions:

1. How has participation in a programme taking an asset-based approach been experienced by members both before and during the Covid-19 pandemic?
  - 1.1 What role did the programme play in participants' lives prior to the pandemic?
  - 1.2 What role has the programme played in participants' lives during the pandemic?
  - 1.3 How did participation in the programme impact on members' feelings of inclusion and belonging prior to the pandemic?
  - 1.4 How has participation in the programme impacted on members' feeling of inclusion and belonging during the pandemic?
2. What impact has the Covid-19 pandemic had on a programme taking an asset-based approach and its members?
  - 2.1 How have the programme and individual members been impacted by the pandemic?
    - 2.1.1 What impact has the Covid-19 pandemic had on the programme?
    - 2.1.2 What impact has the Covid-19 pandemic had on members of the programme?
  - 2.2 What adaptations has the programme implemented as a result of the pandemic, and how have these changes been experienced by members?
    - 2.2.1 What adaptations has the programme implemented as a result of the pandemic?
    - 2.2.2 How have these adaptations been experienced by members?
  - 2.3 How has the programme attempted to support members during the pandemic?
    - 2.3.1 How has the programme attempted to support members



during the pandemic?

2.3.2 How have members felt supported during the pandemic?

2.4 How has the programme attempted to promote social inclusion and belonging during the pandemic?

## **4.2 Ethical approval**

Ethical approval was sought from the University of Glasgow College of Medical, Veterinary & Life Sciences Ethics Committee. Approval for this study was granted in May 2020 (see Appendix C).

## **4.3 Group under study**

During the pilot stage of the original study, links were formed with the organisation dates-n-mates, a friendship and dating agency run by adults with intellectual disabilities for adults with intellectual disabilities (Dates-n-Mates Scotland, n.d.), and they agreed to take part in the adapted study during the pandemic. Dates-n-mates was selected because it had previously been identified as a programme taking an asset-based approach (McNeish et al., 2016). Dates-n-mates is a part of C-Change, a charitable organisation that provides people with additional support and operates with the support of volunteers (Dates-n-Mates, Scotland, n.d.). It was first established in Glasgow in 2008 (McNeish et al., 2016) and now operates five branches across Scotland (Dates-n-Mates Scotland, n.d.).

Dates-n-mates helps people form friendships and romantic relationships through a wide range of activities, events, and workshops (McNeish et al., 2016). Social events include activities such as bowling, club nights, and games nights, most of which take place out in the local community. Since the onset of the pandemic, virtual events have also been offered (Dates-n-Mates Scotland, n.d.). To help members form friendships, a friendship matching service is offered, and events such as speed dating and blind date events are held to help people find a partner (Dates-n-Mates Scotland, n.d.). Workshops are also offered to build members' confidence, relationship skills, independence, and communication skills (Dates-n-Mates Scotland, n.d.).

## 4.4 Conclusion

This chapter provided the research aims and questions that were explored through the work detailed in the rest of this thesis. The aims had to be adapted to the Covid-19 pandemic due to the social distancing guidelines and government restrictions that were in place during the time in which this research was carried out. In the following chapter, the study design and methods used for this study will be explained in detail.

## Chapter 5: Study design and methods

In this chapter, the study design and methods used for this research will be described in detail. To begin, an overview of what case studies are is presented, before describing a single-case embedded design. The recruitment procedure and data collection and analysis techniques used for this study are then described in depth.

### 5.1 Case study

#### 5.1.1 Overview of case studies

This research adopted a case study design. Case study design is considered appropriate for use when the research aims to generate ‘an in-depth, multi-faceted understanding of a complex issue in its real-life context’ (Crowe et al., 2011, p. 100). In addition, according to Yin (2018), case study research is useful when ‘a “how” or “why” question is being asked about a contemporary set of events, over which the researcher has little or no control’ (p. 13). The aim of this research was to develop an in-depth understanding of how a programme taking an asset-based approach and its members responded to the constantly evolving Covid-19 pandemic and the resulting government guidelines and restrictions over time.

Creswell and Poth (2017) claim that ‘case study research begins with the identification of a specific case that will be described and analyzed’ (p. 97). This research selected one programme taking an asset-based approach, dates-n-mates, for study. The authors further explain that case study research is carried out within a ‘bounded system’ (Creswell and Poth, 2017, p. 96). The selected case for this study was delimited by both the organisation (only communications within dates-n-mates or with dates-n-mates members were documented) and time period (data were collected during the Covid-19 pandemic). In summary, a case study design was selected because this research was carried out in a complex and constantly changing context, the primary research questions sought to understand a process or *how* adaptations or changes occurred and *how* they were experienced, and the research was concerned with a bounded system.

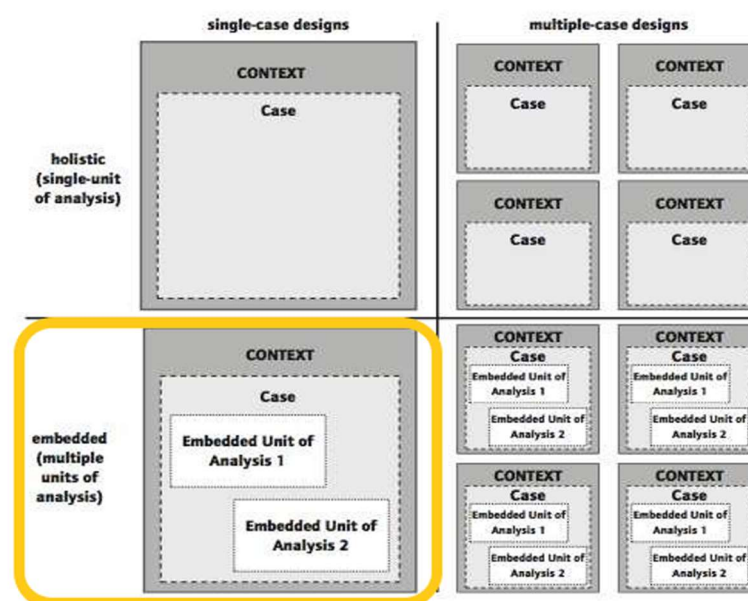
According to Yazan (2015), ‘research methodologists do not have a consensus on the design and implementation of case study, which makes it a contested terrain and hampers its full evolution’ (p.134). There are three major texts on case study research, each written by a different methodologist and each with a slightly different view on how case study research should be carried out (Yazan, 2015). Yazan (2015) lists these primary texts as *Case Study Research: Design and Methods* (2003) by Robert K. Yin, *Qualitative Research and Case Study Applications in Education* (1998) by Sharan B. Merriam, and *The Art of Case Study Research* (1995) by Robert E. Stake. Since Yazan (2015) created this list, Robert K. Yin published an updated edition of his work: *Case study research and applications: Design and methods* (Sixth ed) in 2018. It was this edition that was primarily referenced for the current study.

In his approach to case study research, Yin leans more heavily towards positivism than do the other two methodologists (Yazan, 2015). By contrast, Stake takes a more constructivist approach (Yazan, 2015). According to Boblin et al. (2013), both methodologists are commonly cited when case study is used; however, they argue that this ignores the fact that Yin and Stake come from different philosophical orientations, which they say threatens the credibility of the work. When designing and implementing this research, Yin, Stake, and Merriam were each consulted. Although they have differing ontological and epistemological stances, they each provided valuable insight into the conduct of case study research that was useful when developing this study. While I align more with Stake’s constructivism, elements of case study design as described by Yin were used to guide the design of this research. The approaches of Yin and Stake will be discussed further in the sections below.

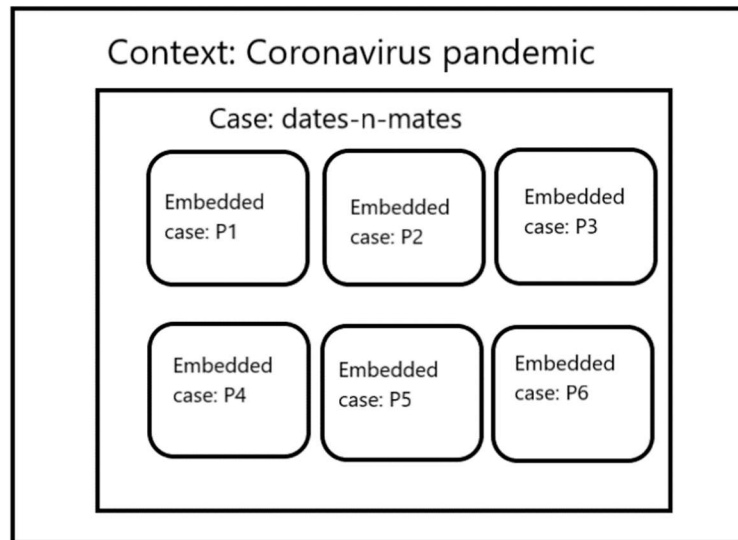
### **5.1.2 Single-case embedded design studies**

A single-case embedded design was selected for this study (Yin, 2003). The rationale for selecting a single-case design was that a case study of dates-n-mates during the pandemic would be revelatory. A case study is considered revelatory when no one has had the opportunity to study the phenomenon before (Yin, 2003). This was the first time that a programme taking an asset-based approach was studied during a global pandemic, so a single-case design was warranted.

According to Yin, a single case study may include analyses at multiple levels (2018, p. 51). He explains that ‘this occurs when, within a single-case (the first level), attention is also given to a subunit or subunits (a second level)’ (Yin, 2018, p. 51) and goes on to explain that ‘no matter how the subunits are selected, the resulting design would be called an *embedded case study design*’ (Yin, 2018, p.52; emphasis in original). For this study the single-case, or first level, consists of dates-n-mates as an organisation. The subunits, or second level, are comprised of six individual dates-n-mates members. Figures 5.1 and 5.2 illustrate how the single-case relates to the subunits both generally and in this study specifically.



**Figure 5.1:** Diagram of Yin's four types of case studies. Adapted from *Case study research and applications: design and methods* (Sixth ed.) by R. K. Yin. 2018. Thousand Oaks, California: SAGE. Copyright 2017 by SAGE Publications Inc. Emphasis on embedded case studies my own.



**Figure 5.2:** Diagram showing the case study (dates-n-mates) in relation to the six subunits of analysis (embedded cases P1 through P6); P = participant and refers to an individual dates-n-mates member

As will be explained in subsequent sections, data were collected directly on both the single-case and on the subunits. When it came time to analyse these data, special attention was afforded the data on the subunits prior to a broader analysis of the larger single-case. The intention was to create robust descriptions of the subunits of analysis before examining all of the datasets as a whole to build a complete picture of the single-case.

## 5.2 Data collection

Case study research typically uses multiple methods of data collection and draws on data from a variety of sources, including interviews, observations, and documents (Merriam, 2001). It has been argued that this combination of data sources is ‘a major strength of case study data collection’ (Yin, 2018, p. 127). For this study, data were collected from several sources, including individual semi-structured interviews, e-newsletters, blog posts, tweets, online observations, and Facebook posts. These sources of data were selected because they could not only provide a wealth of information about the case under study, but they could also be collected on remotely. The ability to collect data remotely was of utmost importance during the time in which this study was carried out. Because this research took place during the Covid-19 pandemic, all data collection procedures had to comply with the Covid-19 restrictions that were in place.

## 5.2.1 Individual semi-structured interviews

According to Yin (2018), interviews are ‘one of the most important sources of case study evidence’ (2018, p.118). When conducting qualitative interviews, the researcher is striving to discover participants’ experiences and perceptions and how they view their world (Patton, 2015). In this study, semi-structured interviews were conducted with six dates-n-mates members.

### 5.2.1.1 Interview procedure

Each participant was interviewed multiple times to capture a ‘snapshot’ of their lives during the Covid-19 pandemic. Repeat interviews are useful when trying to explore change over time (Read, 2018). In this case, I was attempting to capture how participants adapted to the pandemic and government guidelines over time. Five of the six participants completed a total of seven interviews spaced out over a period of three months. A sixth participant took part in two interviews spaced two weeks apart. This resulted in a total of 37 interviews conducted for this study.

According to Booth and Booth (1994), by collecting data over multiple interviews with participants with intellectual disabilities:

It meant that the interviewer could take her cue from the informant; allow the conversation to take its natural course; pursue issues as they arose; postpone sensitive matters until trust was established; and follow digressions to see where they might lead (p. 420).

The use of repeat interviews was helpful in this study because it allowed for a more in-depth exploration of participants’ lives during the pandemic. Repeat interviews allowed time for rapport to be built, for the cross-checking of information, for the ability to follow up on stories over time, and for the introduction of questions that were missed during previous interviews. Over subsequent weeks, participants became more comfortable speaking with the researcher, and a friendly working relationship was established. When meeting with participants for each interview, it was found that participants were often eager to report what they had been doing over the previous fortnight. Only one participant dropped out of the study, but this was due to her mental health at the time and not to the

burden of participating in multiple interviews. Overall, this study showed that repeat interviews were a viable and often fruitful method of data collection to use with participants with intellectual disabilities. By using repeat interviews, richer and more complete data were collected.

To conduct the repeat interviews, the researcher gave the participants the option to be interviewed either by telephone or using video-conferencing software of their choosing. Three participants chose to use Zoom for their interviews, two opted for telephone interviews, and one initially wanted to use the phone but later switched to Zoom. It is suspected that Zoom was selected for all online interviews because that is the software that dates-n-mates was using for its activities. Participants would have been familiar with Zoom had they participated in any activities with dates-n-mates during the pandemic. The implications of adopting these remote interview methods is discussed in detail in Chapter 9.

Each participant who chose to take part in interviews over Zoom provided a contact email address to the researcher. The researcher then sent each participant a password-protected Zoom meeting link every time a new interview was scheduled. A separate link was sent for each follow-up interview. When a participant was more than ten minutes late to a scheduled Zoom meeting, the researcher phoned the participant to see if they still wanted to take part. This occurred on four occasions. The telephone interviews were slightly more straight-forward in that the researcher simply phoned the participant on the arranged date and time. There were no instances whereby the researcher was unable to make contact with a participant.

All interviews were audio-recorded. Permission to record was sought at the beginning of each interview (Bogdan and Biklen, 2007). The in-built recording function on Zoom was used to record all online interviews. Telephone interviews were recorded using a digital voice recorder that was connected to a smartphone using an adapter. Each recording was then transcribed verbatim by the researcher. All recordings were deleted after each transcript was carefully checked for accuracy.



### 5.2.1.2 Interview topic guides

An interview topic guide was prepared in advance of the interviews that allowed for probes and follow-up questions as the interview progressed (Appendix D). In case studies, interviews tend to be conducted in the form of guided conversations (Yin, 2018). The interview topic guide lists the questions or topics to be explored, but the interviewer can probe, ask follow-up questions, and adopt a conversational style within that framework (Patton, 2015). A separate topic guide was created for the follow-up interviews (Appendix E).

During the initial interview, the opening questions were designed to get participants to speak about their experiences of taking part in dates-n-mates. It was assumed that most participants would have found dates-n-mates to be enjoyable to engage with, so these questions were thought to elicit fond memories and provide a nice ice breaker before moving on to questions about the pandemic. Participants were then asked about their experiences of the Covid-19 pandemic and the role dates-n-mates played in their lives during this time. These questions were thought to be a bit more sensitive than the opening questions because of their focus on the pandemic, so they were posed after the participants had relaxed and begun to open up about their lives. This was in line with Valentine's (2005) suggestion that more sensitive questions be asked after building rapport with participants. The final questions asked people about their participation in activities outside of dates-n-mates. These questions were also thought to focus on more positive aspects of participants' lives, and it was thought to be important to end the interviews on this more positive note, as has been advised by Valentine (2005). The questions asked in the follow-up interviews often built upon the previous interviews and attempted to elicit further information, gain the next 'chapter' of a narrative, or seek clarification.

The interview topics were designed to explore social inclusion and belonging. However, questions did not use the terms inclusion or belonging outright in order to avoid leading or confusing participants, as these are terms they are unlikely to use. It was important to hear about inclusion and belonging in participants' own words. Some questions, such as those about going places in the community or participation in various activities, were designed to establish participants' community presence and community participation both before and during the pandemic. Other questions, such as those about relationships, were designed to

explore belonging and reciprocity. Taken together, these questions were used to create a picture of participants' experiences of social inclusion.

### **5.2.1.3 Ethical considerations**

It is important that people with intellectual disabilities are included as participants in qualitative research. People with intellectual disabilities are ““expert witnesses”” when it comes to their own lives, and they can speak from first person knowledge (Booth & Booth, 1994, p. 415). However, when conducting qualitative research with people with intellectual disabilities, there are a number of ethical considerations that must be taken into account. Before the research is conducted, care must be taken to make sure that participants understand the study and what it will entail. Information about the research should be provided in a format that is accessible to participants with intellectual disabilities (Boxall & Ralph, 2009), which often means creating information sheets that are written in plain language and contain pictures to help illustrate what the text means (Harding, 2021). According to Harding (2021), providing accessible information is crucial to the inclusion of people with intellectual disabilities in research (p. S35). In addition, extra time should be given to participants to allow for them to process the information and discuss the information with others (Taua et al., 2014).

In the study described in this thesis, accessible or ‘easy read’ information sheets, privacy notices, and consent forms were developed for participants to help aid their understanding. Participants were given this information a week in advance of the interviews to allow them plenty of time to read through the information and discuss it with other people. In addition, the researcher went through the information sheet with each participant before beginning the first interview and checked each participant’s understanding of the research as suggested by Baxter (2005). As Taua et al. (2014) argue, it is important to make sure that the information about the study has been understood by participants to allow them to make an informed decision about whether to take part. They also recommend that a mechanism of process consent be adopted. Process consent was used in this study, whereby the researcher periodically checked in with participants to make sure they were happy to continue in the study and understood why they were answering questions.

Baxter (2005) also suggested that participants with intellectual disabilities be offered the opportunity to have a supporter accompany them during the interview. In this study, two

participants opted to have a parent support them during some or all of the interviews. One participant had his mother attend all of the interviews alongside him, and another participant had her mother with her during the initial interview. When supporters are present, it is important to provide some ground rules, such as establishing that the supporter is there to help the person articulate themselves, not respond for them (Baxter, 2005). This was important in this study to make sure that the participants' voices were central to the interviews, and the researcher really got a sense of what was important to participants' lives.

It has also been recommended that interviews with participants with intellectual disabilities be kept short and that breaks be offered during the interviews (Baxter, 2005). In this study, most of the interviews were around 20 to 25 minutes, and the longest interview was 47 minutes. The interviews were deliberately kept quite short to reduce participant burden and make sure that participants were able to maintain their concentration. Periodically throughout the interviews, the researcher checked in to see if participants wanted to continue with the interview or if they wanted to break or discontinue for the day. Interviews should be discontinued should participants become distressed (Baxter, 2005). This occurred once in this study, and the interview was immediately terminated. The researcher remained on the videocall with the participant until the participant's mother entered the room to support her and the researcher felt the participant would be okay.

It is also important to consider how questions are asked during qualitative interviews with participants with intellectual disabilities. Simple open-ended questions should be posed 'to manage problems of acquiescence, social desirability and suggestibility' (Beail & Williams, 2014, p. 89). According to Baxter (2005), many people with intellectual disabilities are eager to please, so the researcher has to be careful not to give participants suggestions, or they may simply agree with what the researcher has said if they are confused or do not understand a question (p. 179). It is also important to make sure that questions are not leading and that the researcher avoids the tendency to shape answers (Beail & Williams, 2014). However, Beail and Williams (2014) note that this can be challenging in interviews with people with intellectual disabilities because participants 'may be unresponsive to open questions, have difficulty generalizing from their experiences and thinking in abstract terms' (p. 89). In this study, the questions were kept as open as possible to avoid leading participants. However, at times, some examples needed to be provided to participants to help them understand what was being asked. It is

important to balance the need to avoid leading participants with the obligation to help interview participants fully understand the questions.

The researcher must also consider their relationship to the participants. There needs to be thought given to how rapport is built and boundaries are maintained (Nind, 2008). According to Nind (2008), ‘entering into a research relationship can potentially extend a person’s social network and researchers need to consider what this means and feels like from the perspective of research participants’ with intellectual disabilities (p. 6). In addition, while researchers may think that they are relating to people in a friendly but professional way, interview participants may ‘interpret such “friendliness” at a more personal level’ (Stalker, 1998, p. 11). Therefore, according to Stalker (1998), researchers have a responsibility to think carefully about how they approach people and to provide clear messages about what is being asked of participants and offered by the researcher and to be aware of possible alternative interpretations (p. 11). Due to the longitudinal nature of this study, it was especially important for the researcher to consider the relationships they developed with participants. The researcher was careful to notify participants how many interviews were left in the study and explain that they would not be in contact with participants following the end of the interviews, unless they requested a report of the results. Strong rapport was built with the participants, making it difficult to end the relationship; however, both the participants and the researcher grasped the time-limited nature of the relationship. By giving careful consideration to the ethical concerns of conducting qualitative interviews with participants with intellectual disabilities, the researcher provided participants with an opportunity to participate in research, speak from their experiences, and tell their stories.

### **5.2.2 Social media and other web-based data**

Dates-n-mates already had an online presence prior to the pandemic. They maintained webpages, a Twitter account, and several Facebook accounts and produced occasional e-newsletters and YouTube videos. With the onset of the pandemic and government guidelines restricting in-person socialisation, it was anticipated that these accounts would suddenly gain a newfound importance. It was likely that they would play a much larger role in disseminating information and providing a space for informal chat between dates-n-mates members. This research sought to capture this potential transformation when

investigating how dates-n-mates was impacted by and adapted to the pandemic. To do so, information from these web-based accounts needed to be collected in a systematic fashion.

According to Kozinets (2020) 'it is during the saving operations that information from social media sites is actually transformed into [...] data' (p. 236). Data from dates-n-mates' Twitter feed and primary public Facebook account were saved using screenshots. Using screenshots is considered a reliable way to preserve 'the full visual context of the social media experience available to you' because you can capture all of the elements visible on your screen, such as text, images, links, emoji, hashtags, and 'likes' (Kozinets, 2020, p. 237). This process was carried out systematically to capture and file all of the posts and tweets for a specific range of time. Every post or tweet on each account was saved beginning with the first post or tweet in March 2020 and ending with the last post or tweet in June 2021. Each screenshot was then saved with unique identifier and carefully filed by account type and date.

In addition to the social media accounts, data from dates-n-mates' official website and Mailchimp account were also collected. Both the website and the Mailchimp account were used by dates-n-mates to share news and updates related to the programme. The website contained various news items and blog posts on its pages, and the Mailchimp account was used to produce and disseminate the official dates-n-mates e-newsletter. Each post made to these accounts between March 2020 and June 2021 was printed and saved as a PDF and organised by its source account.

### **5.2.3 Observation**

Finally, a small amount of data was collected through observation. These observations were used to help corroborate the participant reports obtained through the interviews but were not subject to formal analysis. Observations were conducted of three social events held by dates-n-mates online. The observations were carried out in the form of observer-as-participant (Gold, 1958) whereby the researcher 'attended' the events over Zoom and occasionally participated in activities and interacted with the participants and staff. The researcher was always introduced to the group members, and members were welcome to ask any questions they may have had. These observations provided the researcher with a better understanding of how the online activities were run and how they might be

experienced by members. Field notes from the observation sessions were always typed up immediately following the events and entered into a predetermined observation schedule.

#### **5.2.4 Other potential sources of data**

While additional sources of data were identified during the research process, it was not feasible to collect and analyse all sources of available data. This problem is not uncommon when conducting case study research. According to Bogdan and Biklen (2007), the subjects of case studies continue to evolve throughout the data collection period, which may present the researcher with the temptation to modify the direction of the research. While the researcher should retain some flexibility, they note, the researcher cannot adjust for all the changes encountered and still complete data analysis and finish the study. In other words, there are potentially endless sources of data, but an end point needs to be defined (Bogdan & Biklen, 2007). For this study, it would have been particularly useful to obtain staff member accounts about how dates-n-mates was run during the pandemic through the use of qualitative interviews. Unfortunately, given the time constraints placed of the PhD, this was not possible.

### **5.3 Participant recruitment**

Between four and six primary participants were sought to participate in the semi-structured interviews. Recruitment took place in May and June 2020. Primary participants were adults with intellectual disabilities who were currently members of dates-n-mates. In some cases, additional informants were also invited to take part. These were people who knew the primary participant well, such a family member or support worker. These informants were agreed upon with the primary participant.

#### **5.3.1 Eligibility criteria**

Criterion sampling was used to select interview participants. According to Creswell and Poth (2017), 'criterion sampling works well when all individuals studied represent people who have experienced the phenomenon' (p. 157). Because this study was focused on the experiences of dates-n-mates members during the pandemic, criterion sampling was considered appropriate. In criterion sampling, criteria are developed to select certain

individuals for study (Creswell and Poth, 2017; Salmons, 2015). All potential participants in this study were selected using the study eligibility below:

Inclusion criteria:

1. Aged 16 years or over
2. Has an intellectual disability
3. Is a current member of dates-n-mates
4. Lives in Scotland

Exclusion criteria:

1. Had not regularly attended group events prior to social distancing measures going into effect.

### **5.3.2 Recruitment procedure**

While dates-n-mates was not fully staffed at the time of recruitment, some staff members continued to work from home and maintain contact with group members via social media, online events, and telephone calls. I contacted these staff members to explain the study and ask them if they would help recruit participants matching the eligibility criteria.

These individuals were asked to identify people they thought would be interested in taking part in the study and provide them with an information leaflet (Appendix F) and a brief explanation of the research or the full study information, when possible. I arranged for easy read versions of the full study information, including participant information sheets (Appendix G), consent forms (Appendix H), and privacy notices (Appendix I), to be posted to all interested potential participants. Potential participants were asked to discuss this information with someone they trusted and contact me via telephone or email if they had questions or would like to take part. When an individual expressed an interest in taking part in the study, I offered to schedule a telephone or online interview, depending on participant preference.

I was not in contact with potential participants unless they had expressed an interest in participating in the study. All participants had information sheets, consent forms, and privacy notices for at least 48 hours before they were invited to consent to the study. Informed consent was obtained from all participants prior to data collection. Consent was

taken remotely, whereby the interviewer read each item on the consent form in turn and obtained a verbal response from the potential participant. This process was recorded, and the recordings were retained. All participants demonstrated an understanding of the interview topic and process. The primary participants who volunteered to take part in this study all had mild to moderate intellectual disabilities.

## **5.4 Data analysis**

### **5.4.1 Hermeneutics**

During data analysis, the researcher drew from hermeneutics. The term ‘hermeneutics’ comes from the Greek ‘hermeneuein’, ‘which means “to interpret” or “to understand”’ (Crotty, 1998, p. 88). It has its origins in the Greek Enlightenment, when efforts were made to understand writers such as Homer (Sandage et al., 2008), and it came into its modern usage during the seventeenth century when it was used for biblical interpretation (Crotty, 1998). Put simply, ‘hermeneutics is the study of interpretation’ (George, 2021). It is an interpretive theory and provides guidance for the analysis of any sort of text, including interview transcripts (Patton, 2015).

According to Schwandt (2000), when taking an interpretivist point of view, human actions differ from the movements of physical objects in that human actions are inherently meaningful (p. 191). The inquirer must ‘grasp the meanings that constitute that action’, and this can only be done in relation to the ‘system of meanings’ to which that action belongs (Schwandt, 2000, p. 191). The inquirer must interpret what the actors are doing in order to understand what the action means (Schwandt, 2000). In hermeneutics, when one gains this understanding, they can be said to have been successful at interpretation (George, 2021). However, there is a recognition that understanding always remains incomplete (George, 2021), and there is never a ‘correct’ interpretation, which puts hermeneutics in opposition to naïve realism and objectivism (Schwandt, 2000). While the view that there is never a correct interpretation is held by some constructivists, hermeneutics differs in that it does not see meaning as constructed but rather, negotiated (Schwandt, 2000).

Within the literature on hermeneutics, the idea of the ‘hermeneutic circle’ consistently arises (Crotty, 1998). With the hermeneutic circle, ‘the meaning of the whole text informs the meaning of the parts, and the meaning of the parts illuminate



the meaning of the whole' (Rennie, 2012). Therefore, there is a circularity to hermeneutics whereby 'every interpretation is layered in and dependent on other interpretations' (Patton, 2015, p. 578). According to Patton (2015), the hermeneutic circle 'offers a process for formally engaging in interpretation' (p. 578) and, as a method:

involves playing the strange and unfamiliar parts of an action, text, or utterance off against the integrity of the action, narrative, or utterance as a whole until the meaning of the strange passages and the meaning of the whole are worked out or accounted for. (p. 578)

Understanding is pursued in a circular fashion through 'an interpretive movement back and forth through possible meanings of our presuppositions that by turn allow a matter to come into view' (George, 2021, section 1.3, para. 2). Importantly, this is not a vicious cycle from which there is no escape; through this process new knowledge is constantly acquired (Debesay et al., 2008).

Because of its circularity, when adopting the hermeneutic circle, it may be difficult to know where to start. It has been suggested that the inquirer break into the hermeneutic circle by beginning with gaining a practical understanding, which can be seen as a starting place for interpretation (Patton, 2015). The hermeneutic circle was used to help guide the analysis of the interview data for this research, and the researcher sought to gain a practical understanding by reading the transcripts several times before formally analysing the data. The specifics of the data analysis process are described in the sections below.

#### **5.4.2 How data were prepared for “formal” analysis**

Data analysis refers to the systematic process of organising and reviewing data in a way that allows the researcher to develop findings (Bogdan and Biklen, 2007). In qualitative research, data collection and data analysis occur simultaneously (Merriam, 2001), and analysis 'is a matter of giving meaning to first impressions as well as to final compilations' (Stake, 1995, p. 71). According to Merriam (2001), data analysis should consist of a continual process of revisiting data, reflecting, and note taking.

In this study, analysis began after the completion of the first interview. Shortly after conducting the initial interview, I listened to the audio recording and reflected on its contents, what went well, and where improvements could be made to the interview questions and my interview skills. I then transcribed the interview without the use of transcription software. This allowed me to become familiar with the contents of the transcript and gain a deeper understanding of what was important to the participant. After transcribing the interview, I immediately typed my reflections at the top of the transcript. This process was then repeated for each of the interviews conducted as part of this study. In this way, I was revisiting the data, reflecting, and taking notes on a regular basis.

In addition, because I underwent this process of becoming familiar with each interview in turn, it allowed the interview questions to be adapted for each subsequent follow-up interview, making them more relevant to the participant and their story. This ultimately allowed me to gain a fuller understanding of each person's experience of the pandemic and experience of being a member of dates-n-mates. Gaining this deeper understanding was important because it would later enable me to develop a thick description of each participant. In this way, by analysing the data continuously throughout the data collection process, I was ultimately able to gain a more complete understanding of the participants and phenomena under study.

Although analysis can be viewed as an ongoing process that occurs continuously throughout data collection as illustrated above, there is a point at which the qualitative researcher focuses their attention on analysis above all else (Stake, 1995). This generally takes place after all data have been collected and entails 'a period of intensive analysis when tentative findings are substantiated, revised, and reconfigured' (Merriam, 2001, p.181). After a large portion of the data for this study were in, I began to prepare the data, and myself, for a more intensive, formal period of data analysis. In preparing for this phase of more concentrated analysis, I adopted suggestions made previously by other researchers.

Yin (2003; 2018), for one, outlines a series of 'analytic manipulations' or ways to 'play' with the data prior to formal analysis. While doing this, the researcher is 'searching for patterns, insights, or concepts that seem promising' (Yin, 2018, p.167). Several analytic manipulations proposed by Yin (2003) were considered for use, but one in particular, arranging the information in chronological order, stood out as an essential first step in preparing the data for formal analysis (see Yin, 2003, pp. 110-111). Because the data in

this study were collected over a period of 13 months during rapidly changing circumstances, locating them within an integrated timeline that included the government guidelines for the Covid-19 pandemic was considered crucial both for analysis and for providing the necessary context for the study. Furthermore, it has been recommended elsewhere that case study data covering a series of events be analysed to show the evolution of the case over time (Creswell, 2007). By placing the data in chronological order, such an analysis would later become possible.

When preparing the social media and other web-based data for analysis a unique set of challenges was presented. Online data are often collected in various formats that can, at times, make qualitative data analysis difficult (Kozinets, 2019). Kozinets (2019) recommends that data from online sources be collated prior to analysis. This process of collation involves identifying what will be coded, separating out any data that will not be used for analysis, reformatting data if necessary, and arranging the data in a way that allows it to be coded (Kozinets, 2019). This study collected large volumes of data from various online sources that came in multiple different formats and included many pieces of data that were not relevant to the research aims. Because of this, this process of collation described by Kozinets (2019) proved useful in preparing the data for analysis.

After collating the social media and web-based data, it was decided that most of this data would not be analysed. This was due to significant overlap between the data sources. The dates-n-mates Twitter account was ultimately selected for analysis because it appeared to contain all relevant information.

After collecting all of the data and preparing them for analysis by arranging them in chronological order and collating them as described above, a more formal and intensive process of analysis could begin. In the following sections, the selection of the data analysis method is described. This is then followed by a description of the procedure that was undertaken to analyse the data in this study.

### **5.4.3 Methods of analysis proposed by case study texts**

According to Yin (2018) data analysis is not particularly well developed in case study research. The analysis of case study data is complicated by the fact that there is often a large volume of it, and it has typically come from a variety of different sources, which

‘may present disparate, incompatible, even contradictory information’ (Merriam, 2001, p. 193). When attempting to analyse case study data, Yin (2018) argues that ‘much depends on a researcher’s own style of rigorous empirical thinking, along with the sufficient presentation of evidence and careful consideration of alternative interpretations’ (p. 165). When selecting a method of analysis for this study, I was concerned with choosing a method that could be used with both of the primary datasets, that could be used either inductively or deductively, and for which there was a detailed description of the procedure in a previous text.

While data analysis in case study research may be largely under-developed, both Yin (2018) and Stake (1995) have described methods researchers can adopt to analyse their case study data. Yin (2018), for instance, identified four primary analytic techniques that can be used to analyse within-case data: pattern matching, explanation building, time-series analysis, and logic models. He additionally describes a fifth, cross-case synthesis, that can be used in multiple-case study designs and will be discussed in a later section. When analysing the within-case data for this study, it was his first technique, pattern matching, that was initially considered for use.

According to Yin (2018) pattern matching is one of the most desirable data analysis techniques in case study research (p. 175). Using this method, the researcher ‘compares an empirically based pattern—that is, one based on the findings from your case study—with a predicted one (or with several alternative predictions, including rivals) made before you collected your data’ (Yin, 2018, p. 175). When undertaking this study, several predictions were developed in relation to some of the research questions. Furthermore, the research was designed to explore participants’ social inclusion and feelings of belonging for which there were established frameworks that could be compared to the findings in this study. For these reasons, Yin’s (2018) pattern matching was carefully considered for use. Ultimately, though, pattern matching was not selected because this study was largely exploratory and, given the unprecedented circumstances under which this research was carried out, it was difficult to formulate pre-established patterns or hypotheses with regard to all of the research questions. Despite this, as will become apparent in the following sections, some procedures congruent with pattern matching were still used in the analysis of the data for this study.

Stake's (1995) preferred process of data analysis differs from the analytic techniques proposed by Yin (2018). When conducting data analysis, he argues that the researcher is often developing meaning through a search for patterns and consistency in the data. These patterns may emerge through data collection, but they can also be discovered by coding the data and aggregating frequencies. He describes two strategies that researchers can use to find meanings in their case study research: direct interpretation and categorical aggregation (Stake, 1995). Through direct interpretation the 'researcher concentrates on the instance, trying to pull it apart and put it back together more meaningfully', and through categorical aggregation, the 'researcher seeks a collection of instances, expecting that, from the aggregate, issue-relevant meanings will emerge' (Stake, 1995, p. 75).

When conducting a case study analysis, Stake (1995) explains, the researcher will move between direct interpretation, or looking for meaning in single instances, and categorical aggregation, or looking for meaning through the repetition of instances (p. 76). He argues that because cases are complex and the researcher's primary task is to understand the case, more time will likely be spent in direct interpretation. However, he notes that in case studies where the case is to be used to help understand a certain phenomenon, the researcher will have a greater need for categorical data. Stake (1995) concludes that 'the nature of the study, the focus of the research questions, the curiosity of the researcher pretty well determine what analytic strategies should be followed: categorical aggregation or direct interpretation' (p. 77). While these analytic strategies proposed by Stake (1995) were considered for use in this study, the text ultimately failed to provide a detailed enough procedure for data analysis for me to feel confident in their application.

The approaches to data analysis described by both Yin (2018) and Stake (1995) outlined above have undoubtedly been useful to many case study researchers and certainly have their merit. However, it remains unclear from the texts just how precisely these methods can be used to code case study data, develop robust categories and themes, and arrive at valid conclusions. As Stake (1995) remarks, 'methods books like [his] provide persuasions, not recipes' (p. 77), and he further urges researchers to discover the methods of analysis that work best for them. Because this was the first case study research I had undertaken, a slightly more prescriptive method of analysis than those proposed by Yin (2018) or Stake (1995) was desired.

#### 5.4.4 Method of analysis selected for this study

After considering a variety of analysis techniques, content analysis as described by Elo and Kyngäs (2008) was chosen for analysing the data in this study. While content analysis was traditionally concerned with quantifying data, it has changed and developed throughout the years and now encompasses qualitative content analysis in addition to quantitative content analysis (Graneheim and Lundman, 2004). The strict distinction between the two has been questioned by Krippendorff (2004) who argues that ‘all reading of texts is qualitative, even when certain characteristics of a text are later converted into numbers’ (p. 16), but he nonetheless illustrates a number of ways in which content analysis has evolved over time to incorporate more traditionally qualitative techniques and ways of thinking. For this study, the method of data analysis adopted is what would be referred to as qualitative content analysis.

Qualitative content analysis has been defined as a ‘research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns’ (Hsieh and Shannon, 2005, p. 1278) and is concerned with both manifest and latent content (Graneheim et al, 2017). Manifest content refers to what is ‘visible’ and ‘obvious’ and latent content deals with ‘interpretation’ and identifying ‘underlying meaning’ (Graneheim and Lundman, 2004, p. 106). It was because of the attention afforded to both manifest and latent content that qualitative content analysis was considered appropriate for use with both of the two major data sets in this study—social media data and in-depth longitudinal interview data—and one of the primary reasons this method was ultimately selected for use over other methods of analysis. It should be pointed out, however, that the primary focus of analysis was not the same for both datasets. When conducting the analysis of the social media data, the primary focus was placed on manifest content, but when carrying out the analysis of the interview data there was a sole focus on latent content.

The analysis of manifest content was considered important when trying to gain a full understanding of dates-n-mates through social media data. As Kozinets (2019) notes, when analysing data from online sources, the researcher may encounter situations where the data need to be ‘quantified or counted’ (p. 345). Content analysis was a useful method of analysis because it allowed for such frequency counts and the categorisation of descriptive data. Once collected, these descriptive data could then be used ‘to describe the system’ and

‘build a conceptual map of the phenomenon’ (Kozinets, 2019, p. 345). Such a ‘conceptual map’ would prove useful when developing an understanding of the case under study. In addition, content analysis had previously been used successfully to analyse data from Facebook groups, both to count the frequencies of types of posts and comments and to develop themes from the content of the posts and comments (Eghdam et al., 2018).

In contrast to the social media data, during the analysis of the interview data, I was only concerned with coding the latent content or ‘meanings’ of participants’ responses during the interviews. According to Wilkinson (2019), in instances such as these when the researcher is primarily concerned with the content of what participants say, not the frequency with which something is said, qualitative content analysis is essentially thematic analysis by a different name. Thematic analysis as described by Braun and Clarke (2006) was considered for use when analysing the interview data for this study and would have been appropriate; however, content analysis was ultimately selected due to the researcher’s preference to use a consistent method of analysis with both of the primary datasets. Although, it does warrant noting here that, as Braun and Clarke (2006) have pointed out, at times researchers claim to be using content analysis to analyse their data when their analysis is in fact thematic. It could be argued that the analysis of the interview data for this study largely falls into that category; however, the researcher is following previously established procedures for conducting a content analysis.

#### **5.4.5 Inductive versus deductive approach**

Content analysis can take either a deductive or inductive approach, and both follow the same primary phases of analysis: ‘preparation, organization, and reporting of results’ (Elo et al, 2014, p. 1). Generally, in deductive analysis, the researcher is attempting to test previously developed frameworks or models or retest data in a new context (Elo and Kyngäs, 2008). Conversely, an inductive approach is adopted when the research is designed to describe a phenomenon about which existing theory or knowledge is limited (Elo and Kyngäs, 2008; Hsieh and Shannon, 2005) and the researcher is not seeking to test previously established hypotheses (Bogdan and Biklen, 2007).

Most qualitative research follows an inductive approach (Bogdan and Biklen, 2007), and this approach was carefully considered for use when designing this study. However, there are some setbacks inherent to this approach. For one, when a purely inductive approach is

adopted, the categories or themes developed during analysis may not reflect the interview questions used in the study (Braun and Clarke, 2006). In addition, the development of themes or categories would not be directed by theory (Braun and Clarke, 2005) and may not fully take into account the context of the research, which can result in a failure to identify important categories (Hsieh and Shannon, 2005, p. 1280). In this study, I wanted to maintain some level of proximity to the research questions and assumptions therein. I was also interested in how participants' experiences of social inclusion and belonging correlated with pre-established frameworks and definitions for these concepts, and I wanted to make sure that the context in which the research was carried out was fully accounted for.

Ultimately, a purely inductive approach was not considered appropriate for use in this study because this research was influenced by previous work on social inclusion and belonging, and a series of assumptions about the phenomenon were developed in tandem with the research questions. However, this research was also ill-suited to a traditionally deductive approach because it was not wholly concerned with testing pre-existing theory or frameworks. This study was carried out during unprecedented and constantly shifting conditions, and there was little existing literature or theory to draw from when exploring how an organisation taking an asset-based approach and its members adapted to such circumstances.

In instances such as this where neither an inductive nor a deductive approach is deemed suitable, an in-between or middle-ground approach can be taken whereby the researcher moves between the two approaches. This strategy of moving between an inductive and deductive approach is referred to as an 'abductive' approach (Graneheim et al., 2017). According to Patton (2015), 'abduction is not widely known, understood, or appreciated' but deserves recognition as a distinct approach (p. 562). An abductive approach was initially adopted in this study because it afforded me some flexibility during the data analysis process, allowing me to remain close to the aims of the research, while at the same time encouraging me to be open to unexpected or contradictory findings. During the process of analysing the data, it was found that a more inductive approach was appropriate to the development of categories to depict the interview data, so the approach to data analysis shifted as I began to work more closely with the data.



### **5.4.6 Selecting the unit of analysis and meaning unit**

Regardless of which approach to analysis is selected—inductive, deductive, or abductive—an essential step prior to conducting data analysis is the selection of an appropriate ‘unit of analysis’ (Elo and Kyngäs, 2008; Elo et al., 2014) and ‘meaning unit’ (Graneheim and Lundman, 2004). It has been suggested that pieces of data such as entire interview transcripts or observation session notes be taken as the unit of analysis because they are ‘large enough to be considered whole’ yet small enough to be held in mind in relation to the meaning units during analysis (Graneheim and Lundman, 2004, p.106). By ‘meaning units’ what are referred to are the pieces of data, such as words, phrases, or sentences, that are given a code during analysis (Graneheim and Lundman, 2004). The meaning unit should be narrow enough so that it does not encompass numerous meanings but broad enough so as to avoid fragmentation (Graneheim and Lundman, 2004).

#### **5.4.6.1 Interviews**

When analysing the interview data, each transcript was treated as a unit of analysis. These transcripts contained enough information to be viewed of as a ‘whole’, while not encompassing so much information so as to lose a sense of that whole. The meaning units were comprised of phrases, mentions, and sentences. It was these meaning units, or segments of data, that were assigned codes during the analysis process.

#### **5.4.6.2 Social media data**

For the analysis of the social media data, each of the social media accounts was taken as a unit of analysis. Individual posts or tweets were initially considered for use as units of analysis; however, they were ultimately deemed unsuitable because many of the individual posts and tweets did not contain information relevant to the research questions, and many contained very little information when taken alone. Had the individual posts and tweets been taken as the units of analysis, it would have resulted in the coding of potentially hundreds of posts and tweets that clearly had no bearing on the research aims. By viewing the entire accounts as the units of analysis, all posts and tweets made through the accounts could be reviewed, while only coding those posts and tweets that pertained directly to the research questions.

### 5.4.7 Developing categorisation matrices

When conducting a content analysis using a strictly deductive approach, either a structured or unconstrained categorisation matrix is developed prior to analysis (Elo and Kyngäs, 2008). The unconstrained matrix is different from the structured matrix in that it is more flexible and allows for the development of additional categories ‘within its bounds, following the principles of inductive content analysis’ (Elo and Kyngäs, 2008, p. 111). Because this study took an abductive approach, the use of unconstrained matrices was adopted. Such matrices would allow for the data analysis to be directed by the research questions, predictions, and previously established frameworks for social inclusion and belonging, while at the same time allowing for novel, contradictory, and unexpected findings to emerge from the data.

One matrix was created for use with the social media data and another for use with the interview data. The two separate matrices were created because the analysis for the social media data was to be slightly more structured than that for the interview data and was intended to capture some purely descriptive elements. However, in remaining true to an abductive approach, in both instances these matrices were considered flexible and allowed for new categories to be developed throughout the analysis process. Essentially, the matrices were used as helpful guides to remain close to the initial aims of the research and the previous work done on social inclusion and belonging while also welcoming unanticipated results.

This use of categorisation matrices was also valuable because the research took an embedded case study design. Some of the interview data were found to pertain directly to the subunits of analysis (individual participants) while not having much relevance to the larger single-case (dates-n-mates as an organisation). However, other interview data were found to be in direct reference to the single-case. By using a categorisation matrix with the interview data, data could be ‘sorted’ into those directly related to dates-n-mates and those only related to the individual participants. This would make it easier to then retrieve the relevant data when developing the findings and presenting the results.

To create the categorisation matrices, elements from the research questions were initially identified as categories. For the individual interviews this included: 1) the role of dates-n-mates in participants’ lives, 2) the experiences of taking part in dates-n-mates during the

pandemic, and 3) the impact of the Covid-19 pandemic on participants' lives. The matrix for the social media data contained: 1) the impact of the Covid-19 pandemic on dates-n-mates, 2) the adaptations dates-n-mates made due to the pandemic, and 3) the support dates-n-mates provided to members during the pandemic. After establishing these research question-driven categories, a few categories were then added to the matrix for the social media data that were designed to capture descriptive elements. These included items to note the primary purpose of each post and to list any activities that were mentioned.

Finally, categories were added to both of the matrices to reflect that this research had a particular interest in the programme participants' social inclusion and belonging. To identify the ways in which dates-n-mates promoted social inclusion and belonging and members experienced social inclusion and belonging, the categorisation matrices were partially designed around previously developed frameworks for these concepts. Specifically, Cobigo et al.'s (2012) definition of social inclusion and Antonsich's (2010) framework for belonging were adopted in this study and subsequently incorporated in the matrices.

Cobigo et al. (2012) developed their recommended definition of social inclusion through a synthesis review of the literature. As mentioned in Chapter 1, they suggest that social inclusion is defined as:

(1) a series of complex interactions between environmental factors and personal characteristics that provide opportunities to (2) access public goods and services, (3) experience valued and expected social roles of one's choosing based on his/her age, gender and culture, (4) be recognized as a competent individual and trusted to perform social roles in the community, and (5) belonging to a social network within which one receives and contributes support (Cobigo et al., 2012, p. 82).

Four elements of this definition—items 2 through 5—were included as categories in the matrices. While the first part of this definition was not included, it was not forgotten. This element was kept in mind to act as a reminder that the other four aspects of social inclusion entail complex and continually changing negotiations between individuals and the groups to which they are included or desire to be included. When using this definition, it was also important to bear in mind that 'social inclusion should be understood as relative to an

individual within the groups to which he or she *wants* to belong’, which implies an element of choice and self-determination (Cobigo et al., 2012, p. 81; emphasis added).

This definition of social inclusion was selected because it was based on an extensive review of the literature and was considered comprehensive. It was also developed with a particular focus on the social inclusion of people with intellectual and developmental disabilities, meaning that it was likely to be of relevance to the participants in this study. This definition also acknowledged that social inclusion should go beyond physical presence to include participation and engagement (Cobigo et al., 2012, p. 76) and took into account reciprocal exchanges and subjective feelings of belonging, the importance of which were previously discussed in Chapter 2. This definition was selected by one of the papers included in the systematic review by Fulton et al. (2021; Lysaght et al., 2017) when exploring inclusion through work for people with intellectual disabilities.

In addition to social inclusion, this research also took a specific interest in belonging. While Cobigo et al. (2012) stressed the importance of belonging in their conceptualisation of social inclusion, they did not provide a definition for the concept. Because of this lack of definition, the addition of a framework for belonging was viewed as essential to the construction of the matrices. It was Antonsich’s (2010) framework for belonging that was selected to be used alongside Cobigo et al.’s (2012) definition for social inclusion.

In his framework, Antonsich (2010) organises belonging around two domains: ‘belonging as a personal, intimate, feeling of being “at home” in a place (place-belongingness) and belonging as a discursive resource which constructs, claims, justifies, or resists forms of socio-spatial inclusion / exclusion (politics of belonging)’ (Antonsich, 2010, p. 645). When he speaks of feeling ‘at home’ he is not referring to home as a physical place but, drawing from hooks (2009), as ‘a symbolic space of familiarity, comfort, security, and emotional attachment’ (p. 646). When he refers to ‘politics of belonging’, he is talking about the belonging that comes through an identification with and acceptance by a group of people.

This framework for belonging was adopted because it has been widely accepted and used in previous research (e.g. Wilton et al., 2018; Strnadová et al., 2018) and contains a spatial element that is often neglected in research on social inclusion and belonging. In particular, the concept of ‘place-belongingness’ was considered to be an important component of belonging that is often overlooked. That subjective feeling of being ‘at home’ included a

familiarity and emotional attachment that was not evident in the components of Cobigo et al.'s (2012) definition of social inclusion and was thus added to the matrices as a separate category.

However, unlike 'place-belongingness', 'politics of belonging' resonated with the fifth component of Cobigo et al.'s (2012) definition of social inclusion: 'belonging to a social network within which one receives and contributes support' (p. 82). Because these two components would likely encompass similar types of data if they were made into separate categories in the matrices, they were combined to create a single category. This resulted in a total of five categories related to social inclusion and belonging being added to the matrices, in addition to those categories driven by the research questions and those designed to capture descriptive elements in the social media data. Overall, a categorisation matrix consisting of eight categories was created for use with the interview data, and a matrix of 11 categories was created for the social media data.

#### **5.4.8 Procedure for analysis**

After preparing the data for analysis and developing the matrices as described in the previous sections, I next read through the data multiple times in an attempt to become immersed in the data, 'obtain a sense of the whole', and grapple with 'what is going on' in the data (Elo and Kyngäs, 2008, p. 109). Once I became sufficiently familiar with the data, I then began assigning codes and categories to the data (Elo and Kyngäs, 2008). Codes here are referring to the 'labels that assign symbolic meaning to the descriptive or inferential information compiled during a study' (Miles et al., 2019, p. 62). Codes are developed in relation to a piece of data and can be either descriptive or more conceptual or metaphorical in nature (Miles et al., 2019). In this study, codes were applied to the meaning units as defined above (see section 5.4.6).

Because categorisation matrices were created for use in this study, the data were coded in relation to the pre-established categories described in the previous section. However, as was explained, these matrices were unconstrained rather than structured, meaning new categories could be developed throughout the analysis process. Therefore, the predetermined categories acted only as guides during analysis; they did not dictate what the codes or categories had to be. When developing new categories during analysis, the procedure used for inductive content analyses was followed (Elo and Kyngäs, 2008).

According to Elo and Kyngäs, (2008), inductive content analysis entails a process of ‘open coding, creating categories, and abstraction’ (p. 109). By open coding they are referring to a process of writing down headings and notes while reading a text. These headings, or codes, are then collected on coding sheets and used to create categories. The resulting categories are then collapsed into ‘broader higher order categories’ through the process of abstraction described below (Elo and Kyngäs, 2008, p. 111).

Before describing abstraction, it is important to note that as data are coded, the codes will likely need to be revised (Miles et al., 2019). Codes can end up being too broad and encompass too many meaning units or too narrow and divide a phenomenon into segments or even fail to appear at all. When a code is revised, each meaning unit attached to the revised code needs to then be carefully relabelled to take the changes into account (Miles et al., 2019).

Abstraction is the final phase in the data analysis process and entails developing more general descriptions of the findings based on the previously defined categories (Elo and Kyngäs, 2008). According to Graneheim and Lundman (2004), abstraction ‘emphasises descriptions and interpretations on a higher logical level’ than simple categorical aggregation. It is through this process of abstraction that the higher order categories were developed for this study. Elo and Kyngäs (2008) note that this process of abstraction should continue ‘as far as is reasonable and possible’ (p. 111), meaning that multiple phases of combining categories into ever higher order categories is to occur. It is ultimately through abstraction that the key findings, often called themes, from the research are developed.

#### **5.4.8.1 Cross-case analysis**

A cross-case analysis was carried out on the interview data related to dates-n-mates participation prior to the pandemic. This was used to answer research questions 1.1 and 1.3 about the role dates-n-mates played in participants’ lives and the impact the group had on participants’ feelings of inclusion and belonging before the pandemic (see Chapter 4, section 4.1.1). The cross-case analysis was important because it allowed for an exploration of how dates-n-mates was experienced before the Covid-19 pandemic and provided a baseline for the data about experiences of dates-n-mates during the pandemic.

All interview data were coded in NVivo 12. A coding example can be found in Appendix J. The set of seven transcripts for each of the participants had initially been coded separately, but at this stage, the codes pertaining to dates-n-mates participation prior to the pandemic were combined across all of the participants. In some instances, codes were merged or modified to better reflect the data in this combined form. After the codes were established, the process of analysis described in the previous section was followed.

#### **5.4.8.2 Social media data**

The analysis of the social media data was used to help inform questions 2.1.1, 2.2.1, and 2.3.1 about the impact the Covid-19 pandemic had on dates-n-mates, the adaptations the group implemented as a result, and the ways in which the group attempted to support members during the pandemic. It was also used to help inform question 2.4 about how dates-n-mates attempted to promote social inclusion and belonging during the pandemic. These data helped to provide important contextual information about how dates-n-mates reacted to the pandemic, which provides a deeper understanding of the embedded cases presented later. While a large volume of social media data was collected and analysed, their analysis primarily yielded descriptive information. It is important to have this information; however, it was secondary to the rich information provided through the cross-case analysis and embedded cases.

The codes for the social media data were developed in Excel spreadsheets. A coding example can be found in Appendix K. Because the social media data consisted of images, it was difficult to attach codes directly to the data. For these data, the corresponding code was entered into an Excel spreadsheet and labelled with the image's unique identifier. All codes were entered in relation to the predetermined categories; however, an 'other' column was created to allow for codes that did not correlate with any of these categories.

#### **5.4.8.3 Embedded cases**

The embedded cases were used to answer questions 1.2 and 1.4 about the role dates-n-mates played in participants' lives and how the group impacted on participants' feelings of inclusion and belonging during the pandemic. They were also used to answer questions 2.1.2, 2.2.2, and 2.3.2 about the impact the pandemic had on participants, how participants experienced the adaptations dates-n-mates made during the pandemic, and how participants felt supported by dates-n-mates during the pandemic. Along with the social

media data, these data were also used to inform question 2.4 dealing with how dates-n-mates promoted social inclusion and belonging during the pandemic. In essence, this analysis was used to explore what participants' lives were like during the pandemic and how dates-n-mates fit into their lives during this time.

For the embedded cases, each participant's set of interviews were coded separately, as mentioned above. This resulted in each participant having a unique set of codes. However, many of the codes overlapped or were similar across the participants. Within each participant, the process for analysis described above was followed (see section 5.4.8).

## **5.5 Conclusion**

This chapter explained what case study design and embedded case studies are. It provided details about the methods adopted in this study, including data collection methods, recruitment procedures, and data analysis methods. The next chapter will provide details of the context in which this research was carried out, including a timeline of key events during the Covid-19 pandemic.



## Chapter 6: Context for the case study

This chapter presents a timeline of key events during the Covid-19 pandemic. This is important to understand the context in which the research was conducted. This chapter will provide important background information necessary to have an understanding of the results presented in later chapters.

### 6.1 Importance of a timeline

When presenting case study research, states Gillham (2000), the researcher 'is seeking to recreate the context and sequence of evidence in a way that enables the reader to see and understand the meaning of what is recounted' (Gillham, 2000, p. 22). This study was conducted during the Covid-19 pandemic throughout which the transmission rates of the virus and the resulting government guidelines were continually changing. In order to fully understand the single-case and the embedded cases, the context in which the data were collected must be understood. To provide this context, a timeline of key events was compiled. This included changes made to the government guidelines and important news items related to Covid-19 that could have had an impact on dates-n-mates as an organisation or on the individual study participants.

Key announcements and events that took place within dates-n-mates were then mapped onto this timeline. This was done to help show the relationships between the government announcements and any changes to or decisions made by dates-n-mates. Without first providing this greater context, it would be impossible to understand the cases because so much of what dates-n-mates and the individual participants did during the study was shaped by the government restrictions. When viewing this timeline, one must bear in mind that it is impossible to create an exhaustive list of events. However, efforts were made to compile enough information in this timeline to provide a framework from which the case could be understood.

Ordering the data chronologically in this way was also helpful when it came time to formally analyse the data. It was one of the 'analytic manipulations' outlined by Yin (2003, p. 111), which was described in more detail in the previous chapter. It allowed the researcher to see how the data and real-world events fit together. Therefore, the following timeline and description of events are not only useful to the reader for understanding the

context in which the research was carried out, but they also served as valuable analytic tools for me as the researcher.

## **6.2 Timeline of events**

The following timeline was created through a careful read of government documents and a review of dates-n-mates' social media pages and website. The timeline of Covid-19 in Scotland compiled by the Scottish Parliament Information Centre (SPICe, 2022) was enormously helpful to this task and was used as a valuable starting point for the timeline presented below. When reading this timeline and the accompanying narrative, it is important to keep in mind that the pandemic continued to evolve. What follows is simply a brief overview and snapshot of a much broader and complex phenomenon. This timeline begins with the first case of Covid-19 confirmed in Scotland in March 2020 (see Figure 6.1) and ends with Scotland's move out of lockdown restrictions in August 2021. It has been broken down into segments corresponding with key events during the pandemic to make it easier to follow.

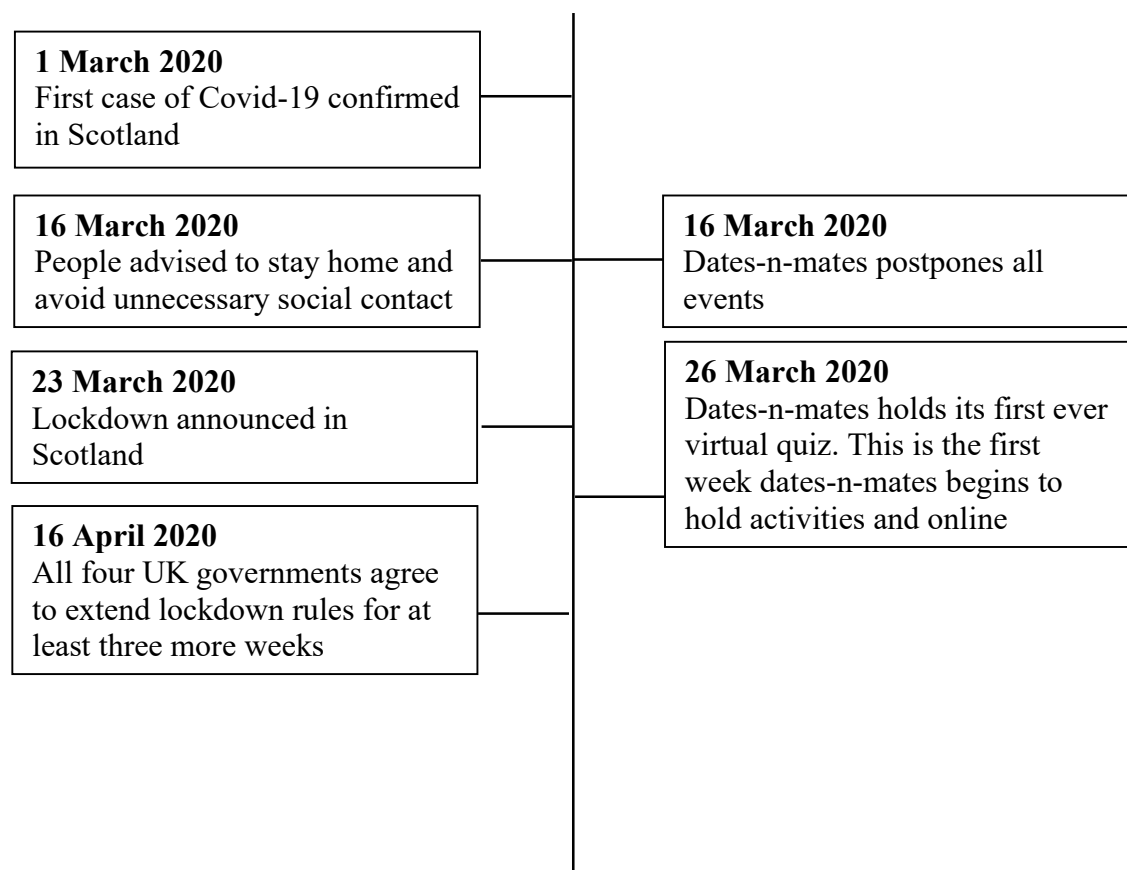
### **6.2.1 Government announcements and dates-n-mates' responses**

On the 11th of March 2020 the first case of a community transmission of Covid-19 was confirmed in Scotland, and the total number of positive cases in Scotland reached 36 (Scottish Government, 2020h). Just five days later, on the 16th, people were advised to limit contact with others and to work from home if possible (Scottish Government, 2020o). That same day, dates-n-mates announced that it was postponing all of its events until further notice. Dates-n-mates began adapting to the changing circumstances relatively quickly, announcing on the 19th that they were already working on developing online activities for members. Unfortunately, the dates-n-mates awards dinner that had been planned for that evening at the Crowne Plaza in Glasgow had to be cancelled. The awards were announced over social media instead.

On the 23rd of March, it was announced that Scotland was going into a full lockdown following a meeting of the UK Government's COBR committee (Scottish Government, 2020i). From the night of the 23rd, residents of Scotland were only allowed to leave their homes to shop for basic necessities, to exercise up to once per day, for medical reasons, to care for a vulnerable person, or to travel for essential work that could not be done from

home (Scottish Government, 2020i). The next day, shielding was introduced to protect people with the highest risk of severe illness (Scottish Government, 2020r). It was recommended that people with certain health conditions remain isolated at home and not have contact with any people outside their household for a period of 12 weeks. This was referred to as ‘shielding’, and people who were meant to shield received letters instructing them to do so. Later that week, on the 26<sup>th</sup> of March, dates-n-mates held its first virtual activity, a virtual pub quiz, for its members over Facebook. The group also began to share some at-home activity ideas with its members. Dates-n-mates further supported its members in the early days of the pandemic by sharing easy read information about Covid-19 and the government guidelines and by sharing tips to help members manage their stress during this time.

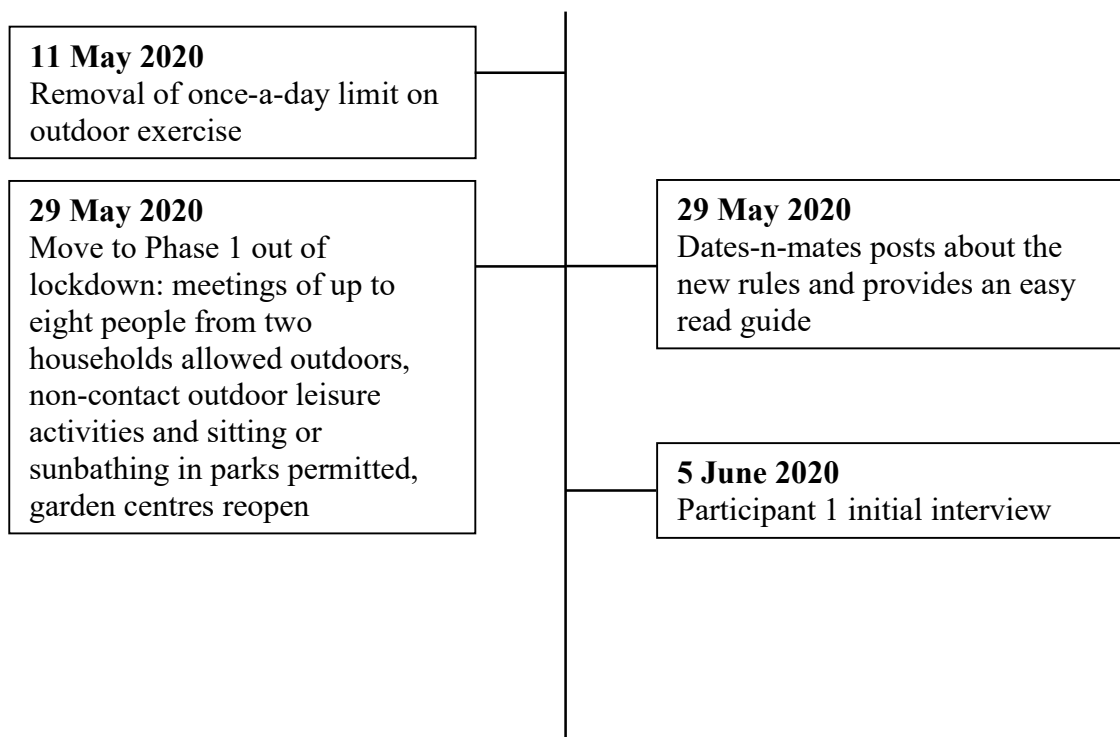
On the 16th of April 2020, all four UK governments agreed to extend the lockdown for at least three additional weeks (Scottish Government, 2020f). It was during this week in April that dates-n-mates began to regularly hold scheduled online activities for members using Zoom. Dates-n-mates also provided members with video guidance to help them access the organisation’s Facebook groups and virtual events. On the 20th of April one of the directors of dates-n-mates began a weekly video blog to communicate with members online. These vlogs were posted to the dates-n-mates Facebook page and summarised some of the activities and events held by dates-n-mates and communicated what was happening within the organisation. The following week, on the 29th, dates-n-mates held its first virtual music and dance party over Zoom as requested by members.

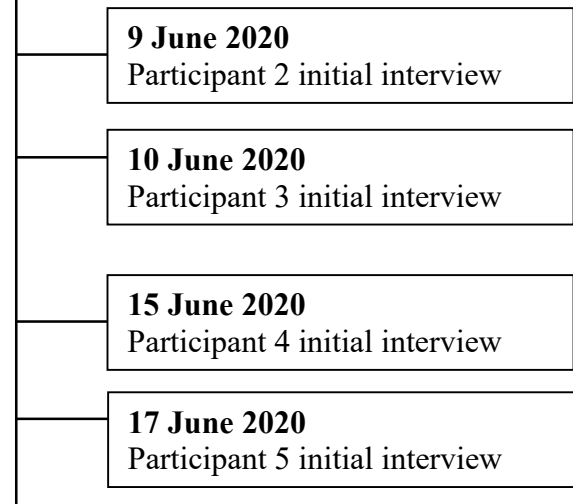




**Figure 6.1:** Timeline of events 1 March 2020 to 29 April 2020

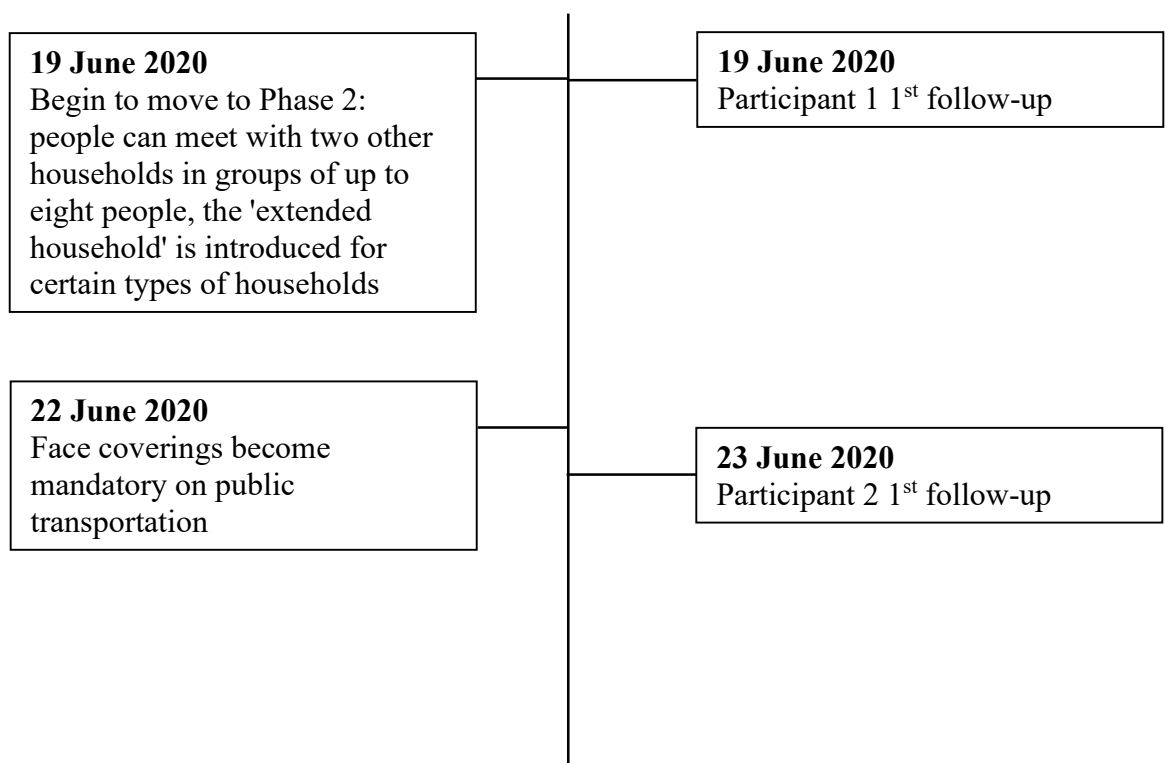
The 11th of May 2020 saw the first easing of lockdown restrictions (see Figure 6.2). From that date, people in Scotland were permitted to exercise more than once a day (Scottish Government, 2020e). The first significant easing of restrictions came on the 29th of May 2020 when Scotland moved into Phase 1 of its ‘four phase route map out of lockdown’ (Scottish Government, 2020g). In this new phase, residents were permitted to sit and sunbathe in parks, participate in some non-contact outdoor leisure activities, and meet with one other household in groups of up to eight people outdoors in a park or private garden. This was the first time most people in Scotland were able to see friends and family outside their own households in over two months. Dates-n-mates communicated these new regulations to members and provided them with an easy read guide. The organisation continued to hold online activities and events for its members over Zoom throughout Phase 1 because social gatherings of more than two households were still not permitted. Participant interviews for this study began during this period.

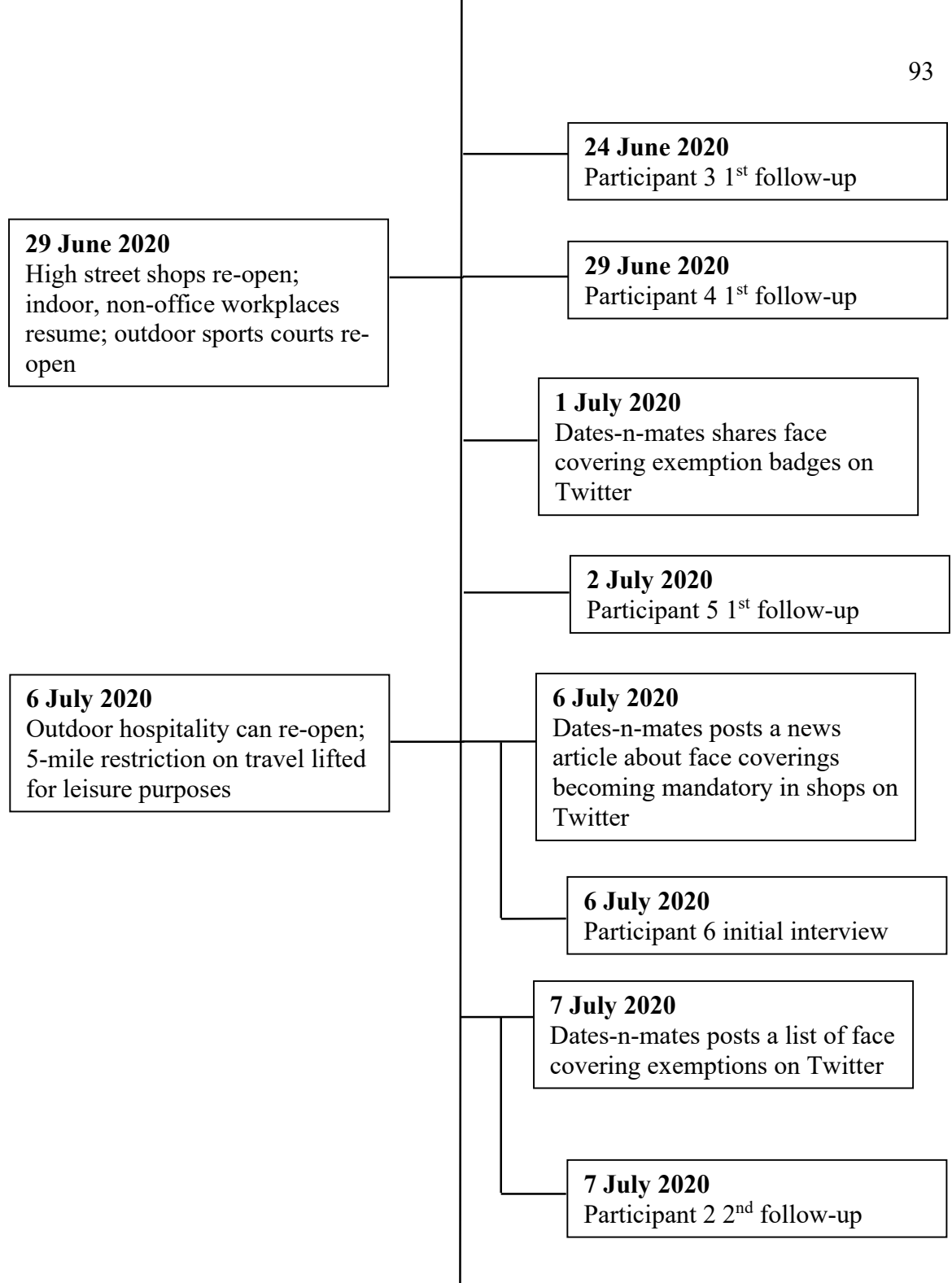




**Figure 6.2:** Timeline of events 11 May 2020 to 17 June 2020

Scotland began to move into Phase 2 of its route map out of lockdown on the 19th of June 2020 (Scottish Government, 2020b; see Figure 6.3). The new regulations allowed people to meet with up to two other households at a time; although, the eight-person limit remained in place. This phase also permitted people who were shielding to meet with another household outdoors and allowed certain types of households to form extended households or ‘bubbles’. Phase 2 also saw the opening of high street shops on the 29th of June 2020. It was also during this phase, on the 22nd of June, that face coverings became mandatory on public transportation. Dates-n-mates shared information about face covering exemptions in response to the new regulations. These exemptions allowed people with certain health conditions to forgo the use of face coverings (BBC, 2020).



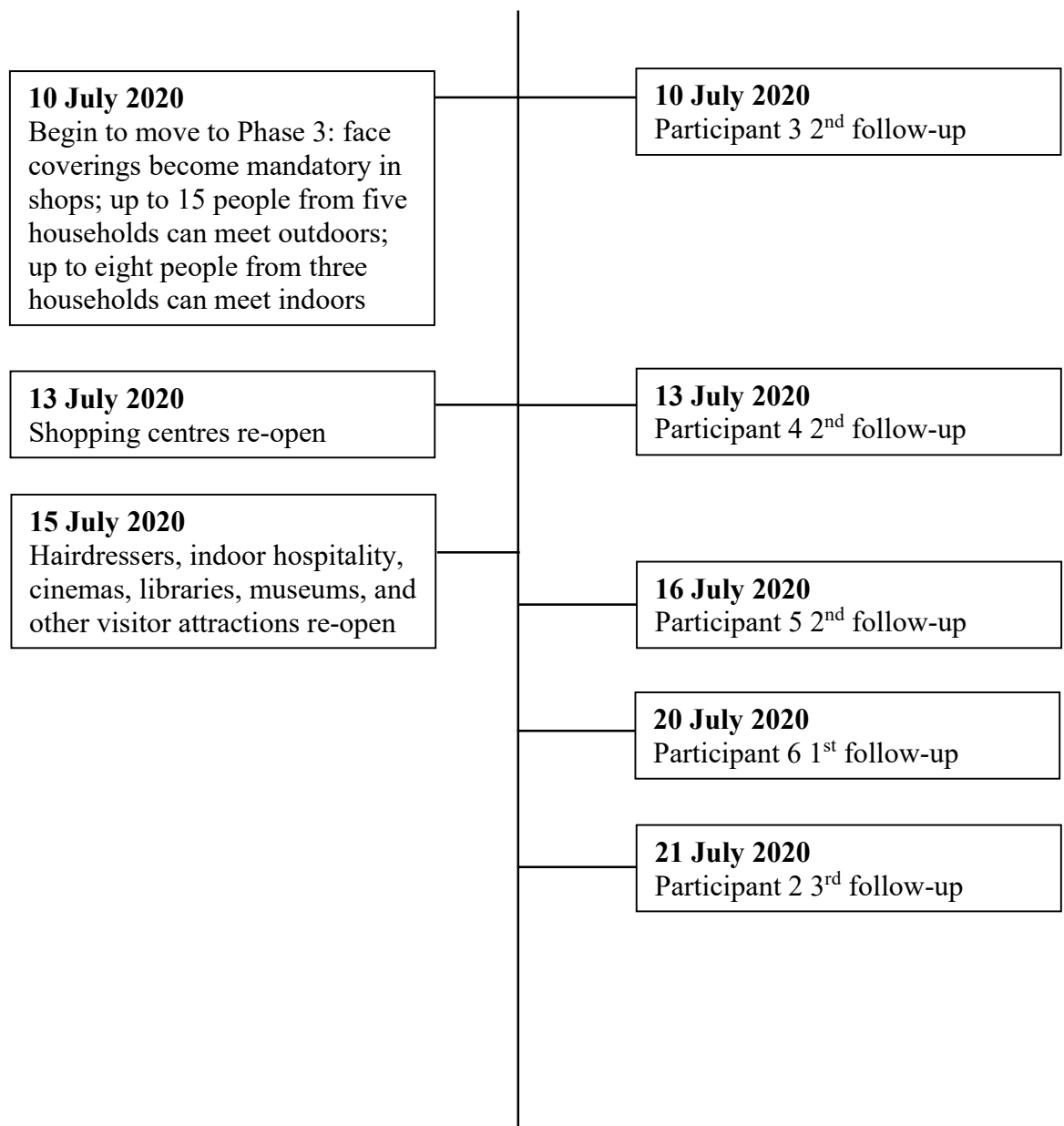


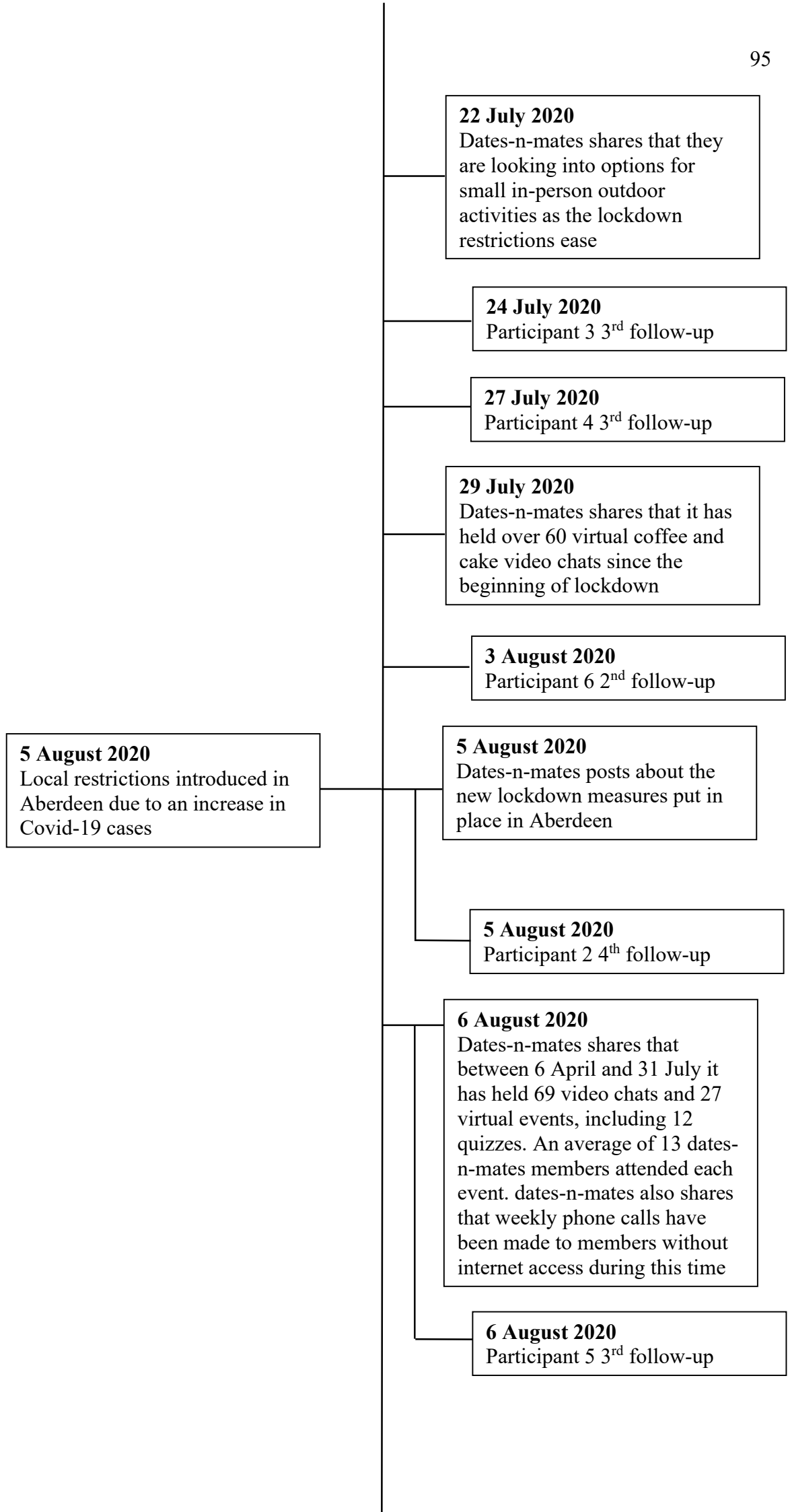
**Figure 6.3:** Timeline of events 19 June 2020 to 7 June 2020

On the 10th of July 2020, Scotland began to move into Phase 3 (Scottish Government, 2020c; see Figure 6.4). This phase saw face coverings become mandatory in all shops. It also relaxed the regulations around socialisation, allowing up to 15 people from five households to meet outdoors or eight people from three households to meet indoors. In addition, on the 15th of July places such as museums, libraries, and cinemas as well as hairdressers and indoor hospitality venues were permitted to re-open to the public. In response to the easing of lockdown restrictions, dates-n-mates announced that they were

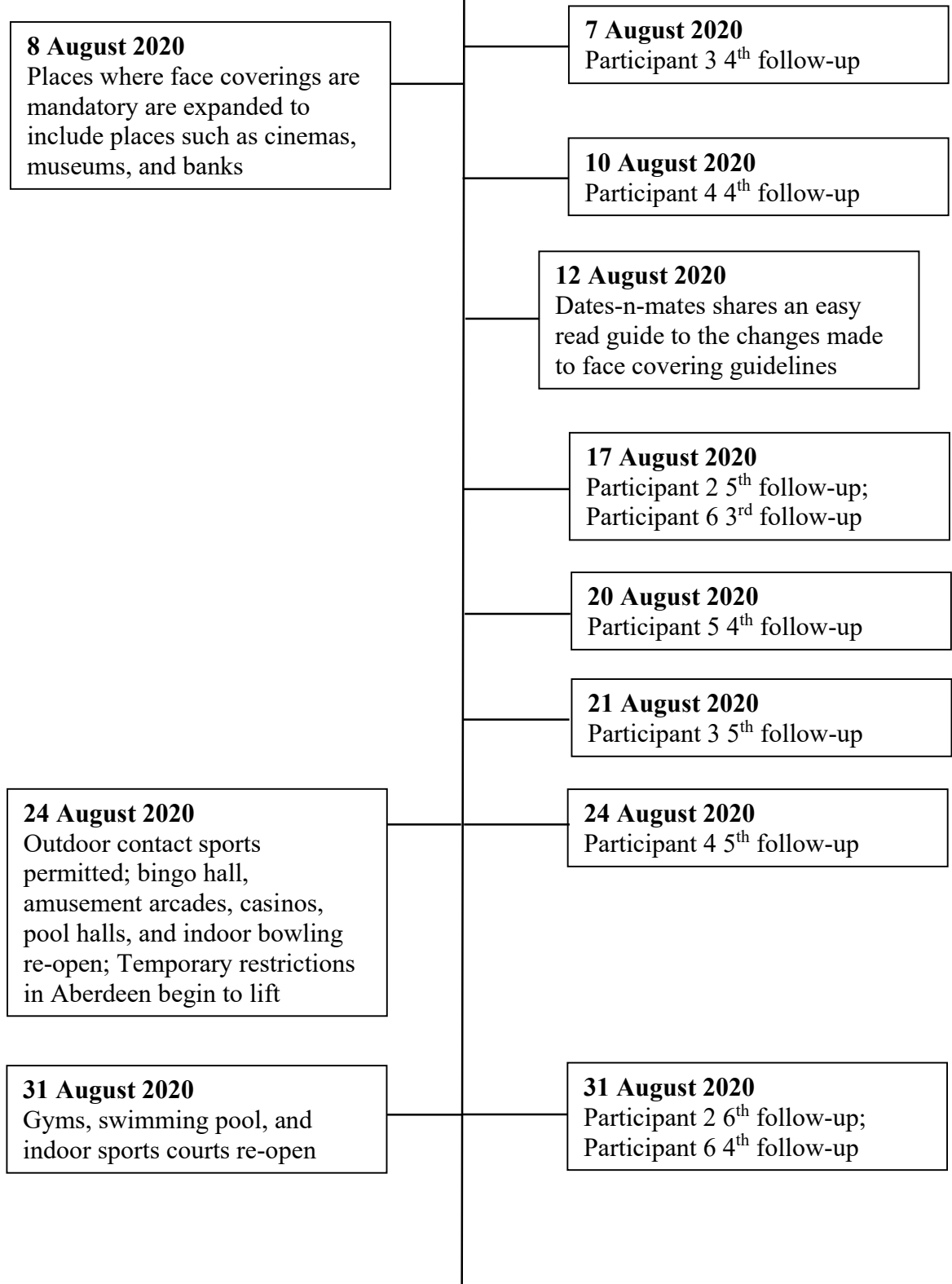
looking into the possibility of holding small in-person outdoor activities for members. Dates-n-mates also shared that between the 6th of April and the 31st of July 2020 it had held 69 video chats and 27 virtual events for its members.

In early August, the number of public spaces where face coverings were required expanded to include places such as cinemas, museums, and banks (Scottish Government, 2020k). Dates-n-mates shared an easy read guide to this change in regulations. By late August additional venues were permitted to open as part of Phase 3, which included gyms, swimming pools, bingo and pool halls, and bowling alleys (Scottish Government, 2020d); however, this did not have an impact on the functioning of dates-n-mates. At the end of August dates-n-mates produced its first month-long schedule of online events for the month of September. Up until this point, dates-n-mates had only released its schedule to members on a weekly basis. This seemed to mark an acceptance of the long-term nature of the pandemic and resulting restrictions.







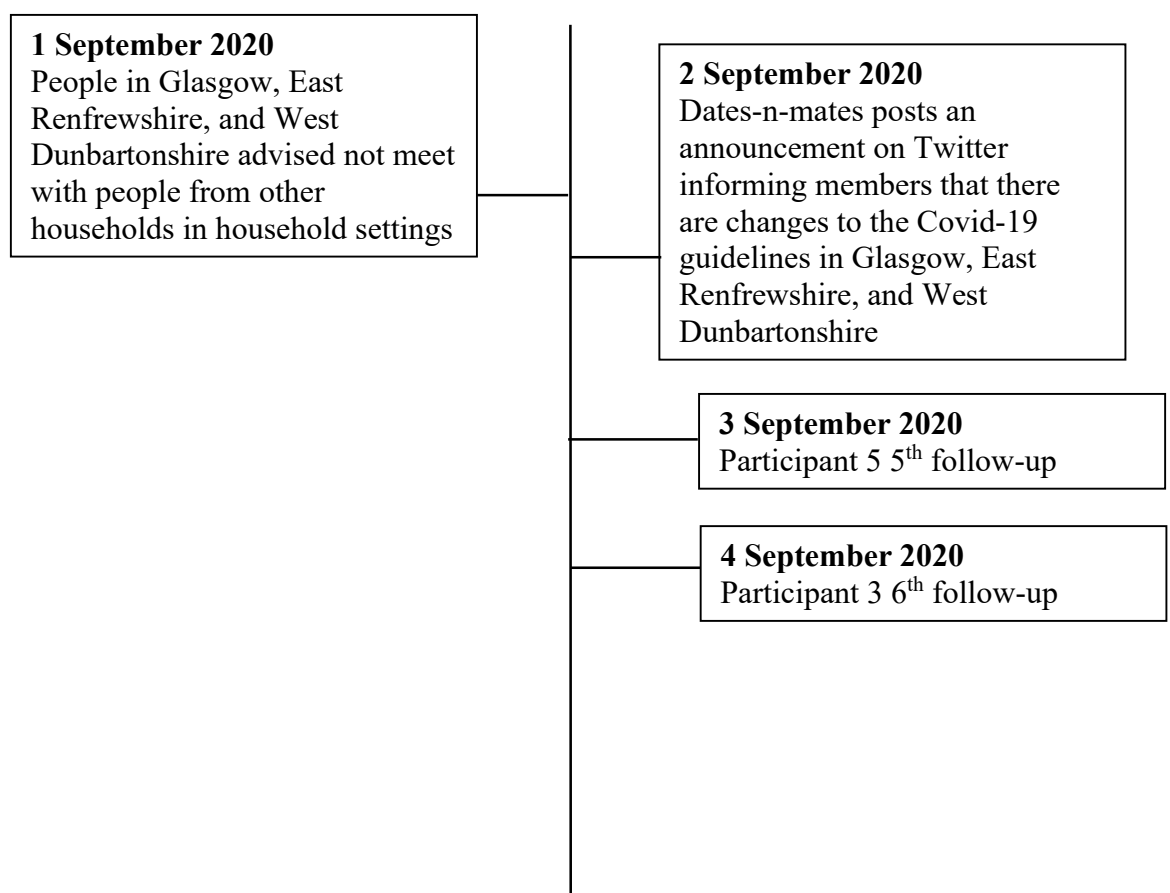


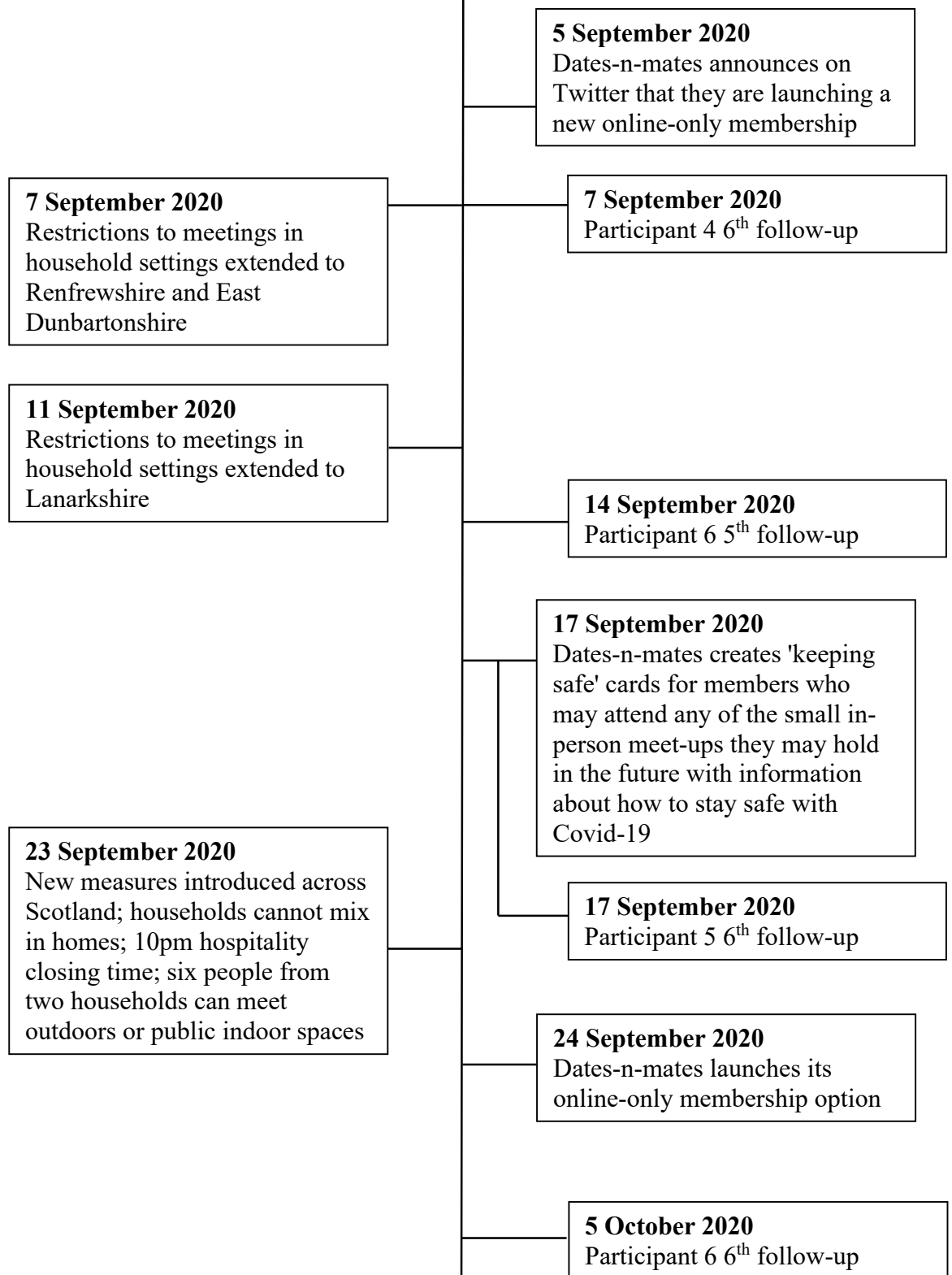
**Figure 6.4:** Timeline of events 10 July 2020 to 31 August 2020

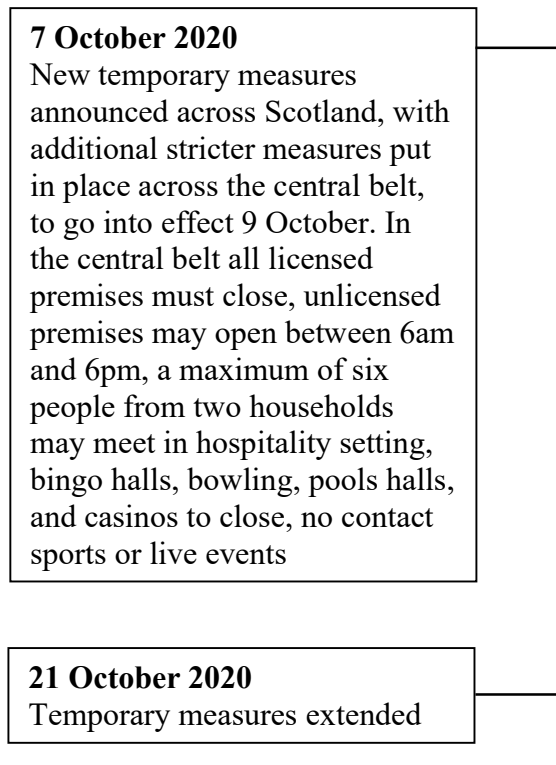
On the 1st of September 2020 it was announced that new restrictions would come into effect in the West of Scotland due to an increase of Covid-19 cases (see Figure 6.5). These restrictions prohibited households from mixing in indoor household settings; although, they still allowed mixing in both outdoor settings and indoor hospitality settings (Scottish

Government, 2020p). Dates-n-mates posted about these changes to its social media accounts. Later that week dates-n-mates announced that it was soon going to launch an online-only membership option that would grant people who could not access the local branches or in-person activities the opportunity to access the dates-n-mates virtual events. In September, dates-n-mates also created ‘keeping safe’ cards for members who were interested in attending small in-person meetings with other members in the future. These cards contained reminders about how to stay safe during the pandemic.

On the 23rd of September new measures were introduced across Scotland. These measures prohibited the mixing of households in household settings, placed a 10pm curfew on hospitality, and restricted the number of people who could meet to six people from two households in outdoor or public indoor spaces (Scottish Government, 2020m). Dates-n-mates shared these new guidelines with its members in an easy read format. Additional restrictions were then introduced in early October in efforts to slow the continuing spread of Covid-19. These restrictions prohibited the sale of alcohol indoors and restricted the hours in which hospitality could open across Scotland. They also led to the closure of a range of venues, including all licensed premises, specifically in the central belt of Scotland (Scottish Government, 2020n). The final participant interview took place two days before these restrictions went into place.

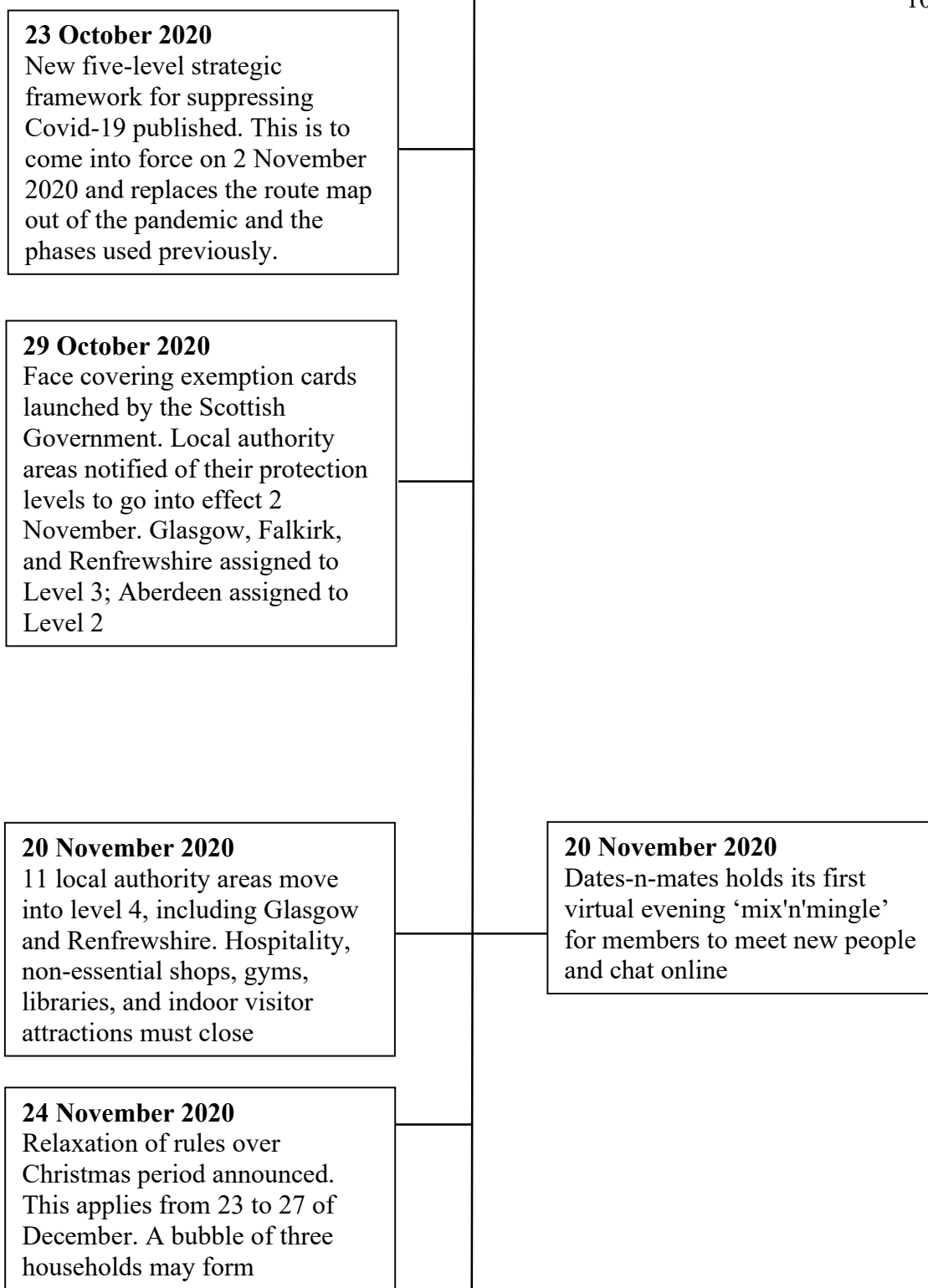






**Figure 6.5:** Timeline of events 1 September 2020 to 21 October 2020

A newly developed five-level strategic framework for the suppression of Covid-19 was introduced on the 23rd of October 2020 (see Figure 6.6) and went into effect on the 2nd of November (Scottish Government, 2020q). This framework consisted of five protection levels and marked a move away from the phased route map that was previously in force. By the 20th of November, 11 local authority areas were placed into the highest level of restrictions, level 4, within this new framework (Scottish Government, 2020t). This was in an effort to curb the number of Covid-19 cases in the weeks running up to Christmas and saw the closure of hospitality venues, gyms, and visitor attractions (Scottish Government, 2021d). Despite the rise in cases, on the 24th of November it was announced that there were plans to relax restrictions over the Christmas period to allow people to celebrate with up to two other households over a period of five days (Scottish Government, 2020a). During the months these changes were taking place, dates-n-mates held its first virtual Halloween party for members and began holding virtual evening ‘mix’n’mingle’ sessions to allow members to meet new people and chat online.

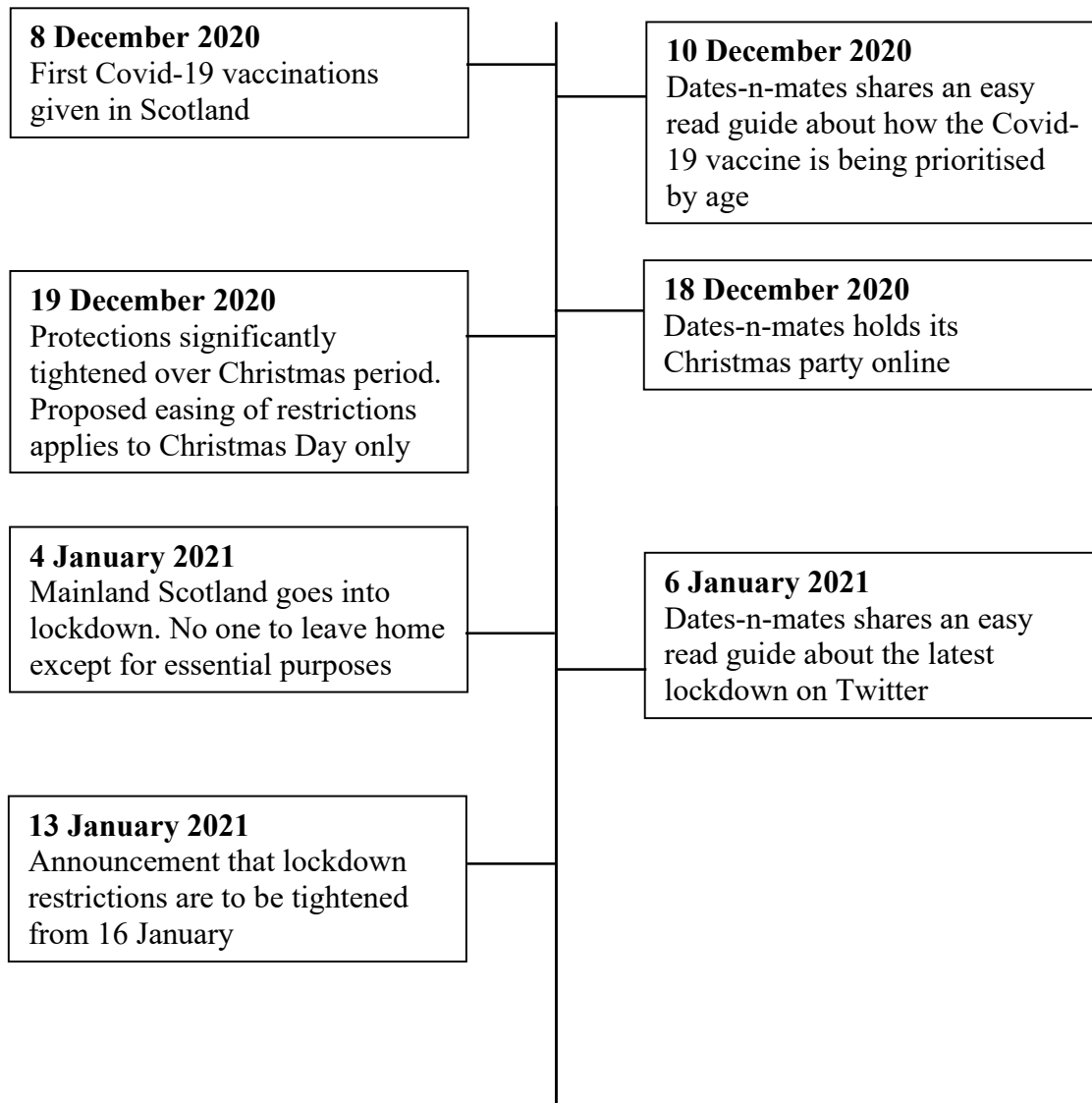


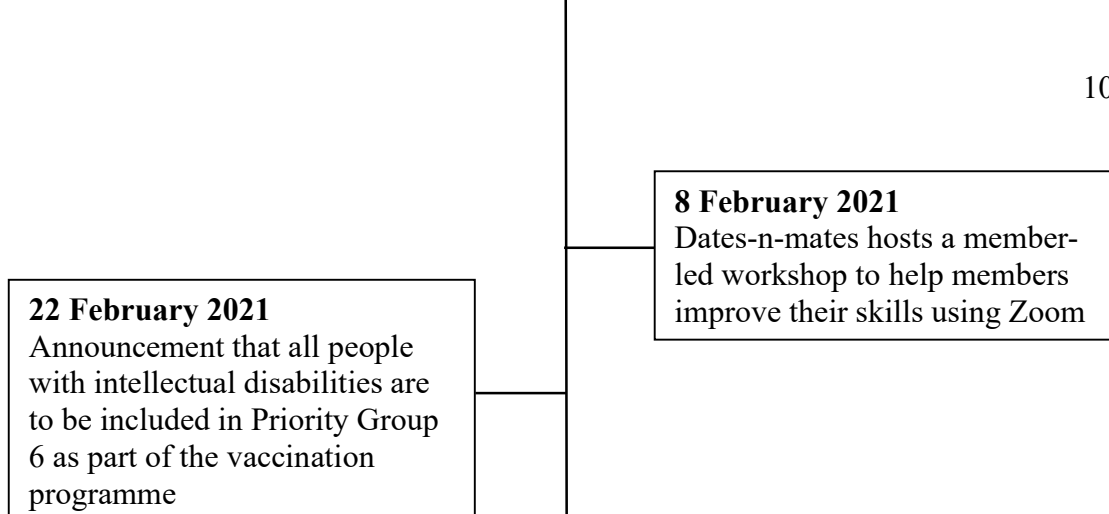
**Figure 6.6:** Timeline of events 23 October 2020 to 24 November 2020

On the 8th of December 2020 the first Covid-19 vaccinations were administered in Scotland, marking the start of the vaccination programme (Scottish Government, 2020j; see Figure 6.7). Two days later, dates-n-mates shared an easy read guide explaining how the vaccines would be prioritised by age. On the 18th of December, dates-n-mates held a virtual Christmas party in place of its usual in-person event. It was on the following day

that the Scottish Government announced that the planned easing of restrictions during the Christmas period would apply to Christmas Day only. This was due to the rapid spread of a new Covid-19 variant, which would later become known as the Alpha variant (Scottish Government, 2020l). Then, on the 4th of January 2021, it was announced that all of mainland Scotland would go into a second lockdown from midnight that night (Scottish Government, 2021i).

Dates-n-mates continued to share brief guides and easy-read information about the new restrictions that were going into place early in the new year. In early February they also held a workshop to help members improve their skills using Zoom and learn how to host their own chats and events. On the 22nd of February the government announced that all people with learning disabilities would be included in priority group 6 for the vaccine (Scottish Government, 2021e). This marked a change from the previous guidelines that did not include people with mild or moderate learning disabilities in this priority group. Dates-n-mates tweeted about the announcement the day after it went public.



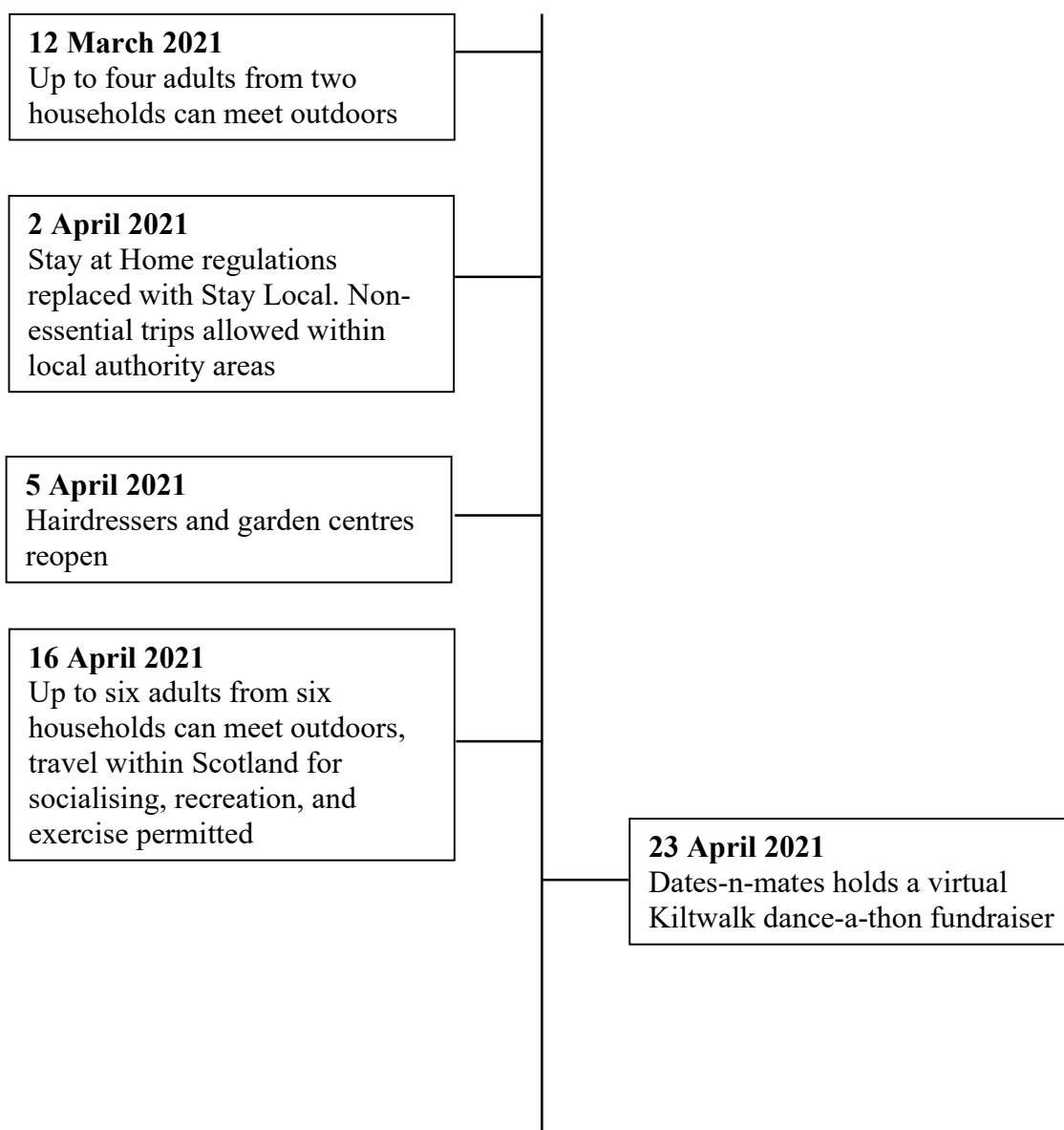


**Figure 6.7:** Timeline of events 8 December 2020 to 22 February 2021

The 12th of March saw the first relaxation of rules since entering the second lockdown (see Figure 6.8). From that date, up to four adults from two household could meet in an outdoor space (Scottish Government, 2021c). By the 16th of April 2021, people were permitted to travel throughout Scotland for recreation and could meet in groups of up to six people from six different households (Scottish Government, 2021a). However, despite the easing of restrictions, the 2021 Kiltwalk, a walk used to raise money for charities, was unable to go ahead as usual. Dates-n-mates held a virtual ‘Kiltwalk dance-a-thon’ for fundraising purposes in place of the usual in-person event. The previous year’s event was cancelled outright due to the pandemic, so this virtual event showed a creative adaptation that allowed for the continuation of the Kiltwalk.

On Monday the 26th of April all of Scotland moved into level 3 of the strategic framework. This saw hospitality venues, non-essential retail, and indoor attractions, such as galleries and museums, re-open (Scottish Government, 2021g). Later that week, dates-n-mates announced that they were beginning to look into the possibility of holding small in-person meetings for members. Then, on the 15th of May, dates-n-mates posted to Twitter that they had held in-person outdoor meetings for small groups of members. These were the first in-person meetings that dates-n-mates had been able to hold since the start of the new year. Throughout the month of May, restrictions continued to ease across much of Scotland (Scottish Government, 2021h), and dates-n-mates continued to hold small in-person meetings between members, including its first pub night in Glasgow in over a year. However, despite the easing of restrictions, dates-n-mates still had to adapt its ‘We’ve Got Talent’ event to take place virtually. The previous year’s event had been scheduled for June and was cancelled outright.

Early in June, Glasgow moved to level 2 of the strategic framework, and 15 mainland local authority areas entered level 1, which saw increases in the number of people who could meet socially (Scottish Government, 2021b). In response to the easing of restrictions, dates-n-mates continued to explore options for getting members together for in-person meetings. Then on the 22nd of June 2021, it was announced that all of Scotland would be moving into level 0 on the 19th of July (Scottish Government, 2021f). This marked the move to the final phase of lockdown restrictions in Scotland and would allow for up to 15 people from 15 households to meet outdoors and up to ten people from four households to meet in indoor public spaces. Scotland would go on to move beyond level 0 on the 9th of August 2021, which saw the removal of physical distancing requirements and limits on social gatherings for the first time since March 2020 (Scottish Government, 2021j). In response to the lifting of lockdown measures, dates-n-mates announced that they would soon begin increasing the number of people at their small gatherings, while still exercising some caution.





**26 April 2021**

All of Scotland moves to level 3. Cafés, pubs, and restaurants can provide full outdoor service and serve food indoors without alcohol until 8pm

**29 April 2021**

Dates-n-mates says on Twitter that they are looking into holding small in-person meetings for members

**11 May 2021**

Announcement that most of mainland Scotland will move to Level 2 on 17 May. Up to six people from three households can meet in homes or gardens without distancing, pubs and restaurants can serve alcohol indoors until 10:30pm, venues such as cinemas, theatres, and bingo halls open

**1 May 2021**

Dates-n-mates launches a podcast hosted by the directors

**14 May 2021**

Announcement that Glasgow and Moray are to remain in Level 3. Travel to and from these areas is prohibited

**15 May 2021**

Dates-n-mates posts about the in-person outdoor activities they have begun to hold for small groups and include photos of a couple recent in-person meet-ups

**19 May 2021**

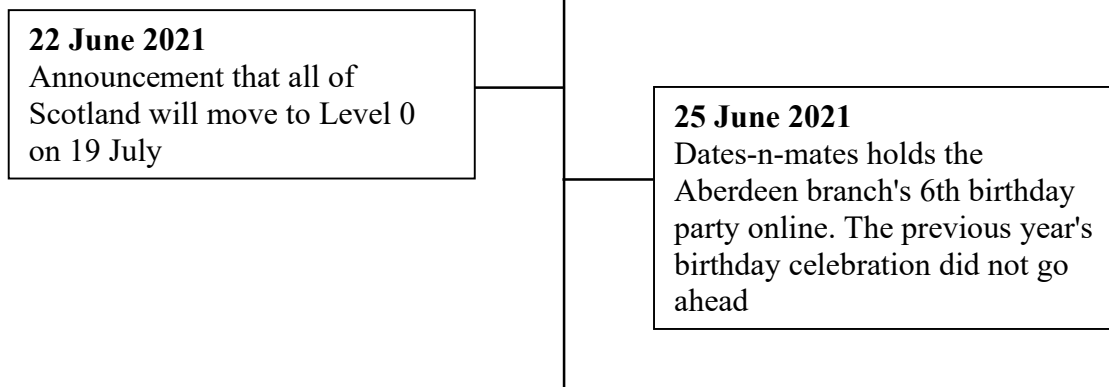
Dates-n-mates posts that it has just held its first pub night in Glasgow in over a year

**5 June 2021**

Glasgow moves to Level 2; 15 mainland local authorities move to Level 1, including Aberdeen City and Falkirk

**21 May 2021**

Dates-n-mates adapts its 'We've Got Talent' event to be held online. The previous year's event was cancelled outright



**Figure 6.8:** Timeline of events 12 March 2021 to 25 June 2021

## 6.3 Conclusion

In this chapter, a detailed timeline of events during the Covid-19 pandemic was provided. Key events related to the government guidelines and decisions made by dates-n-mates are outlined. This chapter describes the context in which the research was conducted. This contextual information is necessary to understand the results of this study. In the next chapter, results from the case study will be presented.

## **Chapter 7: Results from the case study: participants' experiences of dates-n-mates and how the group adapted to the pandemic**

### **7.1 Introduction**

As illustrated in the previous chapter, this study was conducted during a time of continual change and restrictions to social contact. Most of the data collected during this study is reflective of this situation and shows how dates-n-mates and participants were impacted by and adapted to the pandemic. However, data were also collected about how dates-n-mates was experienced by members prior to the pandemic. These interview data are presented below. After describing participants' experiences of dates-n-mates prior to the pandemic, this chapter then turns to a summary of the social media data that were collected. These data were used to help build the timeline in the previous chapter and describe some of the ways in which dates-n-mates attempted to adapt to the pandemic and support its members during this time.

### **7.2 Experiences of taking part in dates-n-mates prior to the pandemic: results from interview data**

#### **7.2.1 Introduction**

As detailed previously, interviews were conducted with six dates-n-mates members. The focus of this cross-case analysis was on their combined experiences prior to the pandemic. The participants ranged in age from their mid-20s to early-40s, and they lived in several different towns and cities across Scotland. The length of their membership to dates-n-mates ranged from one to five years, and they came from three different dates-n-mates branches.

Each of the participants were interviewed on multiple occasions between the 5<sup>th</sup> of June and the 5<sup>th</sup> of October 2020. In total, 37 interviews were conducted. Five participants were interviewed seven times each with two to three weeks between the interviews. A sixth participant was interviewed twice with a two-week space between interviews. Five

categories were identified through the analysis of the data: ‘Taking up space and having a good time’, ‘Finding connection and a sense of belonging’, ‘Feeling valued and supported’, ‘Personal growth’, and ‘It’s not all perfect’. Pseudonyms were assigned to each of the participants.

### **7.2.2 Taking up space and having a good time**

Participants clearly enjoyed the time they spent with dates-n-mates. As Sarah stated plainly in reference to a karaoke event she attended: ‘It was just really good fun. Yeah, it was good fun’. All of the participants reported taking part in a range of activities and events with dates-n-mates prior to the pandemic, and participating in them was often described as a positive experience:

I’ve had the, I’ve done the summer party which was brilliant, and I’ve also done the Valentine’s party which was good as well. Every, every activity that I’ve done—a meal out, eh, going to the pub—all of the events, eh... [...] with dates-n-mates has been, eh, good. (Michael)

When asked what their favourite activities were, none of the participants were able to pick just one. As Sarah said, ‘Oh, there’s been so many favourites’. It was apparent that the participants enjoyed having different types of activities to take part in. When Matthew was asked how he would feel if he did not have dates-n-mates, he replied, ‘I’d feel bad ‘cause see I like to do different things’. Both Mark and Michael compared dates-n-mates favourably to the other groups they took part in because they appreciated the variety of activities and events dates-n-mates held. As a whole, it was clear that the participants did not have many opportunities to engage in a range of enjoyable activities outside of dates-n-mates, and they valued having this space to get involved in different things.

Not only were the dates-n-mates activities enjoyable and varied, but they also provided members with a reason to get out of the house, see other people, and venture into public venues. Dates-n-mates was the only group Jennifer and Sarah participated in, and Sarah said she had been getting out more since joining the group. Mark spoke with pride when he reported that he had been able to go into Glasgow regularly with dates-n-mates: ‘I’ve been everywhere as well. Everywhere. Parties. I’ve been to parties in Glasgow. I’ve been to Falkirk. I could, I could probably be in Glasgow like three times a week between two

dates-n-mates events and going to football'. Matthew similarly appreciated being able to go places with the group: 'It's nice 'cause see, we do, met up in person, go to things like bowling, we go out, go out with dates-n-mates to get coffee and cake' (Matthew). It was evident that the participants valued the opportunities dates-n-mates provided for them to get out of the house and go different places. Having these opportunities is important because it could give members a sense of independence that they may not have experienced outside of dates-n-mates.

By going out to community-based venues, dates-n-mates not only allowed members to get out of the house and experience independence, but it also provided members with opportunities to be visible and claim space in public as part of a group, something they may have felt uncomfortable doing without the support of others. This visibility is important. Presence in community spaces can lead to encounters between people with intellectual disabilities and people without disabilities, which can provide an important first-step towards social inclusion (Bigby & Wiesel, 2011). Based on the interviews, however, it appeared that there was relatively little interaction between dates-n-mates members and people outside of the group. Nonetheless, being in public spaces as part of a group made these outings enjoyable and allowed members to feel comfortable and included in their communities. This is important because people with intellectual disabilities often face exclusion or feel unwelcome in public spaces (E. Hall, 2005).

Although dates-n-mates members typically only interacted among themselves during activities, opportunities were provided to interact with non-members at seasonal parties and Club Late. Club Late was a nightclub open to people with and without intellectual disabilities that was held on a regular basis in Glasgow. Whether there was much interaction between members and non-members is not known, but it was clear that dates-n-mates was making intentional decisions to try to encourage members to occupy spaces that would be expected of all adults and to provide opportunities for people with and without intellectual disabilities to socialise. It may not matter whether relationships were actually formed between members and non-members at these events. Members may have just wanted to attend activities and socialise with their friends rather than trying to forge relationships outside the group. Perhaps what mattered most was that their relationships were visible and validated in a public space.

In addition to providing opportunities to take part in activities in different public places, dates-n-mates also provided opportunities for members to actively participate in discussions about which activities and events would be held. This provided members with the ability to contribute to decision-making within the group. Kyle said that one of the things he missed doing with dates-n-mates during the pandemic was meeting in a pub to generate ideas for the upcoming activities:

Or go to a pub lunch and talk to about what we're supposed to do, put ideas for the next events. [...] I'm missing that as well, putting ideas down for the events. [...] Everybody takes turn to put ideas down. And we, the staff will write it down on a piece of paper. And they'll pick which ones to do for each month of events.

By providing members with some control over the activities, dates-n-mates afforded them some autonomy. This is important because people with intellectual disabilities often rely on others for support, and the decisions they make about their lives are not always respected (Dowling et al., 2019). All dates-n-mates members could have a voice when choosing activities, and this gave them a, perhaps rare, opportunity to have their opinions and preferences heard and recognised. It was clear that dates-n-mates not only provided members with opportunities to enjoy themselves, but it also allowed them to be seen and heard as well.

### **7.2.3 Finding connection and a sense of belonging**

According to Michael, the members of dates-n-mates had formed close bonds and had come to feel like family: 'We were talking about it today, eh, we all feel like just a, a big family kind of thing. [...] Eh, that's what it feels like. We just feel like we're just one big family'. In saying that they felt like family, Michael illustrated how comfortable the members had become with one another and how they felt they belonged to the group. It was clear that dates-n-mates had provided a platform through which its members could connect with others and develop a sense of belonging. Having this sense of belonging is important because it is related to feeling valued and respected (Mahar et al., 2013), and it is an important component of social inclusion (Cobigo et al., 2012; S.A. Hall, 2009a).

In addition to creating a space where members could bond as a larger group and develop a sense of belonging, dates-n-mates also provided opportunities for romantic relationships and friendships to develop. Four participants had joined dates-n-mates because they wanted to find a partner. When asked why he first joined dates-n-mates, Michael explained that he no longer wanted to be single: ‘I’ve been single for a long time. [...] I’m just fed up being single’. Michael had not yet developed a romantic relationship through his participation in dates-n-mates, but three of the other participants had. As Kyle said, ‘If you want to get yourself a girlfriend, [...] dates-n-mates will help you with that’. People with intellectual disabilities may not have many opportunities to form close relationships (Lafferty et al., 2013) and often lack support for these relationships (Healy et al., 2009). Dates-n-mates provided a unique space for romantic relationships to develop, and the group even offered activities, such as blind date events, to help members find a partner. Having the opportunity to meet a partner and feel supported to have a relationship was clearly important to most of the participants.

However, as Michael explained, dates-n-mates was about more than just finding a partner:

It’s a good, eh, group. It gets to - it gets you out there meeting, eh, new people. It’s not just there for just if you want to find a date. [...] It’s there for you to make, eh, new friends and, eh, to let you do activities. It is a, it is something to, eh, keep you going and gets you out of the house, doing different activities and getting to meet people.

In fact, four participants said that one of the reasons they had joined dates-n-mates was to make friends. Being a member of the group was viewed as a good way to establish new friendships. For instance, when asked what he would tell a friend about dates-n-mates, Kyle said, ‘I would say, dates-n-mates is fun and a brilliant way to make new friends’. Sarah backed this claim when she said she had made many friends since joining the group.

Dates-n-mates had clearly provided its members with a space to form connections with others and feel a sense of belonging. This is hugely important because it has been found that people with intellectual disabilities often lack opportunities to develop and maintain friendships (Callus, 2017). Having this platform through which romantic relationships and friendships could be forged seemed very important to the participants and their sense of

self. It was evident that dates-n-mates was performing the role it set out to do, helping people to get dates and make mates.

### **7.2.4 Feeling valued and supported**

According to Mark, dates-n-mates provided care and support to its members: ‘They care about a lot of folk. They definitely do.’ The group also valued members’ skills and enabled them to use those skills in meaningful ways. One way they did this was by providing opportunities for members to contribute to the organisation and showcase their talents. For instance, Kyle was interviewed about dates-n-mates and featured in a video about his experiences online, and Matthew received an award from the group for his skilful dancing at parties.

Dates-n-mates also supported its members to take on important roles within the organisation. Both Kyle and Jennifer were part of a programme called the friendly faces. As a friendly face, it was the person’s role to chat with other members and make sure they felt included at events. Making everyone feel welcome was an important aspect of dates-n-mates events, so this role was highly valued. A third participant, Michael, had recently been hired as a dates-n-mates director. This was a paid position that he felt would utilise the skills he had developed through his previous experiences.

It was important to these members to take on roles within the organisation. These roles provided them with opportunities to use their abilities and contribute in meaningful ways. Kyle, for one, explained that he enjoyed being a friendly face because he liked to help others: ‘Because I want to help out. I’m the kind of person that wants to help out people’ (Kyle). Jennifer reiterated this desire to be helpful, saying, ‘It’s good to help’. People with intellectual disabilities are often on the receiving end of support, so having the opportunity to provide help and form reciprocal relationships seemed very important to Kyle and Jennifer. Having opportunities to both give and receive help are of further importance because it has been found that, as with others, reciprocity is key to how people with intellectual disabilities define friendship (Callus, 2017).

By providing opportunities for members to contribute and use their skills, dates-n-mates demonstrated that it takes an asset-based approach (GCPH, 2011; McNeish et al., 2016).



Dates-n-mates truly emphasises peoples' capabilities and what they can do, rather than focusing on what they cannot do.

### 7.2.5 Personal growth

All six participants noticed positive changes in themselves after joining dates-n-mates. These changes were attributed to the accepting and supportive atmosphere created by the group, as well as the fact that activities took place in public spaces and allowed members to have a sense of independence. Mark had initially joined dates-n-mates shortly following the death of a close friend. He said that dates-n-mates had helped provide him with a renewed sense of purpose and direction in his life:

I'm really glad because, 'cause before, before I went there, I looked like I was lost. [...] I was lost. I didn't, I didn't know what was going to happen. I was like... But, one, one year in, and you have the first date with whoever. [...] It basically just falls into place itself.

Dates-n-mates had clearly allowed for Mark to re-establish connections to others and begin to recover from his loss. Mark was also a member of two other groups, but these groups had not provided the same opportunities to form close relationships. Dates-n-mates was unique in its ability to help him forge new friendships and develop a romantic relationship, which he felt were instrumental to his recovery from loss.

Matthew also joined dates-n-mates with a specific aim related to his personal development. In his mid-20s, Matthew was the youngest participant interviewed, and he and his mother said that he had joined the group so he could feel and act more like an adult. Jennifer likewise seemed to appreciate having an opportunity to feel like an autonomous adult. When asked if she had noticed anything different about herself since joining dates-n-mates, she said that she went there herself. It was clear that she valued the independence that dates-n-mates afforded her, and she seemed proud that she was able to attend activities without support from her parents. Dates-n-mates provided both Matthew and Jennifer with opportunities to feel like they were independent adults no different from anyone else. As Matthew's mother said, he was a part of dates-n-mates so he could 'go out and do things and act like other people'. Sandjojo et al. (2019) previously found that most people with

intellectual disabilities would like to be more independent and lead lives like other people their age.

Three participants said that since they had joined dates-n-mates, they had become less shy and anxious around others, gained confidence, and become more sociable. Kyle said that when he first joined dates-n-mates he was shy, but that over time, he had been able to open up. When asked about the differences he thought his mother had seen in him since becoming a dates-n-mates member, he said that she would say, 'You've come out of your shell now, and you're not nervous now to meet new friends; you talk more.' Throughout the interviews, Kyle frequently said that dates-n-mates had helped him to 'come out of his shell' and begin talking to more people.

Like Kyle, Michael was nervous when he first began attending dates-n-mates activities but said that his anxiety went away over time. He said that he noticed he had become more confident since joining, and he explained how he could tell his confidence had increased: 'I feel that I'm able to go to a lot more groups and managing to stand up for myself. [...] And able to talk, eh, talk more.' Sarah noticed similar changes in herself since joining the group: 'It's made me more confident. [...] It's made me, it's like made me go out more [...] and be more sociable with other people'. Dates-n-mates had clearly helped some of its members overcome their shyness and build their confidence, which then allowed them to interact with more people and form relationships. This is in line with research by McCarthy et al. (2020) that found that participation in dating agencies could lead to increased confidence for people with intellectual disabilities. Overall, it was apparent that dates-n-mates provided a supportive space where its members could develop as individuals.

### **7.2.6 It's not all perfect**

The participants largely spoke about the benefits of taking part in dates-n-mates, but there were some things that did not work well. Matthew, for instance, had not made any new friends through dates-n-mates. The people he spoke to while he was at events with the group were people he knew from elsewhere. However, it is difficult to know whether Matthew was not presented with suitable opportunities to form friendships or if he was simply not interested in forming relationships with the other members. As his mother reported, he was primarily interested in dancing and did not always care about interacting

with other people. It is possible that not everyone who joins dates-n-mates is there to form close relationships. Some people, like Matthew, may just like having opportunities to get out of the house, engage in different activities, and have some independence from their parents.

Michael highlighted some areas where he thought dates-n-mates could improve. He was a member of one of the newer dates-n-mates branches and expressed some frustration that they did not have all of the same programmes and events as the larger and more established branches. He said he would like to take part in friendly faces and blind date events but that he had not had the opportunity to do either. The other four participants did not bring up anything they did not like or would like to change about dates-n-mates, so overall, dates-n-mates was viewed very positively by the members interviewed for this study.

### **7.2.7 Conclusion**

Through the participants' accounts of dates-n-mates, it was clear that the group was taking an asset-based approach. Asset-based approaches focus on strengths and capabilities as opposed to deficits (Sigerson & Gruer 2011; Boelman & Russell 2013; McNeish et al 2016). In addition, returning to the statement by Boelman and Russell (2013), 'social inclusion, opportunity, and control are [...] at the heart of asset-based approaches and the benefits they seek to deliver' (p. 26). Dates-n-mates seemed truly committed to trying to provide each of these things to its members. For one, the group provided members with opportunities to demonstrate their skills and take on roles within the organisation. Three participants had active roles within dates-n-mates that allowed them to use their knowledge and abilities, and a fourth had received an award for demonstrating his ability to dance. Dates-n-mates also gave members the opportunity to exercise some control over group decisions. Members were asked to help select the activities and events that would be held.

Finally, dates-n-mates promoted the social inclusion of its members. They did this by providing members with a space to form meaningful relationships and by offering opportunities to take part in activities in public venues in a way that felt safe and welcoming. By taking an asset-based approach, dates-n-mates allowed its members to feel like capable, valued, and accepted members of society. However, while dates-n-mates embodied the values of asset-based approaches by providing opportunity and control and

promoting social inclusion, the group may have fallen short of allowing its members to achieve full social inclusion.

It was clear that although dates-n-mates provided members with opportunities to participate in community-based activities, this participation was largely contained within the group. Through the interviews, there was no evidence that interaction was occurring between the group members with intellectual disabilities and people without disabilities while members were taking part in activities. Although, it is possible that there were brief encounters between members and non-members. However, while convivial encounters between people with and without intellectual disabilities can help pave the way to social inclusion (Bigby & Wiesel, 2011), these encounters do not constitute inclusion in themselves. Social inclusion requires reciprocal exchanges and a sense of belonging as well (Cobigo et al., 2012). By holding community-based activities, dates-n-mates likely helped its members to feel more comfortable taking up space in public; however, these activities likely did not lead to members experiencing full social inclusion within their communities.

It is important to point out that dates-n-mates members may not have necessarily wanted to interact with others beyond the group. It was clear that most of the participants felt that they belonged at dates-n-mates, so they may not have been concerned about their broader social inclusion while they were with the group. Overall, being a member of dates-n-mates was viewed as a very positive experience. The group provided its members with many opportunities that they had struggled to obtain elsewhere, and importantly, allowed them to feel a sense of belonging.

### **7.3 Dates-n-mates' response to the pandemic: Results from social media data**

While dates-n-mates was clearly able to help its members feel included prior to the Covid-19 pandemic, its operations had to change significantly at the onset of the pandemic. To explore how dates-n-mates was impacted by and adapted to the pandemic, data were collected from dates-n-mates' website and Twitter, Facebook, and Mailchimp accounts from March 2020 to June 2021. As mentioned previously, after collecting the data, it was found that there was significant overlap between the accounts; therefore, only the data from the Twitter account were analysed. The Twitter account was selected because it appeared to capture all of the relevant information; however, a Facebook account would have also been suitable. The Mailchimp account and website were not selected for analysis because they contained less information, and all of the information they did contain was also provided by the Twitter and Facebook accounts.

All posts were categorised based on the type of information they contained. An overview of the posts is provided in Table 7.1. There were a total of 315 unique tweets during this 16 month timeframe. Several of the posts encompassed two categories. This occurred when tweets contained multiple parts or when the activities they were advertising fell within two categories, such as online workshops about human rights. The most common type of tweet was about online chats, activities, and events. Many of these tweets contained a flyer listing information about several upcoming activities or events. News regarding dates-n-mates was the second most frequent type of tweet, followed by information about Covid-19 and the resulting government restrictions. Based on the type of tweets made by dates-n-mates during the pandemic, it was clear that the group was using Twitter primarily to communicate information to members rather than for discussion. The tweets did not actively encourage interaction or conversations. It is possible that more interaction may have occurred through the Facebook accounts.

**Table 7.1:** Type of information contained in Twitter posts by dates-n-mates March 2020 to June 2021

Type of post	Frequency
Online chats, activities, and events	106
Dates-n-mates news	48
Covid-19 pandemic information	31
Learning Disability Week	30
Health, wellness, and human rights information and activities	29
Member, family, and director feedback/interviews	17
Return of in-person activities	16
Activity suggestions	11
Celebrating member achievement/involvement	7
Keeping safe and protecting personal information	7
Reminiscing to time before pandemic	6
Information about staying connected to dates-n-mates and accessing the group and virtual events	5
Staying positive	3
Members' at home activities	2
Staying in touch with others during the pandemic	1
Other	12

In addition to this initial categorisation, the posts were also coded according to the categorisation matrix detailed in Chapter 5. This matrix consisted of categories based on the research questions, the definition of social inclusion by Cobigo et al. (2012), and the definition of belonging by Antonsich (2010). It was found that one of the largest impacts the Covid-19 pandemic had on dates-n-mates was that it forced the group to cancel in person activities and key events, such as dates-n-mates' anniversary celebrations and Christmas parties. Dates-n-mates adapted to these cancellations by moving activities and celebrations online using Zoom. A total of 129 online activities and events were held by dates-n-mates between March 2020 and June 2021.

Virtual parties often encouraged members to dress up and come along for evenings filled with music, dancing, and games. Other online activities included things such as karaoke, quizzes, cooking classes, and scavenger hunts. Members were in their own homes, but they were able to see each other and engage in activities together. In addition to activities and events, dates-n-mates held regular afternoon chats for members. These were 40 minute sessions that allowed members to engage in unstructured conversations with each other as

a group. At the beginning of lockdown, these chats were held daily, but their frequency decreased to twice per week by the end of summer 2020. It is possible that interest in the chats began to wane as government restrictions eased and members were able to see more people in person or that members became tired of interacting over Zoom.

Through the posts, it was clear that dates-n-mates offered its members a range of support during the pandemic. They did this by providing resources, such as easy read information about Covid-19 and the government guidelines, ideas for activities to do at home, tips for managing stress and anxiety, and opportunities to socialise with other members. Dates-n-mates also offered workshops to help people learn how to use Zoom and navigate the internet safely, so members could go online with confidence and interact with their friends and family remotely. It was apparent that dates-n-mates was concerned about the health and wellbeing of its members during this time and wanted to make sure members had the resources they needed to stay connected with others and keep healthy during lockdown.

Most of the social inclusion and belonging categories of the categorisation matrix had very few data coded to them. No posts addressed gaining access to goods or services during the pandemic, and only three related to Antonsich's (2010) concept of place-belongingness. However, there were multiple posts containing information from the directors, who have intellectual disabilities themselves, which showed that members were taking on valued social roles during the pandemic. In addition, at times, members also led online workshops or events, which demonstrated that dates-n-mates recognised the competence and abilities of members during this time. It was also clear that members were provided with many opportunities to feel as if they were a part of a social network. As detailed above, dates-n-mates hosted chats, activities, and events to its members so they would have opportunities to socialise and maintain their friendships.

Overall, the social media data showed the wide range of activities and types of support that dates-n-mates provided to members during the Covid-19 pandemic. It helps provide an overview of what dates-n-mates was doing as an organisation during this time. This data was also used to help create the timeline of events presented in Chapter 6 and provides further context for the embedded cases in Chapter 8.

## 7.4 Conclusion

This chapter is the first of two results chapters. The results presented in this chapter included the themes identified from participants' experiences of dates-n-mates prior to the pandemic and the descriptive data outlining the ways in which dates-n-mates attempted to adapt to the pandemic. In the next chapter, themes will be presented that depict participants' experiences during the Covid-19 pandemic.



## **Chapter 8: Results from the embedded cases: participants' experiences during the pandemic**

### **8.1 Introduction**

This chapter presents the results from individual interviews. Themes are presented that depict participants' experiences during the pandemic. In reading the following six case studies, it will become apparent that there are many similarities and overlaps between the themes identified for each of the participants. This points to the universality of many of the challenges faced by everyone in Scotland during the Covid-19 pandemic. All of the participants faced the same government restrictions and the continuous reminders that the world was under threat of a deadly disease. Even though there was overlap between the cases, each person's case highlighted some of the unique challenges people faced during the pandemic and the resources they drew on to meet these challenges. These differences make each of the six cases worthy of in-depth discussion. It is also important to point out that many of the challenges faced by the participants existed in some form prior to the pandemic. In many instances, the pandemic simply highlighted or exacerbated pre-existing issues. These will be discussed in more detail below. Pseudonyms were used throughout the case reports.

### **8.2 Participant 1: Jennifer**

#### **8.2.1 Introduction**

Jennifer was quiet and reserved and very short with her responses. During the initial interview, she seemed a bit apprehensive about the interview and wanted her mother to stay nearby to help her answer the questions. At times, her mother seemed to be answering the questions for her because Jennifer would simply repeat what her mother had said without ever disagreeing or offering additional information. However, she did take part in the second interview without help while her mother stayed in a room nearby. At the time of the interviews, Jennifer was in her mid-30s and lived with her parents outside of Glasgow. Prior to the pandemic, she lived in her own flat a short drive from her parents, and she missed the independence that living on her own had afforded her. She had been a member of the Glasgow branch of dates-n-mates for several years and was not a member of any

other groups. She did have a part-time job in a kitchen, but at the time of the interviews, her workplace was closed due to the pandemic. To keep busy during the pandemic, she would go for walks, bake, and take part in the online chats and activities held by dates-n-mates. She was also in regular contact with her partner, whom she met through dates-n-mates.

Jennifer was interviewed twice over Zoom on the 5<sup>th</sup> of June and 19<sup>th</sup> of June 2020. The intent was for there to be a total of seven interviews with each participant; however, Jennifer chose not to take part in any interviews beyond the first follow-up because she was struggling with her mental health and did not feel capable of continuing in the study. She had become upset during the second interview, and it was clear that the effects of the pandemic and lockdown were causing her distress. During the analysis, two main categories were identified to best represent the data. The first category, 'I need my independence', consisted of two subcategories: 'It's hard to move back home' and 'Yearning for independence'. The second category was 'My laptop helps me get by', which contained the subcategories: 'Coping with change' and 'Missing people and maintaining relationships'.

## **8.2.2 Categories**

### **8.2.2.1 I need my independence**

#### *It's hard to move back home*

When it was announced that Scotland would be entering a lockdown, it was decided that Jennifer should move from her own flat back into her parents' home. This would allow her to receive ongoing support during this time. However, she struggled with the loss of independence and autonomy she experienced as a result of this move. When Jennifer's mother left the room just before the start of the initial interview, Jennifer disclosed that she was finding it difficult living with her parents and that she wanted to return to her own flat. By waiting for her mother to leave the room, it was clear that at the time of this interview

she did not feel she could say this to her parents. She seemed to think her parents would not approve of or support her desire to live on her own during the pandemic.

However, despite wanting to be in her own space, Jennifer seemed ambivalent about whether a return to her own flat would be the better option. While she wanted her independence, she also felt frightened and upset at the prospect of being on her own without regular interaction and support from her parents. For one, she said she was afraid she would not be allowed to hug her parents if she were to move back to her flat. At that time in Scotland, separate households were not permitted to mix indoors, and people from different households were instructed to maintain a distance of at least two metres from each other. This meant that if Jennifer lived in her own flat, she would not be allowed to visit her parents in their home or go within two metres of them, which seemed to be of concern to her. Her mother added that she did not think Jennifer would be able to cope with living on her own during this time. Jennifer repeated this; however, it was difficult to tell if she really felt this way or if she was simply agreeing with her mother to avoid conflict.

During the follow-up interview, Jennifer spoke much more freely because her mother was not in the room with her. At the beginning of the interview, she announced that she was returning to her own flat later that day. It was clear that by the time of this interview, Jennifer had been able to discuss her desire to live in her own flat with her parents. She initially seemed very happy about this and indicated that she was feeling fed-up with staying at her parents' house. However, she also said she was worried about feeling lonely. She became visibly distressed when speaking about loneliness. At this point, it was agreed that the interview should be terminated, and her mother came into the room. Jennifer was being forced to choose between having her independence and being able to interact with other people, and this was clearly a difficult decision to make. She wanted her own space, but she was afraid of feeling lonely and potentially struggling to cope on her own.

### *Yearning for independence*

To Jennifer, having independence meant not only living in her own flat but also going out on her own. Prior to the pandemic, she would go out places without the help of her parents, such as dates-n-mates events and work. There was the sense that she had only recently begun to feel she was independent from her parents, and it was clear that being able to do

things on her own was vital to her sense of self. At the time of the interviews, her workplace as well as non-essential shops and hospitality and entertainment venues remained closed, so there were few places she could go outside her parents' home. When asked how it felt to be able to go out and do things on her own, she replied: 'Good, great, uh huh. But not just now, I don't think. [...] So, I just go to the shops and that. And I just go there then come back, so, yeah. So, that's that.' Jennifer's independence had largely been taken away from her during the pandemic, and it was clear she felt as if she were taking a step backward. It was difficult for her to have to rely on her parents and be confined to their home after enjoying the freedom to look after herself and go places on her own.

### **8.2.2.2 My laptop helps me get by**

#### *Coping with change*

During the pandemic, Jennifer also had to adjust to the changes resulting from the government guidelines. She was aware of the guidelines but felt they were not always easy or pleasant to follow. For instance, she wondered how social distancing would be possible at work: 'I think it's going to be hard when I go back because of the distancing. [...] How can you distance in the kitchen?' She also found it difficult to wear a facemask: 'So, I tried the mask, and nope. I took it back. I gave it them back'. She did not appear to be afraid of catching Covid-19 herself, which probably led to her being less willing to adopt some of the safety measures.

One way she attempted to cope with the changes imposed by the pandemic was by purchasing her own laptop. She made a point of saying that she had paid for the laptop using her own money. It was clearly important to her that she had been able to provide for herself. Having a laptop was important because it allowed her to watch Netflix on her own and take part in online activities with dates-n-mates, which afforded her some freedom from her parents and allowed her to socialise with friends. She said that being a member of dates-n-mates during the pandemic was helpful, and she enjoyed attending the online chats and activities. When asked how dates-n-mates were helpful, she replied: 'Just, you know, the Zoom things, you know. It's really good, you know. You can chat to people. [...] So,

it's really good'. Dates-n-mates clearly provided Jennifer with a meaningful way to spend her time and connect with others during the pandemic.

### *Missing people and maintaining relationships*

The government guidelines around social interaction meant that Jennifer was unable to see some of the important people in her life. At the time of the interviews, she had not been able to see her support worker or brother at all during the pandemic. However, she mentioned that she could connect with people using her laptop. In being able to access the internet, Jennifer had been able to keep in regular contact with people from dates-n-mates and her support worker, local area coordination team, and partner during the pandemic. Jennifer said she spoke to her partner regularly over Facebook. During the initial interview, she also reported that she had recently been able to attend her partner's birthday celebration that was held in his garden. She said that this was the first time she had been able to see him in person since the beginning of lockdown. She spoke frequently about her partner, and it was clear that her relationship was very important to her. She had met her partner through dates-n-mates, and the staff and other members were very supportive of the relationship.

### **8.2.3 Interpretative summary**

The tension Jennifer experienced between wanting her independence and wanting to avoid loneliness during the pandemic came across strongly during the two interviews. When the lockdown was announced, people were often forced to make difficult decisions about where they would live for the coming weeks or months. Because households were not permitted to mix, this decision would largely determine who people could interact with and had the potential to leave people isolated and unsupported should they continue living on their own. In Jennifer's case, it was decided, perhaps primarily by her parents, that she would be unable to cope with life on her own during this time. Despite Jennifer placing great value on her independence, it was ultimately determined that her need for support from others outweighed the negative impact that her loss of independence would have.

Jennifer's situation is not unique; many families faced similar circumstances during the pandemic and had to make equally difficult decisions that often had huge impacts on their lives. For instance, many mothers decided to have their adult children move from

residential settings back into the family home during this time (Vereijken et al., 2022). Through the contradictory feelings Jennifer had about living with her parents, it was clear that there did not exist a correct decision or perfect solution. In March 2020, when lockdown went into effect, it was not known how long it would last or what the trajectory of the pandemic would be. People were having to make the best decisions they could during a time of great uncertainty.

It was also clear that, while Jennifer enjoyed her independence, she often felt she needed the support of her parents. During the initial interview, she wanted to have her mother sitting beside her. When a question was asked, Jennifer typically looked to her mother, and her mother often answered the question first before Jennifer repeated what she said. Jennifer seemed to lack the confidence in her ability to respond in an acceptable way. She seemed to feel there was a right way to answer the questions and felt that she would get it wrong if she did not have help. This created a situation whereby it was difficult to know if she was providing her true thoughts and feelings or simply restating her mother's interpretation of events. This became of particular concern when her mother left the room, and she began to quickly and quietly divulge information she had not shared while her mother was present. It was clear that there were certain things she did not feel comfortable speaking to her mother about at that time, which meant that she may not have been providing an accurate portrayal of her life during the interview while her mother was present.

During the second interview, Jennifer's mother was in another room of the house, and Jennifer answered the questions without assistance. She was much more open about her thoughts and feelings during this interview. However, she continued to seem to lack confidence in her ability to answer the questions unaided and at one point wanted to ask for her mother's help. Once she was reassured that she was answering the question appropriately, she felt able to continue on her own. There clearly existed a tension between Jennifer wanting to have the space to do the interview on her own and tell her own story and feeling that she could not do the interview correctly or provide the information that was being asked of her.

One way Jennifer enacted her independence from her parents was through the maintenance of her relationship with her partner. This is significant because people with intellectual disabilities often have limited opportunities to form romantic relationships (Lafferty et al.,

2013). Through this relationship, she was able to give and receive support with someone outside of her family and take control over an aspect of her life. As Lafferty et al. (2013) note, close relationships can allow people with intellectual disabilities to ‘escape the confines of stringent rules and controlled environments that accentuate the vulnerability of having a learning disability and which reduce their autonomy in decision-making’ (p. 1085).

However, it is important to point out that maintaining this relationship did require support from family. Jennifer’s mother, for instance, drove her to see her partner in his garden after multiple households were permitted to mix outdoors. Jennifer’s need for this assistance is perhaps unsurprising; it has previously been found that caregivers often play a key role in helping people with intellectual disabilities form and maintain their relationships (Fulford et al., 2018). In providing help, Jennifer’s mother was demonstrating that she was supportive of the relationship. This is important because many people with intellectual disabilities do not feel they have their families’ support for their relationships (Healy et al., 2009). It seemed hugely important to Jennifer that she had been able to establish a lasting relationship that was recognised and encouraged by her family.

## **8.3 Participant 2: Mark**

### **8.3.1 Introduction**

Mark was very forthcoming and seemed eager to talk. He was in his late-20s and lived at home with his mother and brother outside of Glasgow. He informed me that he had a visual impairment and used a wheelchair and that he was exempt from wearing a face covering. He also told me he relied on a personal assistant to take him places and had carers to help him with personal care. At the time of the first interview, he had been a member of the Glasgow branch of dates-n-mates for just over a year. In addition to dates-n-mates, he attended one other social group and a drama group. He was also an avid football fan and enjoyed watching wrestling. He said that when he first heard about lockdown he was ‘absolutely gobsmacked’ and that he didn’t know what normal was anymore.

Mark was interviewed over the telephone on seven separate occasions between the 9<sup>th</sup> of June 2020 and the 31<sup>st</sup> of August 2020. Three primary categories were developed through

the analysis of the transcripts. The first category, 'It's tough, but I'm managing' described his experience of being in lockdown and consisted of three subcategories: 'Experiencing loss and difficult emotions', 'Feeling confined', and 'Keeping going'. The next category, 'Getting out when nothing seems normal', described his experience of coming out of lockdown and becoming more active in the community and was comprised of the subcategories: 'Dealing with uncertainty', 'Longing for connection', and 'Regaining independence'. The final category, 'Getting help and giving back' contained two subcategories: 'Having a sense of value to others' and 'Thinking about others'.

### **8.3.2 Categories**

#### **8.3.2.1 It's tough, but I'm managing**

##### *Feeling confined*

During the national lockdown, Mark found himself in particularly challenging circumstances and contended with feelings of fear, anger, and disappointment as well as an intense longing to reconnect with his partner in person. Just prior to Scotland entering lockdown, his personal assistant left their post, meaning he did not have someone to take him out of the house when the government guidelines began to allow for it. At the time of the initial interview, people living in Scotland were permitted to participate in outdoor leisure activities and could meet with another household outdoors, but Mark had not been able to enjoy these new freedoms. He expressed that being confined to his home was extremely difficult, saying during the initial interview, 'It's like a torture chamber. You're basically trapped in a cage. [...] In, in your own house.' During the second follow-up interview, which took place at the beginning of July 2020, he said he had begun to look for a new personal assistant. At that time, he reported that he had been out of his home for the first time in 16 weeks in order to meet with a potential personal assistant at a supermarket carpark. He said that it had been so long since he had left his house that he had forgotten what it was like to wear shoes or a jacket.

##### *Experiencing loss and difficult emotions*

In addition to confining Mark to his house, the pandemic also seemed to bring up a lot of difficult emotions for him. In particular, he had a fear of losing people close to him, which



appeared to be connected to the previous death of his friend. He described these feelings during the initial interview: ‘I think with the amount of people that were dying at the start, I was like, oh no. [...] [Friend], here we go again.’ During the first follow-up interview two weeks later, he expressed worry that someone close to him may contract Covid-19. He said that if someone important to him died from the virus, it would ‘open a bigger wound’ than that already left by the death of his friend. He said he largely stayed away from the news and relied on his mother to inform him about what was happening with regard to the pandemic. He also became frustrated when people talked to him about the pandemic and the trajectory it could take. This avoidance of the news appeared to be his way of attempting to cope with the fears he had related to losing someone and the prospect of a prolonged lockdown that could keep him confined at home.

### *Keeping going*

Despite the difficulties he faced during the pandemic, Mark frequently said that he was ‘managing’. On the surface, he appeared to be saying this for my sake, and at one point, he even told me not to worry; however, I got the impression that he kept saying he was coping in order to reassure himself. This seemed particularly evident in the moments when he contradicted himself. For instance, in both the second and third follow-up interviews he said that he was ‘really at the end of [his] tether’, but he also said that he was ‘fine’. This contradiction showed his willingness to continue to try to cope with and adapt to the pandemic despite the difficult circumstances he faced. One way he coped with lockdown was by taking part in online social activities from home. During the initial interview, he said that having Zoom during lockdown had been helpful and that he had once ‘booked three Zooms in one day’. In continuing to seek out activities and build structure in his life, Mark showed resilience in the face of his challenging situation.

### **8.3.2.2 Getting out when nothing seems normal**

#### *Dealing with uncertainty*

Across the seven interviews, it became apparent that Mark faced a lot of change and uncertainty during the pandemic. When asked how he felt when he first found out about lockdown, he said, ‘It was like, “whoa” what is, what is normal anymore?’ Some of this uncertainty was initially created by the cancellations that occurred due to the lockdown. At

the time of the initial interview, he said the hardest part about lockdown was ‘just basically having to reschedule everything’. In addition, there was always the looming possibility that the restrictions that had been lifted could be re-imposed. During the third follow-up at the end of July, Mark expressed his fear that there would be a move from phase 3 of the roadmap out of lockdown back to the preceding phases. Scotland did go on to impose new restrictions, but this took place after all seven of our interviews had been completed.

As time went on, it became clear that one of the largest contributors to the uncertainty Mark experienced was the difficulty he was having hiring a new personal assistant. Finding a new personal assistant was important because it would allow him to get out of the house and regain a sense of independence and autonomy. Over a period of several weeks, beginning just before the second follow-up interview in early July 2020, he hired three different personal assistants, none of whom worked out. This caused him a considerable amount of frustration, and at times, he vented his anger during the interviews. At the time of the fourth follow-up he said he was ‘absolutely having no luck at all’ when it came to hiring a new personal assistant and that he was ‘getting emotionally drained with it all’.

It was not until the day of the fifth follow-up in the middle of August that Mark finally had a personal assistant in place. Just two weeks later, during the sixth follow-up interview, he reported that he had already been out with his new personal assistant on seven or eight occasions and that he had even taken a break from his online activities ‘just to enjoy having [his personal assistant] a bit’. He seemed very pleased that he had been able to get out and participate in everyday activities again, and it was clear that he valued these in-person activities over online activities.

Not only did having a personal assistant mean that he could get out of his home more regularly, but it also meant that Mark was able to see his partner more often. At the time of the sixth follow-up, he said that his personal assistant had taken him to see his partner three times since she had been hired and that they had another visit planned for that week. Throughout our interviews, it was evident that getting to see his partner and reconnect with her in person was of utmost importance to him. However, it was also apparent that the social distancing guidelines, which required that people from different households

maintain a two-metre distance from each other, were difficult for him to observe, particularly when he was with his partner.

### *Longing for connection*

Throughout the pandemic, Mark seemed to be longing for connection but felt the social distancing guidelines were making this connection challenging, and it was not known when these guidelines would change. While he was able to see his partner and reconnect with her in person more regularly as the pandemic went on, there still existed some uncertainty surrounding when it would be safe or acceptable to get close or have physical contact. Having this intimacy with his partner was clearly very important to him, and it was evident that he was finding it challenging to have to wait to be told by others when he would be allowed to hug or kiss his partner again. During the first three interviews he remained adamant that everyone should follow the government guidelines; however, during the third follow-up, he said that ‘at some point somebody’s going to have to gamble’, and he admitted that he had given his partner a hug when her mother left the room.

Mark explained his attitude with regard to bending the social distancing guidelines: ‘I mean, I, I see people out hugging people all the time, and I’m like, they shouldn’t really be doing it. So, I’m like, no, if they’re doing, I’m doing it’. It seemed very difficult for him to watch other people make their own decisions to resume physical contact with their partners, while he had not been permitted to make that decision for himself. He ultimately did decide to resume an intimate relationship with his partner; however, this had to be done when his partner’s mother or his personal assistant were turned away.

### *Regaining independence*

Across the interviews, Mark continued to express a sense of uncertainty surrounding the scheduling of his regular activities, even after he had hired a new personal assistant. During our final interview he simply stated that ‘you can’t plan for anything’. He seemed frustrated that he was unable to schedule activities and have a guarantee that they would go ahead. This frustration was particularly pronounced when he spoke about trying to attend football matches. He said that he did not know whether to buy tickets because concrete decisions had not been made about whether the matches could go ahead. He also expressed

a sense of frustration that dates-n-mates had yet to plan any in-person meetings since he hired his personal assistant. At our final interview he said, ‘the only box that needs to be ticked [...] is the dates-n-mates box [...] After that box, I’ll be fine’. However, at that point it was unclear when dates-n-mates would begin to hold regular in-person activities. Because it could be challenging to schedule activities, he said it could be difficult to find things to do with his personal assistant. Consequently, having a personal assistant did not in itself provide a sense of certainty or normality. Even though Mark was slowly finding connection with others and regaining a sense of independence, he was still very clearly living in uncertain times.

### **8.3.2.3 Getting help and giving back**

#### *Thinking about others*

Throughout our interviews, Mark described his roles as a son, an active member of dates-n-mates, and a supportive partner. During the first few months of lockdown, he did not have a personal assistant or carers in place, and he relied on his mother to help him with his personal care and daily tasks, get him out of the house, and keep him informed about the pandemic and government guidelines. Having this help from his mother was crucial to get him through his days, and during the first follow-up interview, he said that because of this support he was ‘managing fine’. He seemed to consider the impact that caring for a son during that pandemic must have had on his mother. For instance, while it may have been a necessary discussion, he said that it must have been challenging for her to inform him that he could no longer hug his partner. He was also very conscious that his mother had provided support for him while he was trying to get a new personal assistant and carers in place. Therefore, his mother clearly played a key role in his life during the pandemic. Without his mother’s support, it would have been much more difficult for Mark to cope, something which he clearly recognised.

#### *Having a sense of value to others*

In addition to his mother, Mark also received support from dates-n-mates during lockdown. He regularly took part in the online activities and events held by dates-n-mates and seemed to rely on them to give him meaningful activities to do. While he never mentioned having close relationships with the other members, aside from his partner, he did seem to enjoy

taking part in the activities and wanted to return to in-person meetings with the group. He also mentioned having trusting relationships with some of the staff members. Importantly, at the second follow-up interview, he reported that he was hosting an online singalong event for dates-n-mates. He said that for the event, he was going to select the songs, and be the 'lead singer' while the other members followed his lead. It seemed important to him to be trusted to take on this active role in the group. In assuming the role of host, his ability to provide support to dates-n-mates was recognised and appreciated.

While Mark mentioned receiving support in relation to both his mother and dates-n-mates, it was the supportive relationship he had with his partner that he spoke about the most. He and his partner were regularly in touch with each other during lockdown, and he said they sometimes spoke 'maybe ten times a day'. He made it clear throughout the three months in which the interviews took place that his partner was experiencing a difficult time and that he was trying to provide her with support. He told me during the first follow-up that he had been helping her, and during the fifth follow-up, he said he had called her that day 'just to cheer her up'. However, he did say that it could be difficult to provide this support during the pandemic: 'It's, it's hard to sit and listen to her cry [...] and not physically be able to do something about it.' This also points to how difficult the social distancing measures were for him. Not only did he provide support in this relationship, but he also received support. At one point he stated, 'Honestly I don't, I don't know what I would do if she wasn't here'. It was clear that this was truly a reciprocal relationship in which Mark both gave and received comfort and support.

### **8.3.3 Interpretative summary**

One of the greatest challenges Mark faced during the pandemic was the withdrawal of the support he had received from carers and personal assistants prior to the pandemic.

Interruptions to care were experienced by many people with disabilities during this time (E. Hall, 2021; Jesus et al., 2021). Throughout the first few months of the pandemic, Mark relied solely on his mother for assistance, and this included help with his personal care. It was undoubtedly difficult for Mark, a man in his late-20s, to have to return to having his mother help him with daily tasks such as showering and dressing. There were no other options available to him, and he was grateful for his mother's help. However, this likely impacted on his sense of independence and dignity because he was a very capable man who had no choice but to rely on his mother to shower and dress him. He expressed a

sense of relief when carers were finally permitted to return to his home. This afforded him more of the independence and privacy he had enjoyed prior to the pandemic.

Likewise, before hiring a new personal assistant, Mark had to rely on his mother if he wanted to go anywhere outside of his home. When he had a personal assistant, it was up to him where he went and how he used his time, which gave him some autonomy. Many people likely faced similar circumstances during the pandemic. Restrictions regarding social interaction and the mixing of households meant that a lot of people were likely relying on family for care or were without vital support altogether (Hall, 2021; Jesus et al., 2021). Mark's situation illustrates what those experiences may have been like.

When Mark visited his partner, he was always with either his personal assistant or his or his partner's family members. This meant that someone was essentially always watching over him and what he was doing. He had witnessed through social media that some people had been hugging and kissing their partners during the pandemic despite the restrictions. It angered him that people were not 'following the rules', and he could go on at length about this during the interviews. However, underneath this anger was a sense of injustice. He was upset that other people had the opportunity to break the rules, but he did not, and he desperately wanted to physically touch his partner.

Ultimately, Mark was able to hug and kiss his partner, but this occurred while her mother and his personal assistant were distracted. His inability to make these types of decisions for himself and to take risks had a clear impact on his sense of autonomy. In line with Mark's experience, it has previously been found that while caregivers can help support intimate relationships, they can also limit the interactions between partners (Fulford et al., 2018). In addition, personal assistants have been found to reject or correct the decisions made by people with intellectual disabilities (Dowling et al., 2019). Mark may have felt that his decision to break the rules would not have been supported by his personal assistant. While having a personal assistant allowed for Mark to have some control over his life it also prevented him from ever having full independence and autonomy. Carers, along with their perceptions, knowledge, and methods of providing assistance, shape the autonomy of the people they care for (Björnsdóttir et al., 2015).

Despite the difficulties he was confronted with during the pandemic, Mark did appear to remain hopeful. He frequently told himself that he was managing the situation in order to

remind himself that he could meet the challenges he faced. He clearly demonstrated resilience throughout the interviews.

## **8.4 Participant 3: Kyle**

### **8.4.1 Introduction**

Kyle was talkative and upbeat during the interviews. He was in his mid-30s and lived in a flat in Glasgow on his own but had both immediate and extended family members living nearby. At the time of the interviews, he was not involved in any groups aside from dates-n-mates. He did, however, have a part-time job that he had recently been able to return to after a hiatus caused by the national lockdown. He worked two days a week and reported that he enjoyed going to work and socialising with his co-workers. When he was not at work or taking part in dates-n-mates activities online, he spent time visiting with family, watching films, and cleaning his flat. He also enjoyed taking trips to his family's caravan but was disappointed that the activities at the caravan park were suspended due to the pandemic. He said that when he first heard about Covid-19 he was afraid and stayed at home. Throughout the pandemic, he said that he followed the government guidelines without complaint but that he was looking forward to a return to normality.

Kyle was interviewed seven times between the 10<sup>th</sup> of June and the 4<sup>th</sup> of September 2020. The first three interviews took place over the telephone, after which we switched to Zoom. Three primary categories and seven subcategories relating to Kyle's experience of the pandemic were identified during the analysis. The first primary category, 'Longing for connection with others', was about his desire for social contact and had three subcategories: 'Having valuable relationships and roles', 'Maintaining relationships during the pandemic', and 'Being alone and missing others'. The second primary category, 'Struggling to keep occupied', dealt with boredom and contained two subcategories, 'Lacking activity' and 'Keeping busy'. The final primary category, 'Being cautious but yearning for normality', was about life as the restrictions lifted and encompassed two subcategories, 'Getting out while keeping safe' and 'Looking forward to normality'.

## 8.4.2 Categories

### 8.4.2.1 Longing for connection with others

#### *Having valuable relationships and roles*

Throughout the interviews, what Kyle most frequently spoke about were his relationships and the people he interacted with in his life. He always became very animated when he talked about people, and it was clear that having relationships and social contact with others were hugely important to him and played a large role in his life. It was evident that he was extremely sociable and got a lot of satisfaction out of being a family member, a co-worker, a partner, and a friend. Kyle's workplace had been shut during the first 11 weeks of the pandemic, but he had been able to return to work two days before the initial interview. He was glad to return to work because his workplace played an important social role in his life, and he valued his relationships with his co-workers:

I'm happy. I was excited to see them back. [...] I was bored last week without them, but I'm happy to see them back. [...] And I was talking to them, and we carry on at work, wind each other up.

He said that he had friends at work, and his return to work provided him with a place to regularly socialise and connect with others face-to-face.

It was clear by the importance he placed on the social aspect of work that even prior to the pandemic, work provided him with one of the few opportunities he had in his life to have meaningful interactions with others: 'I'm just happy I get to speak to my friends, and I'm happy I'm back to work. I'm too happy, on Monday and Tuesday, I'm happy'. However, he did not interact with any of his co-workers outside of the workplace. While he was clearly having friendly and enjoyable exchanges with work colleagues, it is difficult to say that he was actually forming deep or lasting friendships. The emphasis he placed on the importance of these relationships gave the impression that he did not have enough friendships in his life to satisfy him.

When Kyle attended work, he also had his only opportunity to see his partner. His partner worked in the same place and on the same shift. He had been looking forward to seeing her



outside of work and wanted to be able introduce her to his family, take her on a date, and take her to visit his family's caravan. However, his partner had been unable to meet with him outside of work during the pandemic. This was due to a few different reasons. Kyle said that his partner had to ask for her family's permission to go to his family's caravan, and she also turned down his invitations while she was getting settled into a new home. Kyle also said that his partner did not want to go on a date during the pandemic: 'She's like the kind of person wants to wait for things to get back to normal first. [...] Wait for the right time and take her on a date.' It was difficult to tell whether this was because his partner was afraid to go out during the pandemic, her family did not want her to go out, or she did not actually want to meet up with him outside of work.

During the fourth follow-up, Kyle announced that he had told his partner he loved her, to which she responded with a smile. He seemed pleased with her response, but the sentiment was not reciprocated. It appeared that Kyle placed a lot of value on being a good partner and invested more thought and energy in this relationship than his partner did. This made the relationship come across as unequal, and it seemed as though Kyle's love for his partner may have been unrequited. From how he described their relationship in the interviews, he gave the impression that his partner's parents may not have been fully supportive of the relationship. This was never stated explicitly, and her family may have just been very cautious due to the pandemic, but her parents did not seem to want to facilitate their daughter actually meeting up with Kyle. It is possible that her parents were being protective of her or did not think she should date. This was in contrast to his previous relationship with someone he met through dates-n-mates. In this relationship, both he and his former partner received support from their parents to pursue and maintain the relationship.

Throughout the pandemic, Kyle received support from his immediate and extended family members, and he regularly provided his family with help in turn. It was very important to Kyle to foster some truly reciprocal relationships and to be able to provide help and support to both his friends and family. As he stated, 'I like helping out. [...] I was born that way'. By providing help, he wanted to feel he played a valued role in the lives of others and show that he could give as well as receive support. This included taking on an

established helping role at dates-n-mates.

Kyle performed the role of a ‘friendly face’ at dates-n-mates, whereby he helped other members feel included and return home safely. When he explained why he became a friendly face, it was obvious that he took pride in adopting this role: ‘Because I want to help out. I’m the kind of person that wants to help out people. [...] Help, like, people get taxis, and uh, help—be there for them when they need help’. Dates-n-mates was important in his life partly because it provided him with a platform through which he could take on a valued adult role and provide support to others.

During the pandemic Kyle’s opportunities to provide help were limited. While he said he was able to help his parents by watching his niece, he was unable to fulfil his role as a friendly face and help his friends at dates-n-mates.

### *Maintaining relationships during the pandemic*

Throughout the pandemic, Kyle attempted to maintain connections with his friends and family. One way he did this was by taking part in many of the online activities held by dates-n-mates over Zoom. He also kept in touch with friends online using FaceTime and Facebook Messenger; although, he remarked that he could have issues with his internet connection, making it difficult to communicate at times. He had one friend with whom he met in person multiple times as the restrictions began to lift. He was very happy to be able to invite this friend to his home even though there were limits placed on the length of her stay by the government guidelines at that time: ‘I did see my friend last Saturday. My other friend came down from [neighbourhood], came to my house, stayed for half an hour, like 12 till 2. [...] It’s just one baby step at a time. It’s baby steps.’ Despite wanting to spend time with people, Kyle showed a willingness to try to abide by the rules.

During the time of the interviews, Kyle had only met with this one friend in person. While he said that he had been able to speak to his friends as much as he would have liked to during the pandemic, he seemed to want additional social contact. However, Kyle was able to visit with his family regularly. He had cousins who lived nearby, and he saw a large network of both his immediate and extended family members throughout the pandemic. He enjoyed visiting with family and said he visited them during the pandemic when he was feeling bored: ‘Sometimes I get bored, just being by myself. And when I get bored staying

by myself, then I go around to see my cousin and have fun or go around to see my family’. It was apparent that his contact with family during this time helped him cope with the isolation of lockdown. Based on the frequency with which he spoke about his family, it was clear that his relationships with his family members played a large and positive role in his life. They provided him with his primary means of support and way to socialise with others both before and during the pandemic.

### *Being alone and missing others*

Throughout the pandemic, Kyle often found himself alone and missing social interaction. At times, his family members were busy, so it was not always an option to visit with them, which meant he spent much of his time on his own: ‘It’ll just be me this week. [...] All alone, all alone. [...] All my family’s busy this week, busy’. When his family was not available, Kyle clearly struggled to keep himself from feeling lonely. It was apparent that his interactions with friends tended to be highly planned and infrequent, a problem which was likely exacerbated by the pandemic.

When asked what the most difficult part about lockdown was, Kyle replied, ‘The difficult part is, it’s a bit hard to see my friends just now.’ In particular, he missed seeing his friends and staff members from dates-n-mates in person. Meeting with dates-n-mates over Zoom did not provide him with the same level of satisfaction or social connection: ‘I’m missing all my friends, I want to give them a hug and wind them up face—it’s not the same to do it on Zoom, wind them up, I like to do it face-to-face, wind them up for fun’. While Zoom provided Kyle with a means to stay in touch with friends during the pandemic, it left him feeling unfulfilled socially.

Even though restrictions allowed for people to meet in person during the time of the interviews, Kyle did not meet with any of his friends from dates-n-mates, and it was clear that he had not seen any of them outside of the official dates-n-mates activities and events prior to the pandemic either. While he may have formed valuable friendships within the group, they did not exist outside the group. This led me to question the depth of the

relationships that are formed through dates-n-mates and whether the group can truly lead to lasting friendships.

In addition to his friends from dates-n-mates, Kyle also missed seeing people he knew in community-based venues. He mentioned missing staff at both the hairdresser and his favourite restaurant. While these relationships probably helped provide him with a sense of belonging to his community, the importance of these acquaintances points to the limited opportunities he had to form meaningful friendships prior to the pandemic. When he was unable to see his co-workers or these acquaintances during lockdown, he was left feeling very isolated despite having a supportive family and online activities with dates-n-mates.

#### **8.4.2.2 Struggling to keep occupied**

##### *Lacking activity*

Kyle experienced disappointment over the dates-n-mates events that had to be cancelled as a result of the pandemic. He was also disappointed that the activities he typically took part in at his family's caravan had remained closed throughout the time of the interviews. Despite his disappointment, he did remain hopeful that events and activities would go ahead in the future. For instance, he continued to go on walks to practice for the Kiltwalk, a long walk held to raise money for charity, even though it had been cancelled that year. During the final follow-up, he recognised that activities would resume gradually: 'It takes time, things are slowly opening up now, slowly, slowly, slowly opening up now'. He expressed understanding around the closures and cancellations; however, the lack of activity often left him feeling bored: 'Lockdown can be a bit boring sometimes—all the time. Sometimes, shops keep on shutting down, and there's not things opening up yet'. It was evident that he did not have enough activity to keep him occupied during lockdown.

Online chats and activities with dates-n-mates did help to keep him busy at home, as he pointed out: 'Without dates-n-mates, I'll be bored'. However, even with these online activities, he was limited in what he could do:

I still find it boring still. [...] Can't go out and about and see them, do events, like can't go to snooker night... [...] And games night and...can't go to karaoke night. [...] Real karaoke. Like that. [...] Real events like Club Late.

He made a very clear distinction between activities that were held online and activities that took place in person. He referred to the in-person activities as being ‘real’ activities, which suggested that the online activities were not as fulfilling to take part in.

### *Keeping busy*

Despite the seeming importance of the online activities with dates-n-mates, Kyle admitted that he sometimes failed to attend because he was tired from work or doing other things. Even though online activities clearly played an important role in his life during the pandemic, he did not always prioritise them. In addition to preferring face-to-face activities, he also had problems with the online format of activities during the pandemic. For instance, at the time of the initial interview, he did not feel confident using Zoom, stating, ‘Sometimes I need to get training first on how Zoom works first.’ He participated in the study over the telephone for the first three interviews before receiving help from his mother to learn how to navigate the Zoom software. Having sufficient data on his mobile phone also prevented him from taking part in online activities. Online activities were clearly helpful overall, but they also introduced their own set of problems.

When not involved in online activities with dates-n-mates, Kyle would go for walks around his neighbourhood and a nearby park, watch films, and spend time cleaning his home. He said he enjoyed keeping his home clean, and he seemed to get a sense of satisfaction out of maintaining his home: ‘I like, I like keeping my house tidy. [...] After this, after this call, I’m going to tidy up this house for when my friends come up tomorrow. And keep my house tidy, like that.’ He mentioned cleaning several times across the interviews, and it was clear that cleaning provided him with something meaningful to do. He also clearly took pride in his ability to take care of his own home. At one point, he even said that cleaning was his favourite thing to do to keep himself busy: ‘I like doing my washing as well. I like tidying up like that. [...] Yes, I like it. Keep myself busy. [...] That’s my favourite thing. I like, my favourite thing is tidying up’. While cleaning may not have actually been his favourite activity, it did appear that cleaning provided him with a sense of achievement. By cleaning his home, he was able to prove his competence and show that he was capable of caring for himself.

### 8.4.2.3 Being cautious but yearning for normality

#### *Getting out while keeping safe*

Kyle said that he was initially afraid of Covid-19 and stayed at home at the beginning of the pandemic: ‘I was a bit scared of it at first. [...] And, uh, I just stayed in for a couple weeks. [...] And I followed the rules’. He also expressed some anxiety about catching the virus as he began to go back out. This anxiety did not prevent him from going to public places, however. As the weeks went on, Kyle reported that he had been able to go to a shopping centre, have his hair cut, and eat out at pubs. During the fifth follow-up, he was asked how he felt about returning to pubs, to which he replied:

It was, it was weird at first, and... You need to get used to it now and then. And after it will be, sooner or later, it will be back to normal. [...] Just for wearing a mask just for right now, getting rid of the virus right now. Getting rid of it.

He clearly felt the government guidelines were in place to help protect him and control the spread of Covid-19. He said he did not mind having to wear a mask, and during several of the interviews, he described the protocols he followed while he was in public. He also said he liked to keep up with the news and follow what Nicola Sturgeon, the First Minister of Scotland, said. During the early stages of the pandemic, Nicola Sturgeon gave daily briefings to the country about the state of the pandemic.

It was clear that Kyle took pride in his ability to be knowledgeable about and follow the current guidelines: ‘I always watch the rules. I know how to understand it. Some people don’t understand it that well’. Understanding and following the news and guidelines allowed him to feel like a competent and responsible citizen. In watching the news himself and making his own decisions about the guidelines, he was able to exercise autonomy and demonstrate that he could keep himself and others safe.

However, during the interviews, it also became apparent that he had been visiting his cousins in their home during a time in which the mixing of households was not permitted. At no point did he mention that this was in violation of the restrictions. It is possible that he had not realised this was the case. Alternatively, he may have been aware this was a violation but had not realised that he was contradicting himself during the interviews. He

seemed to have been trying to impress upon me that he followed the rules without realising that he was providing information that indicated otherwise. His willingness to go against the restrictions in this instance also points to how isolated he could feel at times. Overall, he did appear to be very concerned with following the guidelines, so it would seem that he must have been desperate for social contact to go against them.

In addition to trying to follow many of the guidelines, Kyle took extra precautions against catching Covid-19 as he began to go back out in public. During the final follow-up, he said he tried to stay away from crowds in order to protect himself: ‘I always, always look about, not go to the big crowds place. [...] Sit outside where not much crowd is, the entrance, small places. [...] If it’s busy, we will get it’. While Kyle had said during the first follow-up that he was not worried about going back out, it was clear that he did have some anxieties about catching Covid-19, which prompted him to take additional measures to try to keep himself safe. However, while he felt the need to take safety precautions, it was apparent that he was looking forward to a time when such precautions would no longer be needed:

And at least it’s getting closer and closer to being normal, and at some time you won’t need to wear facemasks in the shops, sooner or later. [...] I like wearing a facemask just, just waiting for when you don’t need to wear it in, like, Glasgow or pubs now. [...] Like when they say, ‘that’s you, back to normal, no facemasks’. Just waiting for that word.

Throughout the interviews, Kyle clearly wanted to keep himself safe and wanted to show that he could follow the current guidelines; however, he also wanted a return to how life was before the pandemic.

### *Looking forward to normality*

Kyle clearly longed for a return to normality: ‘I think come to next year, it will be back to normal. [...] I’m praying for near Christmas getting the family together, getting together for Christmas, I hope’. He greatly missed being able to interact with people face-to-face and looked forward to being able to see his friends again:

I just want to go out there and say, ‘Guys, I love you guys, and I miss you’. Go

out there, like that. I can't wait to say that I miss you, and I love you. [...] See their faces. [...] Don't want to say it to them on Zoom. I want to say it to their face.

However, when asked how he felt about the prospect of meeting with dates-n-mates in person he said, 'I'll be a bit nervous meeting people at first'. While he clearly longed for a return to normality, he also suggested that this return would take adjustment and may cause some discomfort.

### **8.4.3 Interpretative summary**

Kyle clearly experienced a lot of loneliness during the pandemic, and it became apparent during the interviews that this was an issue that preceded lockdown. I was hesitant to pry too deeply into his experiences of loneliness and what it meant to him because Jennifer (Participant 1) had previously become upset when I asked these types of questions. However, it was evident that Kyle was a very sociable person and needed a lot of interaction with others to feel fulfilled socially. He seemed to be someone who could become lonely quite easily. Unfortunately, it seemed difficult for him to form strong relationships with others and receive the amount of social contact he desired.

Dates-n-mates was the only group that Kyle was a member of. His mother had helped him find the group, and he said it was the right type of group for him. Kyle came across as very outgoing during the interviews, so I was surprised when he said that he used to be very shy when meeting new people. I think this shyness may have partly been to do with the fact that his speech could be difficult to understand at first. At times, I had trouble making out what he was saying, and he said that this tended to occur when he met new people. This probably made it difficult for him to feel he could open up and belong to a group.

However, despite his initial shyness, dates-n-mates had allowed him to socialise with other people and form friendships. In fact, he said several times that dates-n-mates had helped him to 'come out of [his] shell'. Although, it was striking that he did not meet with any of his friends from dates-n-mates outside of the activities and events organised by the group. This led me to question how strong or lasting these friendships could actually be. Kyle also referred to his co-workers as friends and said he enjoyed exchanging banter with them; however, similar to his friends from dates-n-mates, he did not see them outside of the



workplace. It was clear that while Kyle could socialise and make friends easily, he had difficulty establishing friendships that could move beyond a single context. It was apparent that he felt he belonged to these social networks, yet he could not forge deeper friendships that would provide him with enough social contact to fulfil his social needs.

Kyle said he was also friends with people who worked at the hairdresser and local restaurants. The encounters he had with these individuals clearly provided him with a sense of belonging to his community. They seemed to help make him feel welcome, and he looked forward to returning to these venues as the restrictions eased because he knew friendly people who worked in them. However, as with dates-n-mates and work, it was clear that he only spoke to these people within a specific context. From the outside, these individuals appeared to be acquaintances rather than friends. However, this may not have mattered to Kyle. It is possible that he simply liked being known when he went out. In addition, according to Bigby and Wiesel (2011), convivial encounters are an element of social inclusion that have the potential to lead to longer term relationships or friendships, so the importance of these acquaintances in Kyle's life should not be dismissed.

Unfortunately, Kyle had not been able to see his partner outside of a specific context either. He and his partner had been unable to meet outside their workplace. It appeared that either she or her parents did not want her to meet him for a date. It is not uncommon for people with intellectual disabilities to experience resistance against their relationships from their family members (Healy et al., 2009). It is likely that this resistance would make it difficult for people to form and sustain romantic relationships. Kyle's relationship with his previous partner differed from that with his current partner in that both he and his previous partner had mothers who were openly supportive of the relationship. This was illustrated well in the YouTube video he wanted to share with me in which both his mother and former partner's mother were interviewed about the relationship. This relationship was initiated through a blind date event at dates-n-mates, and both Kyle and his previous partner were being supported in their pursuit of a close relationship. It is possible that Kyle's current partner was being supported to be in the relationship but was unable to meet with him outside work due to the pandemic. He said that she was trying to keep safe, so she may have simply felt uncomfortable joining him for a date at that time.

Kyle often relied on his family to help him with regular tasks, such as shopping. It seemed that he had not had many opportunities to take complete control over his life. It has been found that while people with intellectual disabilities need support from others, they would

like to experience greater independence (Sandjojo et al., 2019). However, it did appear that Kyle had been supported to make many of his own decisions in his adult life. Mothers have been found to feel a sense of responsibility for the decision making of their children with intellectual disabilities and often have difficulty allowing their children to make decisions for themselves (Curryer, 2020). This highlights the significance of the fact that Kyle was able to make his own choices surrounding his safety during the pandemic. He kept up with the news and made informed decisions about when to interact with others and when to go to public venues. He took this opportunity to show that he could be a responsible adult and care for himself and his community seriously.

## **8.5 Participant 4: Sarah**

### **8.5.1 Introduction**

Sarah came across as shy and reserved, and it could be difficult to get her to open up or provide detailed responses. She was in her late-20s and lived outside of Aberdeen with both of her parents. She said she had joined her local branch of dates-n-mates around the time it was first established, and she was not a member of any other groups or clubs. She did have a part-time job, but at the time of the interviews, her workplace remained closed due to the pandemic. Throughout the interviews, she seemed very eager to return to her workplace and reconnect with her co-workers. To keep busy during the pandemic, she did activities at home, such as painting and baking, went out for walks, and took part in the regular online chats and activities held by dates-n-mates over Zoom. She said that when she first heard about the pandemic, she was afraid and found it frightening being told you could not leave your home.

Sarah was interviewed by telephone seven times from the 15<sup>th</sup> of June to the 7<sup>th</sup> of September 2020. Having seven interviews with Sarah was particularly helpful because it allowed her to become more comfortable speaking with me and provided me with the opportunity to ask questions in ways to elicit more in-depth responses. However, getting her to open up proved to be a struggle throughout the interviews. Through the analysis of the transcripts, two primary categories and four subcategories were identified. The first primary category was 'Adapting to a new normal'. It related to the changes in her life during the pandemic and contained four subcategories: 'Life during the pandemic', 'Keeping busy during lockdown', 'Staying in touch during lockdown', and 'Getting back

out and seeing friends during the pandemic’. The second primary category, ‘Feeling fed up’, did not contain any subcategories.

## 8.5.2 Categories

### 8.5.2.1 Adapting to a new normal

#### *Life during the pandemic*

Sarah initially found it difficult to adapt to the national lockdown and the changes it brought. The pandemic and lockdown came to her as a shock, and she said she felt afraid at first. It altered her normal routine, which she found challenging and frightening:

It’s quite scary when you have to stay at home all the time. [...] That was quite annoying. Um, like, difficult not going to the shops or not—being told what not to do. [...] It’s just quite strange. [...] Because normally you just get to do what you want, but obviously they’re telling you you’re not allowed to do all these things. [...] That was quite difficult.

She said that while she did keep up with the news surrounding the pandemic, she did not watch the news more than once a day. She thought it was important to know what was happening, but she was clearly trying to manage her fears about the pandemic by switching off from the news for most of the day. However, it is important to note that she spent lockdown with her parents and used the pronoun ‘we’ when speaking about watching the news, so she may have been following her parents’ lead and guidance about when and how much media should be consumed.

Sarah had always lived with her parents, and it seemed as if spending lockdown with them was beneficial to her. She said she received a lot of support from her parents and participated in activities with them. Because she lived with her parents, she was not completely isolated during lockdown. During the interviews, she did not mention her parents very often, and this gave the impression that her family life was unfolding as it typically would. However, this could also represent her hesitance in providing details about her life. When Sarah was asked what was most important to her during lockdown, she listed things that did not seem to differ from the things that would have been important to

her at other times. Her response was generic and did not really reflect the current situation. This illustrated a general struggle throughout the interviews to get Sarah to open up and provide details about her experiences of the pandemic.

### *Keeping busy during lockdown*

After adjusting to the initial shock of the lockdown and being restricted to her home, Sarah described how she began to find new ways to occupy her time. She found it easy to provide this more surface-level information and quickly listed off what she had been doing. During the initial interview, she said she went for walks, baked, painted, and coloured in during lockdown. She said that before lockdown she would not have had the time to take part in these activities and that she enjoyed being able to do something new, saying ‘it’s quite good to do new skills that you wouldn’t normally do before’. She reported participating in these activities through to the final interview but said she probably would not have the time to carry on doing them as the lockdown restrictions were lifting. Lockdown provided her with an opportunity to engage in activities she would not normally be able to do, and she found she enjoyed the opportunity to do different things. These may not have been the activities she would have chosen to do had she been able to get out of the house or meet with other people; however, she did get satisfaction out of doing them.

In addition to the activities she did at home with her parents and on her own, Sarah also took part in the online chats and activities held by dates-n-mates on most days of the week. During the second follow-up interview, she said she took part in the chats they held nearly every day and regularly attended their online activities and events. She found having these activities to be both enjoyable and helpful:

I really enjoyed doing the quizzes and stuff. [...] Yeah, that’s been good fun, and doing our, like, random daily chat things that we have. [...] So, yeah, I really enjoy, I’m really enjoying them, so, yeah. They’ve kept me going through all, throughout all of this.

She also said she would not have changed anything about the group during lockdown. When asked what she thought lockdown would have been like without dates-n-mates, she replied ‘I think I’d be going crazy. I feel like I’d be going mad and probably getting a bit bored out of my skull a bit more.’ She repeated she thought would be bored without dates-

n-mates during subsequent follow-up interviews. The chats and activities with dates-n-mates provided Sarah with a meaningful way to spend some of her time, and her regular interactions with the group helped her maintain a sense of fulfilment and connection.

Sarah did not participate in any groups aside from dates-n-mates either during or prior to the pandemic, and it was clear she had limited opportunities to take part in activities with other people and connect socially during lockdown. Having contact with dates-n-mates during the pandemic was crucial for her to maintain her sense of wellbeing. However, during the fifth follow-up interview, she reported that as the restrictions began to ease, she took part in fewer online activities and chats because she was busy doing other things or was out of the house. While the online activities and chats played an important role in her life during lockdown, she did not need to rely on them as much once she was able to take part in some of her pre-pandemic activities and meet with friends in person. She clearly preferred to see people in person and do activities out of the house to meeting people and doing activities online.

### *Staying in touch during lockdown*

During lockdown, Sarah kept in touch with friends and family online and over the phone. She said she and her co-workers had even formed a group on Facebook Messenger. When talking about the social contact she had during lockdown, she often said she spoke to people ‘now and again’. It was apparent that while she was in touch with friends and family, this was not a frequent occurrence. During the second follow-up interview, she said the only people she had spoken to online over the previous two weeks were through the dates-n-mates chats and activities.

Not only did the chats and activities with dates-n-mates allow Sarah to stay in touch with people she knew from the Aberdeen branch of dates-n-mates, but they also allowed her to meet new people from the other branches. The chats and activities were held for all dates-n-mates members regardless of which branch they were a member of. Sarah liked having the opportunity to get to know the members and staff from the other branches:

The best part is just to see like, well, for me anyway, to see different people from different branches. [...] So, like seeing, like seeing new people from Glasgow and Renfrewshire and Falkirk. [...] You know, it’s nice to see

different people from—it's nice to get to know members from, from there and also their staff members as well.

Opportunities to meet people were extremely limited during the pandemic, but the online chats and activities provided one place where Sarah could get to know new people. In fact, had it not been for the pandemic, she may not have ever had the opportunity to meet the members from the other branches. It was only because activities had to be held online that she was able to get to know these other members. Prior to the pandemic, it seemed she had not had many opportunities to meet new people in her daily life, so the online chats and activities provided a unique experience for her to connect with a wider network of people.

### *Getting back out and seeing friends during the pandemic*

As the government restrictions eased, Sarah began to go back out in public and visit with friends in person. During the second follow-up, she reported that she had just been to the shops for the first time since lockdown began, and during subsequent follow-up interviews she mentioned that she had been to a variety of places including, a pub, a castle, the hairdresser, and a shopping centre. During the third follow-up, she said she was happy that places were reopening, but she was glad that this was happening slowly: 'I'm glad things are opening up again. [...] But, yeah, [...] I'm glad that Scotland are doing things slowly. [...] We're going slowly, so.' It was evident that while she wanted the restrictions to continue to ease, she was afraid that if they relaxed too quickly, it could have a negative impact on the trajectory of the pandemic. It also became apparent that it was easier for her to adapt if things reopened slowly, so she could have time to adjust to the changes.

Sarah expressed anxiety around returning to some of her pre-pandemic activities. For instance, she was finding it challenging to learn to use the buses again: 'It's a bit nerve racking because I haven't been on a bus for so long [...] And it's like trying to build my confidence back up by going on a bus again.' She also said she had been nervous returning to the shopping centre. It seemed like she needed to redevelop routines and rebuild her confidence. She expressed similar anxieties around her return to work; however, her anxiety did not prevent her from welcoming this return: 'I'm feeling a bit nervous. [...] But

I also feel—I'm mostly excited to get to see my workmates again.' It was clear that despite her anxiety, she was eager to return to ordinary life.

A lot of Sarah's anxiety centred on adapting to change. She pointed out that the new procedures and rules that were in place due to the pandemic could feel strange: 'It felt strange because it had like stickers on the floor going in like a one-way [...] system', and 'They had hand sanitizer when you went in, so that was kind of a bit strange'. However, Sarah also repeatedly said that going out felt normal. She seemed both surprised and relieved at how routine things felt once she adapted to the changes. She felt that she could adjust to the differences and feel at ease in public places despite them.

In addition to getting back out, during the time of the interviews, Sarah had also begun to visit with friends and prepare for a return to dates-n-mates. During four of the follow-up interviews she reported that she had met a friend of hers in her friend's garden. She said that it was good to catch up. When asked if anything felt strange about meeting in person, she replied, 'It felt a bit strange because you always have to sit two metres apart. [...] And that felt a bit strange. But apart from that, it was fine.' During the fourth follow-up she said she had met a different friend in town to go out for lunch and shop. She said she had known both of these friends for a long time, and it was clearly important to her to reconnect with them in person. Neither friend was a member of dates-n-mates, so it became apparent that her strongest friendships had been formed outside the group. Sarah's account also made it clear that while dates-n-mates could help people form friendships, these friendships did not tend to exist much beyond the scheduled activities held by the group.

However, despite this, Sarah was looking forward to a return to dates-n-mates in person. There had been uncertainty about when the group was going to be able to meet, especially after Aberdeen went back into a temporary lockdown: 'We were supposed to be, um, we were supposed to be doing something, but obviously that changed now. [...] So, I don't know when that's happening now.' While dates-n-mates had been preparing for a return to in-person activities, this return had not happened during the time of the interviews, so Sarah's meetings with her other friends provided her with her only way to socialise with friends face-to-face. This face-to-face contact clearly brought her a greater sense of

connection than the online contact, and it allowed her to re-establish her friendships and regain a sense of normality.

### **8.5.2.2 Feeling fed up**

During the initial interview, Sarah said that she missed being able to do her regular activities. While she attempted to keep busy at home and began to get back out as the restrictions allowed for it, the pandemic continued to limit the activities she was able to participate in. For instance, before the pandemic she had made plans to take part in in-person dates-n-mates events and to go on a holiday, all of which had to be cancelled. While she was disappointed that her plans could not go ahead, she also expressed understanding: 'I was a bit disappointed. [...] But under the circumstances, obviously...'. She was willing to accept that certain measures had to be in place in order to control the spread of Covid-19 even if that meant that she could not participate in some of her usual activities and events. However, that did not stop her from feeling disappointed and frustrated. When asked during the initial interview how she felt about being in lockdown she replied, 'I've been, to be honest, I've been a bit fed up [...] with being a home'. She clearly wanted to return to her regular activities. She felt like she did not have enough to do, and she was tired of feeling confined.

### **8.5.3 Interpretative summary**

Throughout the interviews, Sarah remained very reserved and did not provide many details about her life or her experiences. In order to obtain detailed accounts of participants' lives, it is necessary to build rapport (McGrath et al., 2019). Attempts were made to build rapport with Sarah, and she always seemed eager to speak to me and answered the phone quickly when I called at the arranged time. However, I struggled to help her open up. At one point, she said that she was shy when she met new people, and I felt this to be the case over the three months we met. She did seem to relax as the weeks went on, which was one of the benefits of having multiple interviews, but this time still did not allow her to feel comfortable enough to provide much depth to her responses.

I had hoped that Sarah would begin to open up more over the weeks, and I had attempted to help her describe her experiences by developing follow-up questions intended to elicit more in-depth responses. However, time and the new questions did little to encourage her to expand on her responses. She continued to provide a lot of very concrete and factual



information but did not say much about her thoughts or feelings or offer up any stories to illustrate her points. It has been found that people who are shy will open up in qualitative interviews under the right circumstances (Scott, 2004). The participants should be reassured that their responses will be anonymous and that there are no right or wrong answers (Scott, 2004). I was careful to emphasise these points when meeting with Sarah, but I still failed to create an environment in which she felt safe enough to speak about her life and experiences. She just did not seem to want to give much away about her life.

Interestingly, she did not want to take part in interviews over Zoom despite the fact that she regularly used Zoom to take part in online activities. I got the sense that she did not want for me to see her. Her reluctance for me to know much about her seemed to have extended to knowing what she looked like. It is also possible that she did not want to be able to see me while we spoke. It has been found that some participants in remote interviews feel more comfortable when they cannot observe the interviewer's reactions (Weller, 2017). She may have also simply felt that she would be less nervous speaking over the phone. In addition, while she seemed happy to do the interviews, perhaps because she was bored, I got the sense that she may have felt an obligation to do them. She was asked to take part by staff at dates-n-mates, and she may have felt she could not say no.

## **8.6 Participant 5: Matthew**

### **8.6.1 Introduction**

Matthew was a young man in his mid-20s and shared that he had Down syndrome and epilepsy. He struggled with verbal communication and often required additional explanations in order to help him understand the interview questions. He was interviewed alongside his mother who helped to clarify his contributions while still allowing him to express himself. This arrangement worked well during the interviews, and Matthew was very engaging, expressive, and keen to offer up his opinions and stories. His mother was also quite talkative and had a lot of information to contribute to the interviews. However, the aim was to keep the focus on Matthew and allow him to get his views across. At times Matthew and his mother spoke over one another, which could make the interviews quite chaotic, but they had a positive dynamic that allowed Matthew the opportunity to express himself. He and his mother clearly respected one another and there was a warmth between them in the interviews. However, crucially, he was not afraid to disagree with her, and he

always made certain that his views were heard. In addition, his mother allowed him the space to disagree and express himself. This meant that Matthew's voice truly came through during the interviews, and I was not worried that I was simply getting his mother's opinions.

Matthew lived with both of his parents in a town in central Scotland. In addition to dates-n-mates, he was a member of a dance company and a separate dance group. He was always very eager to talk about dance, and it was clear that dance played a very important role in his life. During the pandemic, he also enjoyed watching videos on YouTube, lifting weights, going to his family's caravan, and watching wrestling and his favourite television shows. He expressed some anxiety about getting back out during the pandemic and was finding it difficult not being able to hug his family and friends.

Seven interviews were carried out with Matthew over Zoom between the 17<sup>th</sup> of June 2020 and the 17<sup>th</sup> of September 2020. Four primary categories were identified through the analysis of the resulting transcripts. The first category was 'I am a dancer', which encompassed two subcategories, 'Dance is what is most important' and 'Dance is where I belong'. The second category, 'Adapting to the pandemic' contained three subcategories, 'Facing change', 'Feeling afraid but wanting closeness', and 'Getting by with dance and technology'. The third was 'Preferring to be active', which consisted of the subcategories, 'Online dates-n-mates is not my thing' and 'Staying active'. The final category, 'Becoming an adult' contained the subcategories, 'Enjoying new freedoms' and 'Taking things seriously'.

## **8.6.2 Categories**

### **8.6.2.1 I am a dancer**

#### *Dance is what is most important*

From the outset of the interviews, it became immediately apparent that dance was very important to Matthew. He became very happy and animated whenever he spoke about dance and would, at times, demonstrate some of his dance moves. This could make the interviews quite lively and fun. Matthew defined himself as a dancer and had dreams of becoming a professional dancer. He had been with a dance company for four years and

enjoyed his dance classes. He also took part in a separate dance group. Even though he consistently took part in dance classes and activities six days per week throughout the pandemic, he said he wished he could do even more dance. He said he enjoyed learning from choreographers and wanted to improve and be able to dance like them. When he was not taking part in his scheduled dance classes, Matthew liked to practice dance and teach himself new choreography. He saw this as part of what made him a dancer: ‘I teach myself how to dance ‘cause see, see me, I’m a dancer’. He took pride in the fact that he was able to teach himself new dances. It made him feel like a serious dancer and gave him a sense of satisfaction and achievement.

Matthew also gained satisfaction from his ability to teach others to dance and display what he learned. He received an award from dates-n-mates because he was always on the dancefloor. He was also able to teach his dance group a dance and received recognition for his contributions to his dance company. Matthew did not have a job and did not take part in other activities, so dance provided him with an identity and sense of achievement that he did not get elsewhere. When he was not dancing, Matthew enjoyed watching television shows and YouTube videos focused on dance. He said he liked anything to do with dance. Dance clearly gave Matthew a sense of fulfilment and provided him with a meaningful activity to focus his attention and energy on.

In addition to taking part in a dance company and dance group, dance also featured strongly in the activities he took part in with dates-n-mates prior to the pandemic. When he attended in-person activities with the group, he particularly enjoyed the activities that allowed him to dance. His mother said that it did not matter if he had friends at dates-n-mates events because all he wanted to do was dance:

Mother: But at the end of the day, when he goes to these things, it doesn’t matter to [Matthew if he knows anyone] because he just goes on the dancefloor [...] and dances himself all night anyway.

Matthew: I do.

Mother: Whether he knew anybody or not.

Dancing did not require him to converse with the other dates-n-mates members, so he was able to interact with other people without having to rely on his communication skills. These opportunities to connect through shared activity were important because he

struggled with verbal communication. He also just really enjoyed dancing and appreciated the opportunities to dance in new venues.

### *Dance is where I belong*

Dance was not only important to Matthew because it provided him with a meaningful activity and gave him a sense of satisfaction, but also because it gave him opportunities to connect with other people. He felt a sense of belonging to his dance company and enjoyed interacting with the other dancers. He had formed friendships through his years at dance and had even been able to meet up with one of his friends from his dance company on multiple occasions during the pandemic. Matthew described the close relationships between the dancers as being akin to family:

Matthew: See, [the dance company], it's kind of like a family thing. [...] We stay as a group, kind of thing.

Mother: They're like his other family, he says, [the dance company].

It was clear that dance was not only important to Matthew because it was an activity he enjoyed taking part in but also because it provided him with a way to form close friendships. He felt that he belonged when he was with the other dancers, a feeling that he had not been able to experience elsewhere outside of his family.

### **8.6.2.2 Adapting to the pandemic**

#### *Facing change*

Throughout the pandemic, Matthew was confronted with change. Initially, this change consisted of closures and cancellations, which caused him some disappointment and frustration. For instance, he experienced disappointment due to the cancellation of the awards ceremony with dates-n-mates, during which he was meant to have received his award:

Mother: [Matthew] was awarded the 'rising star'. [...] But the ceremony was cancelled. We missed that, didn't we?

Matthew: Yeah.

Mother: He was a bit disappointed.

Matthew: I was.

It was clearly meaningful to both Matthew and his mother that he had received this award to recognise his contributions to dates-n-mates. By receiving this award, it allowed him to feel like he was part of the group, which was something he had struggled to achieve.

He also found it difficult that he could not do many of his usual activities during the pandemic. In particular, he missed going out to eat, attending parties, and being able to dance with other people. His family also owned a caravan where they usually spent a lot of time in the summer. During the initial interview, he said the thing he most wanted to do but could not currently do was visit the caravan. The caravan park finally reopened around the time of the first follow-up. However, while he was looking forward to going to the caravan park, he struggled with the fact that the activities and events he typically attended while he was there had not resumed:

Matthew: 'Cause see we heard on an email from [name of caravan park].

[name of caravan park] is kind of caravan thing. It said, we are ready to get back, it's just a caravan. We're opening no shop, no bus, or anything, just the caravan.

Mother: Nothing will be open when he goes is what he's saying, so it'll just be the caravan. He won't be able to go dancing. [...] The facilities won't be open when we get there, so...

Matthew: Mm hmm.

Mother: He's looking forward to it in a way, but at the same time he's not because it's just the caravan. For him, there's no partying for him.

When asked what he was most looking forward to doing after the restrictions were lifted, he replied, 'I'm looking forward to the most going back to my [dance company] again. [...] Getting back to dancing, like, do contemporary dance'. He and his mother went on to explain that in contemporary dance, the dancers worked in close physical proximity, which could not be replicated through remote classes. At this point, Matthew illustrated what they meant by demonstrating some of the moves with his and his mother's arms, which caused

his mother some irritation. Moments such as this could happen during the interviews, but the tension always quickly dissipated.

Matthew and his mother said that when Matthew attended in-person dance classes before the pandemic, he had also had the opportunity to interact with the other dancers during the lunch break. He missed having this informal space to catch up with his friends. Over Zoom, he was unable to choose the individuals he spoke to. His mother also said he missed just being in the company of others, to which he agreed. It was clear throughout the interviews that he liked to spend time with other people even though he could find it difficult to communicate verbally.

As the restrictions began to ease, Matthew returned to some of his usual activities and began to visit people in person. He went to the caravan several times and was able to see both friends and family while he was there. During the final follow-up, he also reported that he had met with a friend from dance in a pub, which he said he enjoyed. As the restrictions began to lift, he and his mother said they were careful to observe the government guidelines. Both Matthew and his mother seemed readily able to adapt to the changes in the guidelines, and Matthew adopted the new rules without complaint:

Mother: He's not out a lot, enough to wear [his mask...] But he knows he has to—he's not made a fuss about wearing it...

Matthew: No.

Mother: When he's had to.

While it did seem as if they followed the rules carefully, it was striking how often his mother made a point of describing the rules and how they adhered to them. There was a sense that during the interviews, she wanted to impress upon me that they were always in keeping with the government guidance. For instance, she pointed out that they maintained distance from people from other households:

Mother: And because my sister was there with her wee boy, we could all go for a walk together. [...] So, we went out for walks, didn't we?

Matthew: Mm hmm.

Mother: And obviously, just—we had to stay apart from them. They were one wee group, and [Matthew] and I were another wee group, so.

Throughout the interviews, she wanted to make it clear that they observed the guidelines.

*Feeling afraid but wanting closeness*

While Matthew adapted to the changes posed by the pandemic, he faced a number of difficulties as well. For one, he did admit that he could become bored on occasion. At the beginning of the pandemic, he was also very afraid to go out for fear of catching Covid-19. He regularly watched the news, so he was aware of the number of Covid-19 cases and deaths in Scotland and across the UK. This seemed to have frightened him and made him reluctant to leave home. According to his mother, he had told his parents he did not even want a facemask: ‘He wouldn’t even let me order him a mask because he said he wasn’t going out’.

As restrictions began to lift, Matthew worried about returning to in-person activities and events because he thought this would put him at greater risk of catching Covid-19. For instance, when asked during the second follow-up what he was most excited about being able to do as the restrictions eased, he replied, ‘Ooo...that is a good question for me now. ‘Cause there’s lots and I don’t know. Um, right now, I’m not actually bothered about going back right now ‘cause see, I’ve got problems with that’, to which his mother added, ‘I know, but, yeah, he’s worrying about going back’. When he did go out, he could feel ill at ease around other people. For example, he found it difficult when his grandmother would come within two metres of him, and he also did not like to be in crowds. Throughout the time of the interviews, he clearly remained frightened of Covid-19 and becoming seriously ill. This fear appeared to provide him with his motivation to closely observe the government guidelines as a way of keeping himself safe.

However, despite his discomfort around others, his mother said that he really wanted to be able to hug: ‘So, one minute he’s worried about it, and the next minute he’s wanting to hug everybody, so’. He agreed that he found it difficult not being able to hug:

Matthew: People sometimes need a hug, ‘cause see, people can’t hug other people you know.

[...]

Mother: I know.

Matthew: It's quite hard for me.

While it was clear that he was worried about contracting Covid-19, and this fear limited his interactions with others and reduced his willingness to go out, there were certain things for which he seemed prepared to take the risk. Matthew missed being able to hug and spend time with his friends and family in person:

Mother: He misses socialising, that's his big thing...

Matthew: I do.

Mother: That he does. He's a very sociable person, so.

When asked if there were certain people he missed seeing, he replied, 'I've got too many. I've got too many people'.

### *Getting by with dance and technology*

Even though he could not regularly see many of his friends and family in person during lockdown, Matthew did keep in contact with people online. During lockdown, his parents bought him his own iPad that he could use to connect with people via video call, which allowed him to talk to friends and take part in online activities. While he did say that seeing people in person was preferable to speaking to them on a screen, he felt that using technology to communicate during the pandemic could be positive:

Mother: Do you like, prefer to see them in the, the person beside you or do you prefer, like to talk to them on the screen.

Matthew: Yeah, I like to sit with somebody and sometimes be on Zoom, sometimes. [...] Depends what it is.

Through this conversation, it was clear by her tone of voice that Matthew's mother thought in-person contact would be preferred; however, Matthew provided reasons why connecting online could be advantageous in some situations. He said he had friends who lived far away and found video calls to be a good way to keep in contact with them. He also liked that video calls allowed him to speak to people any time he wanted. While seeing people in person may have been his preferred method of interaction, he did seem to be accepting of remote communication methods. This was just one example where he backed up a



response that seemed to surprise his mother.

The support of Matthew's parents was instrumental to his being able to communicate with friends and take part in activities during the pandemic. His mother reflected on the fact that she felt Matthew was privileged to be able to live with other people and have a means for connecting with people online, which not everyone was able to do. Matthew's mother felt that it was dance in particular that helped Matthew cope with the pandemic: 'He's not missing [his usual activities] in a way that's affecting him because he has got his dancing and all that, but if he didn't have the dancing then he would be really struggling', to which he agreed. During the pandemic, Matthew also enjoyed keeping himself occupied on his own at home:

Matthew: I think, I think for me, see if I was in the house, no one wants to here, but see, I love doing that.

Mother: He likes staying in the house. You do.

Matthew: Mm hmm. Doing my own thing. More fitness, more WhatsApp with [friend].

Matthew frequently said that he liked to do his own thing. He was comfortable in his own company and could find ways to spend his time in a manner that was meaningful to him. Part of the reason he liked to spend time on his own was that he appreciated having some downtime amidst all of his dance classes. Matthew had managed to remain busy throughout the pandemic.

### **8.6.2.3 Preferring to be active**

#### *Online dates-n-mates is not my thing*

During the fourth follow-up interview, Matthew and his mother announced that his dates-n-mates membership had been postponed until the group was able to meet in person again. He was relieved that his membership had been put on hold, saying:

Matthew: Yeah, it's more, more better. 'Cause some people are not like me. [...]

Mother: Some people are not like you. He doesn't really—he's not formed any friendships with the people in the coffee and chat thing.

[...]

Matthew: No, not at all.

He had not had many friendships at dates-n-mates that pre-dated the pandemic either, and he found that the chats and activities held by the group online did not provide him with a way to form new and meaningful relationships. They also did not allow him to be physically active in the same way dance did. He and his mother said that he did not know what to say during the chats and that he was not interested in the topics of discussion. His mother said that he often seemed lost in the chats and that the other members talked around him. She gave the impression that the other members of dates-n-mates had stronger verbal communication skills than Matthew. He had been encouraged by his mother to continue to attend the regular chats held by the group. She said it stressed her out that he was not taking part, but that it was his decision whether he attended. When asked if he was happy to take a break from dates-n-mates, he wiped his brow and gave a resolute 'yes'.

Matthew's mother noted that there were limitations to the activities dates-n-mates could offer during the pandemic and reported that Matthew was simply not interested in what they could provide: 'So, really, they're kind of limited to what they're doing really, and it's not, em—[Matthew] keeps on saying, "It's not my thing"'. However, he had enjoyed going out to events and activities with the group before lockdown. For instance, he liked taking part in events such as parties or Club Late, a nightclub regularly held by dates-n-mates:

Mother: It's the physical things that he likes to do that...

[...]

Mother: That you can't do, isn't it?

Matthew: Mm hmm. That's the truth.

Matthew wanted to be able to physically engage in activities and found that dates-n-mates was not able to provide many activities that allowed for this during the pandemic. Ultimately, it was clear that Matthew's medium for expressing himself was dance.

### *Staying active*

The online activities held by Matthew's dance company and dance group provided him with his primary means to keep active while he was at home. When asked if he liked taking part in these dance activities online, he responded, 'Yes, I, I like to do it. I like being more active, sort of thing'. Unlike with dates-n-mates, Matthew also enjoyed the chats and activities held by his dance company and dance group:

Matthew: I really like talking with [dance company].

Mother: You do.

Matthew: My mum didn't say that bit.

Matthew's mother reported that the chats with his dance group were much more organised than the dates-n-mates chats and allowed for each person to speak in turn. The chats with the dance company also had a defined topic that the members were given prior to the chat, so they knew what the discussion was going to be about and could prepare. This provided a structure to the chats that Matthew found helpful. In addition to classes and chats, Matthew took part in other activities with his dance group and dance company such as yoga, I spy, and a talent show that engaged him in a way that the quizzes and chats with dates-n-mates did not. He enjoyed activities that allowed him to interact with others while actively doing something.

#### **8.6.2.4 Becoming an adult**

##### *Enjoying new freedoms*

Attending dates-n-mates and dance provided Matthew with opportunities to engage in activities without support from his parents. Through his dance company, he had even been able to travel to another country on two occasions to take part in weeklong dance residencies. His mother said that the most recent trip was the highlight of his year. He really wanted to be able to travel with the dance company again in the future, and he brought up his previous trips multiple times throughout the interviews, which at times exasperated his mother:

Matthew: And the thing, see, the thing I miss the most about [the dance company], go to [country] again.

Mother: [sigh] Oh, [Matthew].

At one point his mother told him to stop going on about his trips. Matthew did not take offense to this and continued to bring them up. It was clearly very important to him that he had been given the opportunity to travel with his dance company. Aside from these trips with the dance company, Matthew had never travelled without his parents, so these trips afforded him some independence that he had not been able to enjoy previously.

Matthew also took enjoyment out of the fact that he was recognised for what he could contribute and that he was able to make his own decisions. Matthew took particular satisfaction out of being named an honorary uncle to the child of a family friend, a fact that he brought up during three of the interviews. By being named an honorary uncle, Matthew seemed to feel that his ability to take on an adult role was recognised and appreciated. Matthew had also been afforded the ability to make his own decisions with regard to his participation in activities. He saw this ability to make decisions part of what made him an adult:

Matthew: It's up to me if I do it or not.

Mother: It's up to you. That's right. It's up to you.

Matthew: Yeah. Because that's what makes me adult 'cause sometimes I go, 'I'm not going'.

In being given the opportunity to make his own decisions, he was able to feel like an autonomous adult who could take control of some areas of his life.

### *Taking things seriously*

Another way Matthew seemed to feel like he was becoming an adult was by taking things seriously. For one, he thought it was important to stay informed about the pandemic and recognise the gravity of the situation. He regularly watched the news and kept up to date with the trajectory of the pandemic and the government guidelines. He often expressed frustration with the other members of dates-n-mates because he felt they were not focused on what mattered during the pandemic: 'I don't know why people care about football,

football's not important. [...] What's important is people are dying. Because of coronavirus'. He brought this up multiple times throughout the interviews, and when he spoke about it, he could become quite emotional. It was clear that he felt very strongly that people should be following the news and recognising the impact of the pandemic. His mother, however, tried to impress on him that people may want to chat about other things, and that was okay.

Matthew also felt he took the activities with dates-n-mates more seriously than the other members. He became frustrated during a salsa dancing lesson that people were chatting to each other as opposed to following the instructions given by the staff member, saying: 'It's not the time to speak. Just do coffee. The, this person is teaching you to dance, do salsa dancing. [...] You need to do—be quiet.' His mother explained that the other people just wanted the opportunity to speak to one another but that this irritated Matthew because he wanted to focus on the activity. At times, he also became frustrated with the other dancers from his dance company for not listening. He felt it was important to listen during the classes and take them seriously. He saw his ability to take things seriously as an indicator that he was an adult: 'I take things seriously. That's more adult, isn't it?'

Despite trying to take things seriously, he said at times his mother told him he needed to act like more of an adult: 'Cause see, my mum says I need to act more adult because sometimes I don't act like one'. He and his mother said that going out to do things with dates-n-mates helped to make him more of an adult. When asked how going to dates-n-mates before the pandemic made him feel, he replied: 'It made me feel happy. Happy to do it 'cause see it's more, more adult-like, like more adult things to do. 'Cause see it's got serious people in it'.

There was a sense that Matthew's parents were pushing him to act more grown up and that he adopted a serious tone and took part in dates-n-mates activities to try to prove he was a mature adult. This seemed to be what motivated Matthew and his parents to have had him join dates-n-mates in the first place. However, because dates-n-mates could not offer in-person activities during the pandemic, he had limited opportunities to show he could be an adult at the time of the interviews:

Matthew: I am, yes. It's adult, more adult, I want to be.

Mother: You want to be an adult and you can't be. [...] Can't do the adult things.

At one point in the interviews his mother said that the other members of dates-n-mates were more mature than Matthew. He quickly cut in to say that he was mature, and he clearly did not appreciate the comment. It became evident throughout the interviews that Matthew was striving to be taken seriously as an adult. His parents were encouraging him to act like an adult but did not appear to think that he was as mature as his peers. This seemed to cause Matthew some irritation and to motivate him to prove that he was growing up and becoming more mature. It was apparent during the interviews that Matthew and his parents must have been having regular discussions about his becoming older and needing to act like an adult.

### **8.6.3 Interpretative summary**

The interviews with Matthew unfolded very differently than those with the other participants because an additional informant was actively involved in the conversations. It was necessary for Matthew to have the additional support during the interviews. He could have difficulty understanding the interview questions and could struggle to communicate verbally. His mother helped the interviews go more smoothly by rephrasing the interview questions for him, so they were better understood, clarifying what he was saying when it was difficult for me to understand him, and providing detail to add to his often quite succinct responses. His mother also seemed to appreciate having the space to talk about her son, of whom she was clearly proud, and of their experiences during the pandemic. She often provided quite detailed accounts of their lives.

It was clear that Matthew and his mother had a good relationship, and they often built on what the other was saying. They sat close together, and their interactions had a warmth to them, even when they disagreed or irritated one another. The interviews tended to become very lively and at times could even be chaotic. Matthew and his mother could become quite animated when they told stories, and Matthew often communicated using gestures and facial expressions that made his opinions clearly known. They could also contradict each other and cut each other off, which was difficult to manage. However, this revealed what might be a very typical relationship between a mother and her son, who was striving

to assert his independence. Overall, the interviews were enjoyable to conduct and often made me laugh as I was transcribing them.

It was clear that Matthew and his family had been having discussions around his maturity. At times, Matthew could become quite silly during the interviews and make faces or dance about. His mother had little patience for this behaviour. He said that sometimes his parents said he did not act like an adult. It became apparent that he wanted to be treated like an adult and that his parents were encouraging him to act like an adult but that his behaviour was not always reflective of this. Matthew and his parents thought that by joining dates-n-mates he may become more mature. His mother said that the people there were more mature than Matthew was. This comment irritated him, but it gave the impression that his parents hoped that by interacting with people who were more mature, Matthew may begin to act more mature himself. Matthew mentioned that at dates-n-mates he was able to do adult activities, a point which he seemed to take pride in. His mother clarified that these were activities that would be expected of any adult. It was evident that Matthew's parents felt it was important for him to have experiences that were typical for any adult of his age, regardless of ability.

Matthew was also able to develop his maturity through his participation in dance. Through dance, Matthew was able to have his own space away from his parents where he belonged and could be treated as a capable adult who was valued for his contributions. Importantly, dance does not require verbal communication, so it allowed Matthew to fully participate without having to express himself verbally. Dance provided Matthew a place in society like any other adult. People with intellectual disabilities often have limited opportunities to take on valued roles in their communities. Both employment (Robertson et al., 2019) and volunteering rates (Hall & Wilton, 2011) among people with intellectual disabilities are low, and Matthew had neither a job nor a volunteer position.

In addition, because Matthew aspired to be a professional dancer, he gave the sense that while he greatly enjoyed dance, he also treated it like a job. According to Hall and Wilton (2011), participation in the arts may provide an alternative way for people with disabilities to find meaningful activity when paid employment is not obtained. Therefore, his being able to feel as if he was appreciated for his ability to dance was very important to his sense of self.

Matthew depended on his parents for support for many of his daily activities, so it seemed that having this space away from his parents may have given him a sense that he was an independent adult who could experience the world without relying on them. By attending dance and going on trips with his dance company, Matthew was able to experience a level of independence he had not experienced previously, which may have helped him to feel like more of an adult. In addition, having independence can increase self-confidence and self-worth, provide a sense of pride, and lead to improvements in mood among people with intellectual disabilities (Sandjojo et al., 2019). It is likely that Matthew not only felt like more of an adult because of his newfound independence but also gained self-confidence and a sense of pride.

Matthew also felt he was acting like a mature adult by keeping up with the news about the pandemic and by taking the pandemic seriously. He complained that the other dates-n-mates members did not take the situation seriously enough. Watching the news was something he did without being prompted by his parents, and he seemed proud of the fact that he kept up to date with the ongoings of the pandemic. However, while he seemed to think it was important to know the number of Covid-19 cases and deaths, being aware of this information caused him a considerable amount of fear. People with intellectual disabilities may not always understand the news around the pandemic, which can cause stress and anxiety (Embregts et al., 2022; Fudge Schormans et al., 2021). Matthew's fear prevented him from leaving the house during the early stages of the pandemic because he thought he would catch the virus and become seriously ill himself. While performing the role of a mature adult appeared to be a factor in his decision to closely follow the news, I got the impression that the true reason he was watching the news was because he was fascinated by the pandemic and how it was unfolding. Even though this information caused him a lot of anxiety, he seemed to be unable to turn away.

## **8.7 Participant 6: Michael**

### **8.7.1 Introduction**

Michael seemed eager to talk and offered up details and stories without being prompted. He was in his early-40s and lived on his own in a large town in central Scotland. He said he did not have any family living nearby. He reported that he had multiple health problems, including asthma and arthritis and was exempt from wearing a facemask. At the



time of the interviews, Michael had been a member of the Falkirk branch of dates-n-mates for around a year. In addition to dates-n-mates, he was a member of two advocacy groups, both of which he had been involved with for about ten years. He also took part in a walking group and was hired as a dates-n-mates director during the time of the interviews. Michael said that when he first heard about Covid-19 and lockdown it was difficult to understand what was happening and that once he understood the impact of the pandemic on his life, he experienced extreme boredom. He made the decision to shield during the first 12 weeks of the pandemic because he had underlying health conditions and wanted to keep himself safe, and he said he found this period very difficult. At the time of the interviews, Michael was trying to keep busy with online chats and activities and was starting to get back out and visit with family.

Seven interviews were conducted with Michael over Zoom between the 6<sup>th</sup> of July 2020 and the 5<sup>th</sup> of October 2020. Through the analysis of the transcripts, three main categories were identified from Michael's interviews. The first category, 'Feeling afraid and unsupported' consisted of two subcategories, 'Worrying about wellbeing' and 'Getting support was just a nightmare'. The second category was 'Feeling valued', and it contained the subcategories 'Being recognised for contributions' and 'Maintaining connections and receiving support'. The final category, 'Lockdown is challenging, so it's good it's easing', encompassed the subcategories 'Feeling bored and lonely' and 'Reconnecting and getting back out'.

## **8.7.2 Categories**

### **8.7.2.1 Feeling afraid and unsupported**

#### *Worrying about wellbeing*

During the initial interview, Michael reported that he had been shielding during the first 12 weeks of the pandemic. Michael said that he had read that a number of health conditions could put you at a higher risk of dying if you contracted Covid-19. Because he had some of the conditions that were listed, he decided to shield even though he had not received a letter instructing him to do so: 'I just actually done 12 weeks of, eh, isolation, myself without anybody saying to me that I should be isolating [...] because of what I read on the tablet. I just took it that I wanted to be safe.' It was only after he had spent seven weeks in

isolation that he was finally able to speak to his doctor about his concerns, and they said he had not needed to shield, and he should not believe everything he reads online. However, Michael said that he decided he would complete the 12-week isolation period anyway. While he appeared to trust his doctor, he still felt that it was in his best interest to continue shielding.

Michael found his time shielding to be very uncomfortable, but it was clear that his fears surrounding what would happen to him if he were to catch Covid-19 outweighed this discomfort: 'Because I self-isolated myself, I, I was bored to tears. I, I just wanted to get out there. [...] But I wanted to keep myself safe.' Even after he finished shielding, he postponed a trip he had with his mother to a popular coastal town until the following year because he felt he should not be around crowds that year due to his underlying conditions. While Michael never explicitly stated that he was afraid of Covid-19, his actions indicated that he was concerned about his safety during the pandemic. He was clearly worried about what would happen to him should he contract the virus. By making his own decision to shield, he also gave the impression that he was trying to take responsibility for his health and make the best decisions he could with the information he had available to him. It seemed important to him to feel in control of his health.

Despite his fear of catching Covid-19, Michael did not wear a facemask as he began to return to go back out. He had asthma and was exempt from wearing a facemask after face coverings became mandatory on public transport and in shops and public venues in Scotland during the summer of 2020. During the initial interview, he expressed concern over the fact that facemasks had become mandatory: 'It's just getting to the stage now that you've got to wear a facemask everywhere that you go. [...] Which, I understand it for your own safety. [...] But if you've got asthmatic, then you shouldn't have to, eh, wear it.' It was interesting that while he thought wearing a facemask was for the wearer's safety, he did not want to adopt their use. He never stated why he decided not to wear a mask, but it appeared that his health concerns and discomfort related to his asthma outweighed his fears related to Covid-19. However, it is also possible that he simply did not want to wear one. He was also heavily involved in self-advocacy groups and may have felt that he should stand up for his right not to wear a face covering. Regardless of his reasoning, given his fear of catching Covid-19, his decision not to wear a facemask was striking.

Although he did not wear a facemask, Michael did find it important to distance himself from other people. He expressed concerns about being in close proximity to too many people at once. During the third follow-up, he said that what worried him the most about resuming the walking group he took part in was that it would be a big group, and people would not be able to maintain the recommended two metres from each other. When asked during the fourth follow-up how he felt about his return to public spaces, he replied, 'I feel okay as long as you keep your distance'. While Michael felt safe enough to return to community activities as the restrictions eased, he clearly felt the guidelines around social distancing were important to follow. The rules were important to him in order for him to feel safe from Covid-19. This further highlights his seemingly contradictory decision not to wear a facemask.

At the time of the final two interviews, cases of Covid-19 were beginning to increase in Scotland again. During the fifth follow-up, Michael attributed this increase to the people who broke the government rules:

If people's not listening to the rules [...] then how do you expect things to get better? [...] They need to start listening [...] and do what you get told to do. [...] And if they're not going to listen to what's to be done [...] then they should actually be doing time in prison. Automatically. Because then that way they'll learn [...] that they need to be doing something. 'Cause otherwise you're not going to get to the bottom of it.

He clearly felt that the pandemic would continue if people did not follow the government guidelines. He said that he continued to go out in public despite the rise in cases but that he had begun to use taxis more often instead of taking buses. The rise in cases clearly threatened Michael's sense of security, which motivated him to avoid taking public transportation because it would have put him in close contact with many other people.

In addition to worrying about falling ill with Covid-19, Michael was concerned that rising cases would lead to a tightening of the government restrictions:

It's starting to do my head in now [...] with it all starting back all over again and how there's talk about going into another complete lockdown and [...] how

they could end up having a curfew from 10 o'clock at night to 5 o'clock in the morning. It's just a nightmare. It's starting to do my, eh, box in.

Michael was clearly anxious about having to cope with a second lockdown.

### *Getting support was just a nightmare*

Michael found it difficult to identify sources of support after he had made his decision to shield: 'I've contacted the council to see about getting help and support for food hampers and whatever. [...] The council, nobody would help me [...] because I didn't receive a letter.' This seemed to leave him feeling stressed and anxious. He said it was challenging to find support elsewhere:

[The council] were unable to help me. Eh, so I had to try and find somebody that could help me to get shopping in and leave it at my front door, [...] which was a bit of a pain and just a nightmare.

Michael clearly felt his decision to isolate was not respected by others.

Michael also felt that his facemask exemption was not supported: 'Sometimes the bus driver was giving me trouble because I wasn't wearing a mask, [...] and then you've got other passengers on the bus giving me dirty looks'. He felt that it was not right that the bus driver had been questioning his exemption. It clearly angered him and made him feel disrespected. In addition, he said he was told he might not be allowed in some local shops without a mask despite his exemption and was even stopped by the police at one point who demanded he produce his inhaler. The hostility he experienced due to his facemask exemption was making him rethink his willingness to go out, as he said: 'It's getting to the stage now that I'm actually going to be scared to go out'. However, despite the questions and disapproving glances, Michael held firm in his right to be in public spaces without a mask.

### 8.7.2.2 Feeling valued

#### *Being recognised for contributions*

Over the course of the interviews, Michael applied, interviewed, and got hired for a dates-n-mates director post at his branch of the organisation. Dates-n-mates staff members had identified him as a strong candidate and encouraged him to apply. During the fourth follow-up he explained what qualities and skills he thought a good director would have and how he matched these:

I feel to me [...] that what they're looking for in a director's post is somebody that can talk to somebody. [...] Well, I'm good at talking to somebody. [...] Somebody that can organise stuff. [...] Well, I can organise stuff because I've organised meetings in the past.

It was clear he had confidence in his ability to fulfil the duties of the post, and he announced that he had been appointed to the position during the fifth follow-up. Michael had previously been unemployed, so getting this job held a lot of significance for him. In assuming this role, his skills and ability to contribute were recognised, and he felt seen and valued by dates-n-mates. He had not had many opportunities to receive recognition in this way in the past, so this job was very important to his self-esteem and sense of achievement. In addition to getting hired as a director, Michael explained how he had been able to use his knowledge to help someone else who was struggling during the pandemic. He told this story in detail and was clearly proud of his ability to assist another person.

#### *Maintaining connections and receiving support*

Although it was often lacking, Michael was able to find some sources of support during the pandemic. He found a company that would deliver food to his home, and he remained in contact with a few family members. He was also regularly in touch with his physiotherapist, dates-n-mates, and the self-advocacy groups he took part in via text and Zoom. It was through dates-n-mates that he found out about Zoom: 'I didn't know Zoom existed until one of the members phoned me up and explained how I get into Zoom. [...] And they helped me to get set up for Zoom because otherwise I wouldn't have had a clue.' It was because he was introduced to Zoom that he was able to take part in dates-n-mates

and his other groups during the pandemic. He found he preferred speaking to people over Zoom to speaking over the telephone:

With family you can talk to them anytime you want on the phone, [...] but with, eh, dates-and-mates, it is something new. You are actually seeing them; you are actually seeing people face-to-face. [...] So therefore, you're able to talk to them face-to-face [...] like what we are doing now. [...] So, having this and having somebody to talk to face-to-face, [...] and...it, it is good. It made, it made my day kind of thing.

By supporting him to use Zoom, dates-n-mates provided Michael with the opportunity to be able to see other people and feel a sense of connection during a time in which people could not meet in person. This was clearly very important to him. It helped him feel less isolated during the pandemic, which was vital to his wellbeing.

Connecting with dates-n-mates over Zoom was particularly important to Michael while he was isolating:

I self-isolated myself for, eh, 12 weeks, and having the Zoom chat with, eh, with eh, dates-n-mates, eh, 3 or 4 times a week has been magnificent [...] at giving me something to do. Giving me somebody to talk to. Because during the lockdown, not getting to see family or friends, it felt like prison.

He said that overall, dates-n-mates provided him with more support than anyone else during lockdown, and he regularly took part in the online chats, activities, and events held by the group. He stressed how crucial it was to have this support:

I feel to this moment of day, that if it wasn't for the Zoom chats with, eh, with dates-n-mates [...] I don't think I would be here now, if it wasn't for dates-n-mates. [...] I feel that dates-- I feel that the coffee and chat and whatever and conversations I had with the Falkirk, eh, staff at dates-n-mates, eh, had helped me a, a good massive difference. If it wasn't for them, eh, I don't think I would be here now.

Michael repeated that he was not sure where he would be without the support of dates-n-mates multiple times. It was clear that he had struggled greatly during lockdown and that the pandemic had a very negative impact on his mental health. He felt it was the support he received from dates-n-mates that kept him going throughout this difficult time.

### **8.7.2.3 Lockdown is challenging, so it's good it's easing**

#### *Feeling bored and lonely*

Prior to lockdown Michael used to keep himself busy by visiting other people and spending time going out: 'Before I used to kind of go out, gallivant on buses, and go and visit family, friends [...] and just go into the town and whatever [...] and always giving myself, eh, meetings to go to'. He clearly got satisfaction out of being able to go where he wanted and fill his time how he pleased. However, this was not possible during lockdown. Michael reported that he had very few activities to occupy his time during the pandemic and often felt bored. When asked what he had been doing at home, he replied, 'Just watching the TV, just bored. I sometimes go, I sometimes go for a walk. [...] But most of the time I'm just bored, sitting watching TV.' He said he often fell asleep during the day when he did not have any activities planned over Zoom because he did not have anything else to do. I experienced this first hand when he did not show up to one of the interviews over Zoom because he had been bored and fallen asleep.

Michael said he hated being stuck in his house, and he had not identified many activities to do from home. His period of self-isolation exacerbated these feelings: 'I don't stay near any family and because you weren't allowed out because of the lockdown and because I self-isolated myself, I, I was bored to tears. I, I just wanted to get out there'. His feelings of boredom and loneliness came through strongly throughout the interviews.

Michael reported that while seeing people over Zoom was helpful and had a positive impact on his outlook, he missed being able to see people in person. When asked if there were certain people he missed, he responded, 'Yes, people from all the groups that I go to. [...] Just miss, eh, seeing them on, seeing the people from, eh, dates-n-mates that I've built up a relationship with.' Michael's relationships with other dates-n-mates members were

clearly very important to him, and this made him eager to reunite with the dates-n-mates in person.

### *Reconnecting and getting back out*

After Michael finished shielding, he slowly began to go back out and visit with friends and family as restrictions allowed for it. At the time of the second interview, he said that he had been going for walks around his neighbourhood and had been regularly visiting his mother and grandmother:

It's good to be able to get back out to visit them because it was just a nightmare missing them and not being able to go see them there, but [...] now that I'm able to get out and visit them, it feels good.

By the time of the fourth interview, he reported that he had been able to go to a bingo hall with his mother, and during the fifth interview, he said he had resumed meeting with a walking group he took part in. He said that there were some safety measures to adapt to when he went out, but he was accepting of these and said he enjoyed going places again. However, seeing people in person again did require an adjustment. When asked how it felt to see people at his walking group again, he replied, 'It just felt weird. [...] But, aye, it was good'. Overall, despite his fear of contracting Covid-19 and some initial feelings of awkwardness, he seemed very willing to engage with others and return to public spaces. After spending 12 weeks shielding at the beginning of the pandemic, he desperately wanted to reconnect with people and take part in his usual activities.

### **8.7.3 Interpretative summary**

Michael's decision to shield had an enormous impact on his mental health. He was not hesitant to tell me that he had struggled emotionally during lockdown. He wanted to keep himself safe and avoid catching Covid-19 because of his underlying conditions. This led him to make the decision to shield. However, this decision then had a negative impact on his mental health and quality of life during lockdown. Michael's experience was not unique; others have also reported that shielding had a negative impact on their mental health, which can partly be attributed social isolation (Lasseter et al., 2022). Michael was also not the only person trying to make difficult decisions during lockdown. As I witnessed



with Jennifer (Participant 1), the pandemic could force people to choose between what were often two undesirable options, which could then have massive repercussions for the lives of everyone involved.

Interestingly, Michael had been involved in two different advocacy groups for around ten years. It may have been through his participation in these groups that he gained the confidence to make important decisions about his life and his health. Self-advocacy groups have been found to promote resilience (Goodley, 2005) and help people with intellectual disabilities speak up for themselves (Clarke et al., 2015). Michael's experiences in these groups seemed to allow him to advocate for himself when he decided to shield and when he was confronted about not wearing a face covering in public. He knew his rights and had no problem defending them.

Self-advocacy groups have also been found to provide people with intellectual disabilities a platform through which to acquire skills and knowledge, including that about rights (Gilmartin & Slevin, 2009). Being a member of these advocacy groups gave Michael a vocabulary to talk about disability, his health conditions, and his rights in a way that was not exhibited by the other participants. He was not only capable of articulating his own experiences, but he was also able to speak about what other people with intellectual disabilities may have been experiencing. For instance, he felt that his friends with severe intellectual disabilities did not receive adequate support to stay connected socially during the pandemic. This awareness of the challenges faced by others was not shown by the other participants. This does not mean that the other participants did not think about these issues but rather, that Michael was more accustomed to speaking about them.

During the pandemic Michael was hired as a director at dates-n-mates, a role which he seemed thrilled to be taking on. As mentioned above, people with intellectual disabilities have high unemployment rates and generally lack opportunities to utilise their skills (Hall & Wilton, 2011; Robertson et al., 2019). This is despite people with intellectual disabilities often expressing a desire to obtain employment (Hamilton et al., 2017) and is of further concern because paid employment has been found to be associated with better physical and mental health (Robertson et al., 2019). Michael's experience with self-advocacy probably gave him some of the confidence and skills to take on his new role. Involvement in advocacy can provide a sense of empowerment that can be drawn upon in other contexts (Clarke et al., 2015). In speaking to Michael about his new role, it was apparent that

becoming a dates-n-mates director had boosted his sense of self-worth and was going to provide him with something meaningful to do. He was clearly looking forward to taking on this new responsibility.

## **8.8 Conclusion**

In this chapter the embedded case studies were presented. These included individual dates-n-mates members' accounts of their experiences during the Covid-19 pandemic. Each participant was presented individually, and details of their lives during the summer and early autumn of 2020 were provided. The next chapter provides a reflection on the methods used to collect this data. A more detailed discussion of conducting remote interviews will be presented.

## Chapter 9: Reflections on remote interviews

This chapter provides the researcher's reflections on conducting remote interviews. It begins with an overview of conducting remote interviews and moves on to detail the specific considerations that need to be given when conducting interviews over Zoom and the telephone. It ends with some concluding remarks on the utility of remote interviews when carrying out research.

### 9.1 Conducting interviews remotely

Face-to-face interviews have been referred to as the 'gold standard' when conducting qualitative interviews for research purposes (McCoyd & Kerson, 2006, p. 390). However, many researchers have found success when carrying out interviews remotely using both the telephone (Carr & Worth, 2001; Drabble et al., 2016; Holt 2010; Johnson et al., 2019; Sturges & Hanrahan, 2004) and online platforms, such as Zoom (Archibald et al., 2019), Skype (Deakin & Wakefield, 2014; Hanna, 2012; Hay-Gibson, 2009; Johnson et al., 2019; Krouwel et al, 2019; Lo Iacono et al., 2016; Seitz, 2016; Weller, 2017), and FaceTime (Weller, 2017). Furthermore, Deakin and Wakefield (2014) argue that online interviews can 'produce data as reliable and in-depth as produced during face-to-face encounters' and that online interviews 'should be treated as a viable option to the researcher rather than as an alternative or secondary choice when face-to-face interviews cannot be achieved' (p. 604).

However, despite the assertion made by Deakin and Wakefield (2014), according to Salmons (2015), the researcher's rationale for using online interviews as opposed to in-person interviews must be made clear. For this study, the rationale was simple: the interviews were conducted during a time in which face-to-face contact was largely prohibited. The restrictions that were in place to curb the transmission of Covid-19 prevented me from meeting with participants in person or carrying out face-to-face interviews. Therefore, alternative means for conducting interviews were sought. Both interviews using video-conferencing software and telephone interviews were deemed appropriate for use in this study.

Overall, 37 in-depth, semi-structured interviews were conducted for this research. Participants were given the option to take part in the interviews using the telephone or a

video-conferencing software package or video call platform of their choosing. This choice was considered necessary to the success of the interviews because, as was pointed out by Salmons (2015), the researcher may not have the opportunity to explain new technologies to participants, and the participants may not be interested in learning how to use them. For this research, two participants opted to use the telephone for all of their interviews, and an additional participant initially chose to use the telephone but later switched to Zoom. Three participants decided to use Zoom for all of their interviews. This resulted in a total of 17 telephone interviews and 20 Zoom interviews conducted across this study.

In addition to fulfilling a practical purpose in this study, the use of remote interviews had the unintended benefit of allowing me to interview participants from across Scotland. Remote interviewing methods eliminate the need for travel, which allows researchers to ‘transcend geographical boundaries’ (Lo Iacono et al., 2016, p. 3) and save on time (Krouwel et al., 2019; Seitz, 2015; Weller, 2017) and money (Deakin & Wakefield, 2014; Hanna, 2012; Krouwel et al., 2019; Seitz, 2015; Weller, 2017). Had remote methods not been used in this study, it may not have been possible to interview participants outside of Glasgow, where I am based, due to the time and cost that would have been required for travel. Therefore, by eliminating the need for travel, remote interviews made it possible to obtain viewpoints from people who were members of the dates-n-mates branches in Aberdeen and Falkirk.

The use of remote methods also meant that participants could take part in interviews from nearly anywhere that was convenient or comfortable to them. This typically meant that the participant was in their own home. However, one interview took place while a participant was housesitting for his parents, and another took place while a participant was away at his family’s caravan. By meeting over the telephone or online, the participants were granted greater flexibility. It also meant that interviews could be held when they otherwise may not have been, such as when a participant was out of town.

Remote interviews not only allow participants to remain in comfortable environments, but they also prevent the participants from feeling that the researcher is encroaching on their space (Hanna, 2012; Weller, 2017). In fact, it has been found that online interviews may be felt by participants to be more relaxed and informal and ‘less daunting’ than in person interviews because the participants are in comfortable spaces separate from the interviewer (Weller, 2017, p. 618). Since the participant and researcher are in their own spaces, it may

also lead to both parties ‘feeling “less nervous” and “less pressured” compared to being in person’ (Seitz, 2015, p. 230). Additionally, remote interviewing may help less confident participants feel more able to speak because they do not have ‘the pressure of the presence of a researcher’ (Weller, 2017, p. 623).

By conducting the interviews remotely, the health and safety precautions that needed to be taken in conjunction with the research were also reduced (Deakin & Wakefield, 2014) because both the participant and the researcher took part in the interviews from ‘safe locations’ (Hanna, 2012, p. 241). I was never entering an unknown environment or undertaking travel to another location so did not need to perform regular check-ins with another researcher at the university.

However, while there are benefits to conducting remote interviews, it is important to point out that valuable contextual information is lost, which can have a negative impact on both understanding and rapport (Weller, 2017). The researcher is unable to see the participant’s environment and get a sense for how they live their life. This contextual information can provide a broader understanding of the participant and help situate the interview data within the participant’s life.

While some general points about remote interviews were discussed above, there are some additional pros and cons that need to be considered before employing these methods. Below are more detailed discussions of both telephone and online interviews and my reflections of interviewing using these remote methods.

## **9.2 Telephone interviews**

Of the six participants in this study, two opted to use the telephone for all of their interviews, and a third used the telephone for his first three interviews before switching to Zoom. I did not ask the participants directly why they chose the telephone over videoconferencing software; however, in getting to know the participants, I developed a sense of why the telephone may have been selected in some instances.

One of the participants who opted to use the telephone throughout the study told me that she was shy, and she came across as quite reserved and shy during the interviews. I felt that perhaps taking part in the interviews over the phone may have felt less daunting than

taking part over videoconferencing software. Over the phone, the participant would not have been confronted with the interviewer face-to-face and could maintain some level of anonymity. For someone who was shy, the option to participate over the telephone may have felt safer and may have allowed her to open up more than she would have otherwise.

The other participant to use the telephone throughout the interviews had a significant visual impairment. In this instance, the participant would have largely been relying on the interviewer's spoken language to obtain meaning regardless of the medium used. Because of this, it may not have been viewed as particularly helpful for the participant to meet using video. However, these rationales for using the telephone are both just conjectures. It is possible that both of these participants simply felt it was easier and more convenient for me to call them at the agreed upon time rather than having to navigate the computer and Zoom links.

When conducting interviews over the telephone, there is an obvious downside: the researcher cannot see the participant or their nonverbal communication. However, this does not necessarily mean that conducting interviews by telephone makes for poor quality interviews. As Holt (2010) argues, telephone interviews should not be viewed as 'second best' (p. 117). She found that participants enjoyed taking part in telephone interviews and that the interviews produced rich data. In addition, a study using both face-to-face and telephone interviews found that there were no significant differences in the data between the two modes (Sturges & Hanrahan, 2004).

Furthermore, as Sturges and Hanrahan (2004) point out, while participants' nonverbal communication cannot be seen, participants do provide verbal cues, such as hesitations, sighs, and hurried answers to which the interviewer can respond. In this study, it was found that I had a clear sense of the participants' moods and how they felt about certain topics based on their tone of voice. One participant would also use sounds and sighs to indicate when he didn't like or felt fed up with something. Another participant frequently giggled, which I took to be a sign that she was feeling nervous. However, the loss of non-verbal communication would have been detrimental had these participants had difficulty with verbal communication. Telephone interviews would not be very appropriate to use with participants who rely on facial expressions and gestures to help convey what they have to say.

While telephone interviews have been found to feel ‘strange’ for the participants and researcher at first, this ‘strangeness’ has been found to subside after both parties relax (Holt, 2010, p. 119). Unlike this previous research, I did not find the telephone interviews in the study to feel strange at the beginning. However, it is possible that this lack of ‘strangeness’ can be attributed to the fact that I spoke to each of the participants on the phone on two occasions prior to the interview. These informal chats may have helped the interviews feel more comfortable and natural because we already introduced ourselves over the telephone and got used to how each other spoke. Although, it is possible that the participants still found this method of interviewing difficult to adjust to.

It is also of significance that previous research has found there to be some benefits to conducting interviews over the telephone. For one, Weller (2017) found that some participants felt more comfortable with audio-only communication because they could not see the interviewer’s reactions to what they were saying and could therefore ‘avoid embarrassment’ (p. 618). I feel this may have been the case for one of the participants in this study who, as mentioned previously, was clearly very shy and reserved. By not being able to see my reactions, she may have felt better able to answer my questions and begin to open up. Another potential benefit to this type of interview is that it requires the researcher and participant to fully articulate everything they would like to get across, which can ultimately produce a much richer text for analysis (Holt, 2010). Unfortunately, in this study, this potential benefit was not fully explored; however, there did not appear to be any clear differences in the data obtained through the different media.

Weller (2017) also points out that one of the advantages of audio-only interviews is that the ‘props of the research encounter’, such as the interview guide, notes, and recording device, are out of the participant’s view (p. 619). Sturges and Hanrahan (2004) further note that during telephone interviews, the ‘interviewer was able to take notes without distracting the interviewees’ (p. 114). The ability to take such notes is important because the interviewer can use them to later probe the participants about specific topics (Sturges & Hanrahan, 2004). In this study, I found the ability to read and take notes on the interview guide throughout the interviews to be helpful in keeping track of what had been covered and for noting where follow-up questions should be asked.

There are also some challenges or difficulties that can be faced when conducting telephone or audio-only interviews. For instance, when carrying out audio-only Skype calls, Weller

(2017) found that there was a greater ‘propensity to interrupt one another’ because it was difficult to ascertain when the other person had finished speaking (p. 620). In this study, I did not find that the participants and I interrupted each other more during the telephone interviews than the Zoom interviews. However, because I could not see when a participant was still thinking about a topic, there may have been times when I cut in with my next question too quickly. There were also moments when I waited for the participant to expand on an answer for too long, which at times, created awkward pauses that elicited some nervous laughter.

In addition, there is the potential for connection or technical difficulties when conducting and recording telephone interviews. To avoid connection issues, Johnson et al. (2019) has recommended that researchers use landlines to conduct interviews when possible. The interviews for one of the participants in this study were carried out using his home telephone. However, the other two participants and I used mobile phones for the interviews, and no connection issues were ever experienced. To help avoid technical difficulties and ensure the telephone interviews went smoothly, I did perform a test call using the recording equipment that would be used to record the interviews. No technical difficulties were ever experienced during the telephone interviews for this study.

When using telephone interviews, there is also the possibility that the participant will simply not answer the researcher’s call. Fortunately, that was not experienced in this study. Each of the scheduled telephone interviews was conducted as originally planned. There was also never an instance where a participant left an interview prematurely by hanging up the telephone.

Finally, when conducting interviews over the telephone, I found that there was a potential for interruptions or distractions during the call, and at times, there were other people in the background. Two of the participants who selected telephone interviews participated in all of their interviews from their family homes, and the third participated from his own home for two of the interviews and from his family’s caravan for a third. Although I was unable to see the participants or their surroundings, there were three times when I became aware that others were present in the participants’ environments. The interruptions were brief and did not seem to have a significant impact on the interviews. However, while I could only actually hear family members on three occasions, it is possible that others may have been within earshot of the participant at other times and influenced what the participant said.



### 9.3 Zoom interviews

It is of note that each of the participants who decided to take part in online interviews selected Zoom as their video-conferencing software of choice. While I did not ask participants to justify this decision, I felt that Zoom may have been chosen because it was the software used by dates-n-mates to hold online chats, activities, and events during lockdown. Each of the participants in this study reported that they had accessed dates-n-mates activities online, so they all would have had some previous experience using Zoom. However, I learned that at least some participants had experience with other platforms, such as Skype or FaceTime, and I cannot fully account for why Zoom was selected over these other platforms.

The selection of Zoom did benefit me as the researcher because I was already familiar with it. It also has advantages over some other videoconferencing platforms because it allows for the interviews to be securely recorded and stored without the use of third-party software (Archibald et al., 2019). Using Zoom, I was able to easily record the interviews and save them to the cloud. Zoom also indicates to the other party when the recording has begun, which could have helped put participants at ease because they were aware of exactly when they were being recorded. In addition, Zoom does not require the user to download and install software; the participants simply needed to click on the web link I sent to them (Wahl-Jorgensen, 2021). However, the researcher should still be prepared to provide assistance to participants should they need it, and it has been recommended that they ask that participants test Zoom prior to the interview (Lobe et al., 2020).

Unlike telephone interviews, interviews using video-conferencing software allow people to see one another and have a sense of meeting face-to-face even when they cannot meet in person. According to Hanna (2012), online interviews provide this “‘face-to-face’ experience’ while at the same time ‘preserving the flexibility and “private space” elements offered via telephone interviews’ (p. 241). Using Zoom, the participant can both see the interviewer and take part from a comfortable location of their choosing without having to invite the researcher into their space. The ability for participants to see the researcher is significant because it has been found to be important for ‘establishing rapport, building interpersonal connection, [and] adding “a personal touch”’ (Archibald et al., 2019, p. 4). In

addition, when participants had the option to take part in an online interview from a separate space away from the researcher, many reported feeling more relaxed during the interview than they would have had the interview been in person (Weller, 2017). While the researcher and participant may be in separate locations, they create ‘a new digital and socially meaningful space’ through their online interactions (Howlett, 2022, p. 393).

It is also of note that, in the study by Weller (2017), 83% of participants reported that an online interview was ‘as “good as a home visit”’ and 100% felt comfortable with the online format (p. 616). Furthermore, in a study comparing in-person and Skype interviews, the researchers ‘neither experienced nor noted any consistent difference between the nature and character of the interviews by mode’, and the ability to build rapport did not seem to be affected (Krouwel et al., 2019, p. 6). Previous research has also found that participants specifically preferred Zoom interviews over interviews conducted in person, over the telephone, or using other videoconferencing platforms (Archibald et al., 2019). In addition, Zoom has been considered advantageous over other methods of interviewing when it comes to building and maintaining rapport, convenience, simplicity, and user-friendliness (Archibald et al., 2019).

However, despite the advantages, there are some notable downsides to using Zoom or other videoconferencing platforms for interviews: the full range of nonverbal communication cannot be observed, other people may be present in the room with the participant and influence what is said (Salmons, 2015), and the researcher does not have control over the participant’s environment (Howlett, 2022; Lo Iacono et al., 2016). In addition, not everyone has access to the internet, a device with which to use the internet (Salmons, 2015), or the required software (Lo Iacono et al., 2016), and there is the potential for technical difficulties or internet disruptions that can interfere with online interviews (Archibald et al., 2019). Furthermore, the participant must remember to log on to their computer and, in the case of Zoom, access and follow the appropriate link at the agreed upon meeting time. Each of these potential pitfalls to conducting online interviews will be discussed in turn below.

### **9.3.1 Nonverbal communication**

As Weller (2017) noted, when interviewing people online, participants generally adopt the ‘talking heads’ orientation whereby the camera captures a close-up of their face. It is

possible that such a close-up view may ‘facilitate a more intimate connection and a feeling of close proximity, conducive to the building of rapport’ (Weller, 2017, p. 617). However, when assuming such an orientation, the other party is only able to see the face and shoulders, which omits important cues that may be expressed using the rest of the body (Lo Iacono, 2016).

Although the camera angle did not permit the full range of nonverbal communication to be conveyed over Zoom, the use of videoconferencing software did allow for me to observe some nonverbal cues that were lost completely when conducting the telephone interviews. As Salmons (2015) points out, with videoconferencing, ‘some nonverbal behaviors such as physical gestures, body posture, [and] facial expressions’ can be observed and used for communication (p. 207). For instance, because I could see participants’ facial expressions, I could tell when people were still thinking about a question or had more to say on a topic. This nonverbal communication was important because it helped with the flow and pacing of the interviews. For example, if I could see when someone had paused yet still had more to say, I could wait before jumping in with my next question. This was much more difficult to achieve over the telephone where it may have led to the introduction of the new questions prematurely.

It should be noted that while I could clearly witness facial expressions over Zoom, I could not always see much in the way of hand gestures because people were generally quite close to their screens and did not always make gestures within view of the camera. Some of the participants also held their devices during the interviews, which meant that their hands were not free. Despite this, there were some notable instances where gestures were an important part of the online interviews. One participant in particular had more difficulty responding to questions verbally and used a lot of gesture to compliment his speech. He tended to make larger gestures that were typically picked up by the camera. These gestures were very important to the interviews because they conveyed a lot of meaning that was not expressed verbally. Through his gestures, I had a better sense of his personality, when he still had more to say on a topic, and when he agreed or disagreed with what his mother was saying. Most of this would have been lost had I not been able to see the participant at all, making videoconferencing software a valuable medium through which to conduct remote interviews.

In addition to being able to see each other's facial expressions and gestures, the researcher and participant can also make eye contact using videoconferencing software. Eye contact is an important part of nonverbal communication (Jongerius et al., 2020; Kleinke, 1986), and it has been recommended that the researcher strive to maintain 'virtual eye contact' with the participant when conducting online interviews (Salmons, 2015, p. 184). Salmons (2015) recommends that the researcher be familiar with their interview questions to reduce the need to look down at notes, thus breaking eye contact. However, Seitz (2015) notes that making eye contact using videoconferencing software can be difficult to achieve 'because looking at the person on the screen is not the same thing as looking at the camera' (p. 232). Despite this, when conducting interviews for this study, it did feel as if natural eye contact was maintained with participants; although, the participants' views were not sought on the matter, so it may not have felt natural to both parties involved.

Finally, when using videoconferencing software, not only can the researcher see the participants themselves, but the participants have the ability to show the researcher objects during the interviews that may be relevant to the topic at hand (Lo Iacono et al., 2016). This happened with two of the participants in this study. When speaking about personal protective equipment (PPE), one participant showed me the face shield he was required to wear at work and another participant showed me a new facemask he had bought. In a further instance, when I asked about the activities a participant did at home, he showed me his laptop, which had a YouTube video loaded on the screen. In each of these cases, it was not necessary that I be able to see these objects, but in sharing them, the participants brought the conversations to life and showed engagement with the topics.

### **9.3.2 Presence of others and lack of control over the environment**

While online interviews provide participants with the flexibility to take part from anywhere of their choosing, Deakin and Wakefield (2014) point out that this can lead to disruptions. They note that distractions in the participant's environment can affect the flow of the interview, the participant's concentration, and the data collected (Deakin & Wakefield, 2014). Such distractions could also include notifications of the participant's device (Howlett, 2022). Furthermore, other people may be within earshot of participants during online interviews, which can have an impact on what the participant chooses to share (Salmons, 2015). There are also implications for confidentiality because 'participants may be unaware of what is within range of their camera and inadvertently disclose something

that they would rather keep private' (Lo Iacono et al., 2016, p. 10). To help control for such potential issues, it has been recommended that participants find a quiet space from which to attend the interview to prevent disturbances (Lobe et al., 2020) and remain stationary to avoid encountering other people or distractions (Seitz, 2015). However, with online interviews, the researcher ultimately has little control over where participants choose to take part.

For the most part, the online interviews in this study were free from outside distractions. On a rare occasion, a pet or television could be heard or a telephone rang, but these rarely interrupted the flow of the interviews. One participant also had the tendency to walk around the room in circles during the interviews, which could be slightly distracting to me as the interviewer but did not cause any notable issues. There were, however, a couple instances when other people, not consented to the study, entered the participants' environments.

It is important to point out here that one participant, Matthew, did complete the interviews with a support person who provided consent to take part in the study as an additional informant as was discussed in Chapter 8. In this instance, the supporter was present and active alongside the participant throughout all of the interviews. This may have influenced what the participant said, but the presence of a supporter was seen as both helpful and necessary. However, even though there was only one consented informant in the study, there were two additional instances where a person other than the participant came within view of the camera. In one case, this was simply the result of a participant's father walking back and forth a couple times to retrieve items from the room in which the participant was sitting. This was fairly unobtrusive and only lasted for about a minute. The other case, however, was of slightly more concern.

As reported in Chapter 8, the mother of one participant, Jennifer, was in the background during both of the interviews with her. Sometimes she was in the room with Jennifer, and other times she was in another room nearby. During the first interview, she was sitting beside her and largely took on a helping role. However, I could not fully see or hear her, so I was not entirely sure what her full contribution was. At times, when I could hear her, I noticed Jennifer was largely repeating back what her mother had said in response to my questions. This led me to question whether I was truly gaining Jennifer's view. In addition, Jennifer expressed some viewpoints when her mother was not in the room that she did not

state in her mother's presence. It became clear that her mother's presence or absence in the room was having an impact on what she would share with me.

### **9.3.3 Access to the internet and videoconferencing software**

It has been noted that some of the downsides to using online interviews are that not everyone has internet access or access to a device 'with the necessary software and the ability and/or the will to use this technology' (Lo Iacono et al., 2016, p. 5). In order to take part in online interviews, participants need to be able to connect to the internet and need to have a device with working speakers, microphone, and camera (Lobe et al., 2020). The use of online interviews can therefore exclude potential participants if they are unable to access or use the technology, obtain the necessary software, or maintain a stable internet connection (Deakin & Wakefield, 2014).

While the use of Zoom did require participants to have access to the internet and a device with which to connect to the internet, it did not require them to sign into an account prior to entering the interview. Zoom is quite straightforward and user friendly, and research participants have compared it favourably to other videoconferencing platforms, such as Skype (Archibald et al., 2019). The only action required by participants on the day of the interview was to click on the Zoom link that had been sent to them via email and follow the on-screen prompts to enter the meeting. All participants in this study had an email address and requested that the Zoom link be sent to their inboxes; although, the links could have just as easily been delivered using social media had the participants not had access to an email account. However, despite Zoom's seemingly straightforward nature, it warrants pointing out that Archibald et al. (2019) found that 88% of the participants in their study had some difficulty joining Zoom interviews.

There were also some difficulties experienced when using Zoom in this study. There was one participant, Kyle, who wanted to use Zoom for his interviews but was struggling to figure out how to set up Zoom on his device and use the meeting hyperlinks. Therefore, the first three interviews with Kyle took place over the telephone, after which his mother was able to help him get Zoom working on his device. I also attempted to walk him through the process of using the Zoom meeting links while we were speaking over the telephone, but I am not sure this was of much help. After those initial three interviews, Kyle was able to access Zoom without any issues, and we conducted the next four interviews using the

software. The option to conduct telephone interviews was important in this case because as Salmons (2015) cautions, ‘the online interview can create or reinforce an asymmetrical power dynamic if the participant feels inept at using the technology’ (p. 228). By conducting the first few interviews over the telephone, we were able to wait for the participant to become familiar and comfortable with Zoom before conducting the remaining interviews online. Had telephone interviews not been an option, the participant may have been left feeling confused and disempowered.

### **9.3.4 Technical difficulties and connection issues**

When conducting online interviews there is always the potential for technical difficulties and problems with connection. Previous research has found that when using Zoom ‘typical technical difficulties included low Internet bandwidth, outdated hardware, or limited webcam and/or microphone functionality’ (Archibald et al., 2019, p. 5). In their study, Archibald et al. (2019) found that 25% of participants experienced issues with video or audio quality when using Zoom, including dropped calls, lost connections, lag, and muffled audio. Further interruptions were found to be caused by problems such as poor webcam functionality, software incompatibility, and low battery (Archibald et al., 2019). According to Seitz (2015), such disruptions can have a ‘negative impact on establishing rapport and maintaining good interview flow’ and negatively affect ‘the research partnership itself’ (p. 230). However, Krouwel et al. (2019) found that the process of sorting out technical difficulties could become a ‘bonding exercise’ between the researcher and participant (p. 6).

While some technical and connection difficulties will not be within the researcher’s control, the researcher can help mitigate such issues when conducting online interviews. For one, the researcher should make sure they are familiar and comfortable using the selected videoconferencing software prior to data collection (Salmons, 2015). They should also make sure they have a stable internet connection ahead of time and consider carrying out a practice run with each participant (Seitz, 2015). It has also been recommended that the researcher anticipate potential technical problems and ‘either learn to fix them, work around them, or find alternatives that could be quickly made available’ (Salmons, 2015, p. 178). For this study, I was already familiar using Zoom, having used it for meetings since the beginning of lockdown a few months prior to the commencement of the study. There was also the option for participants to take part in the interviews over the telephone, an

alternative which could have been utilised in the event that technical difficulties became too great and prevented an interview from being carried out online.

However, despite my familiarity with Zoom, across the online interviews in this study, several technical or connection issues did occur. During three of the interviews, the lag between when someone spoke and when their voice was heard by the other party became quite pronounced. In these instances, neither the participant nor I could be certain when the other person had finished speaking. At times, this led to both of us speaking at once, and in a couple instances this meant that I began to ask a new question while the participant was still answering the previous one. Unfortunately, when this happened, I ended up cutting the participant off and was left with incomplete answers to my questions.

During a couple further interviews, brief interruptions to the connection were experienced. When this happened, it caused me to miss some of what the participant was saying, though it was generally only a word or two and did not affect my ability to understand their reply. There was only one interview where the video was disrupted entirely. In this case, the audio was left intact, and the problem was solved when the participant re-joined the meeting using an alternative device. Overall, the connection issues during the online interviews for this study were trivial, and an interview never had to be terminated as a result.

### **9.3.5 Absentees**

In two previous studies that used both Skype and face-to-face interviews, 5% and 40% participant absentee rates were reported for Skype interviews, while a 100% attendance rate was reported for the face-to-face interviews in both studies (Deakin & Wakefield, 2014). The researchers for these studies felt that the discrepancies may have resulted in part from the relative ease with which participants could avoid attending an online meeting.

Over the course of this study, there was only one instance when the researcher was unable to get in contact with a participant during the agreed meeting time. However, there was a total of four instances in which a participant did not show up for a Zoom meeting at the scheduled time. Each of these four instances occurred with a different participant. When conducting interviews over Zoom, the interviewer is relying on the participant to



remember to follow the meeting link at the agreed upon time. In each instance that a participant failed to show up on Zoom, I stayed in the Zoom meeting and waited for ten minutes before trying to reach the participant by telephone.

The first time a participant failed to show up for an interview over Zoom, I was unable to get in contact with the participant by telephone and left them a voicemail. This telephone call was never returned, but she did answer a subsequent call I made a week later. She said she still wanted to take part in the study but did not want to arrange another interview at that time. We agreed that she would get in contact with me if she wanted to take part in another interview. Unfortunately, she never did get in contact, so I assumed that she no longer wished to participate. Therefore, her failure to attend the scheduled Zoom interview probably had less to do with the medium that was used and more to do with her no longer wanting to take part in the study.

In the other three instances a participant did not show up for a Zoom meeting, I was quickly able to reach them by telephone. In one instance, the participant was out of town and had clearly forgotten that we had arranged an interview over Zoom. He was still willing to proceed with the interview, however, and I phoned him back with a recording device connected to my telephone and conducted the interview by telephone instead. This was the first Zoom interview scheduled with this participant, so up until this point, he had not needed to remember to follow a link or have internet access in order to attend the interviews. I feel that the change in medium probably contributed to his failure to attend the Zoom meeting.

Another participant did not show up for a Zoom interview because he had fallen asleep. However, he answered my phone call, agreed to proceed with the interview, and joined me on Zoom a few minutes later. We decided it would be helpful for me to send him a reminder text an hour or two before each interview and to resend the Zoom link the night before. Had the interviews been conducted in person or over the telephone, these reminders may not have been necessary. The final instance a participant failed to attend a Zoom interview was the result of a scheduling error. The participant's mother had entered the meeting time in her diary for one hour later than I had. When I phoned the participant's mother, both she and the participant agreed to meet me on Zoom right away. This type of scheduling error was not necessarily unique to Zoom and could have occurred with a telephone or in-person interview just as easily.

## 9.4 Comparison to original study

The use of remote interviews was an unanticipated consequence of the Covid-19 pandemic. As explained in Chapter 3, I had originally intended to carry out a different study that included face-to-face interviews. I decided to use telephone and online interviews when it became apparent that the restrictions on in-person meetings were going to continue for at least many more weeks or months. When adopting the use of remote interview methods, I anticipated that they would be inferior to in-person interviews. I was concerned that the participants and I would not feel comfortable with each other and that some of the meanings behind what they said may be lost if I could not see their full range of gestures or the environment in which they lived. I was surprised by how relaxed and comfortable the interviews felt. It did not seem to matter that we were not in a shared space; most of the participants spoke freely and openly in response to my questions.

However, it is possible that I did lose some of the meaning behind what participants said in not being able to see them or their homes. According to Howlett (2022), the researcher does not achieve the same immersive experience when conducting remote interviews, which could impact on the researcher's understanding. I cannot be certain to what extent my understanding of the participants and their experiences would have been impacted by the loss of contextual information and gesture.

When conducting remote interviews, I also worried that participants would fail to show up at the scheduled time or struggle to use videoconferencing software. I was surprised by how reliably my participants attended the interviews. One reason they may have seemed eager to participate in the interviews is they may not have had much else to do. It has been suggested that people were more accessible during the pandemic because they were 'bored, isolated and confined to their homes' and were welcoming of a distraction (Wahl-Jorgensen, 2021, p. 374). This may have been true for the participants in this study. Before the pandemic, they were typically busy working, attending various group meetings, or going to shops and restaurants. At the onset of the pandemic, these activities largely ceased, which meant that the participants were often at home with little to do. I was also surprised by how comfortable the participants were with using Zoom. They had been instructed on how to use Zoom by dates-n-mates and regularly used the video-conferencing

platform for online activities with the group. This meant they were already adept at using Zoom, and aside from one participant, I did not need to explain its use.

Something I had not thought about prior to conducting the interviews was that when using Zoom, I was not only able to see some of the participants' spaces, but I was also inviting the participants into my space. Prior to the pandemic, interviews would have ordinarily taken place at the participant's home or at my office. However, during the time this study took place I, like many people in Scotland, was working from home. This meant that when I conducted interviews over Zoom, participants could see into my flat. This can be a positive aspect of online interviews; when the researcher allows the participant into their space, it can create a more symmetrical relationship (Howlett, 2022).

However, because I was conducting the interviews from home, I had to make sure that no one else could interrupt or hear the interviews. This meant that the person I shared my flat with went for long walks when I had an interview scheduled. It was fairly easy for me to arrange this, but it would be much more difficult for someone who had children or other caring responsibilities, for instance. It is important to encourage participants to take part in the interviews from places where they will be free from interruptions (Deakin & Wakefield, 2014; Johnson et al., 2019; Lobe et al., 2020), but it is equally important that the researcher find a quiet place to conduct the interviews where they will not be disturbed (Seitz, 2015). When conducting interviews from home, sometimes this cannot be helped; someone may come to the door or a neighbour's dog may bark, but interruptions should be minimised as much as possible.

## **9.5 Concluding remarks on remote interviews**

Face-to-face interviews have generally been viewed as superior to telephone and online interviews (Johnson et al., 2019). Indeed, some previous research using both in-person and remote methods has found that remote methods produce interviews of slightly lesser quality than in-person interviews (Johnson et al., 2019; Krouwel et al., 2019). However, other research has found there to be no difference between face-to-face and telephone interviews (Sturges & Hanrahan, 2004) and has even found that participants were more responsive and rapport was built more quickly when conducting interviews online (Deakin & Wakefield, 2014). There are also some benefits to conducting interviews remotely. They save money (Deakin & Wakefield, 2014; Hanna, 2012; Krouwel et al., 2019; Seitz, 2015;

Weller, 2017) and time (Krouwel et al., 2019; Seitz, 2015; Weller, 2017), remove geographical barriers (Lo Iacono et al., 2016), allow the participant to take part from a comfortable environment without feeling the researcher is encroaching on their space (Hanna, 2012; Weller, 2017), help the researcher and participant feel less anxious or 'pressured' (Seitz, 2015, p. 230), and reduce the health and safety precautions that need to be taken (Deakin & Wakefield, 2014)

In this study, 20 interviews were conducted using Zoom and 17 interviews were held over the telephone. While there were some issues resulting from minor interruptions, interference from others, poor internet connections, and absentee participants, overall, these issues were minimal, and the interviews were generally carried out as expected. There was only one instance when a participant could not be contacted during the agreed meeting time. In this case, the participant chose not to take part in the remaining interviews. All other interviews were completed as planned, even in the few instances a participant did not enter the Zoom meeting at the scheduled interview start time. While the quality of the data from the interviews in this study could not be compared to face-to-face interviews, the data collected from these remote interviews were found to address the research questions. It should also be pointed out that the differences in the data between the online and telephone interviews conducted for this study were not analysed. However, while there was some variability between the participants' levels of engagement and the depth of their responses, this did not appear to be the result of the medium through which the participants were interviewed. Both the most reserved and the most forthcoming participants took part in interviews over the telephone.

Because this study was conducted during the Covid-19 pandemic, remote methods of interviewing were required. I was prohibited from meeting with participants face-to-face and had to adapt to the circumstances. Both telephone and online interviews were deemed appropriate for use in this study. Providing participants the option to select the medium through which their interviews were conducted was considered important to the success of the study because it ensured that each participant could access the interviews and felt comfortable using the technology required. While it is unknown how the quality of the data may have differed had the interviews been conducted in person, overall, in this study, both telephone and online interviews were found to produce rich data and to be viable alternatives to face-to-face interviews.

This chapter detailed the researcher's experiences of conducting remote interviews using Zoom and the telephone. It provides information about the considerations that need to be made when using these remote methods of data collection and reflections about the researcher's own experiences. Further reflections on method and recommendations for other researchers attempting to use remote methods are provided in the following chapter. The next and final chapter will provide an in-depth discussion of the issues brought forth throughout this work.

## Chapter 10: Discussion

This chapter provides a comprehensive discussion of the issues raised by this body of work. It begins by briefly outlining the thesis before moving on to discuss key concepts, such as asset-based approaches and social inclusion. It discusses how the Covid-19 pandemic had an impact on people's lives and provides the key implications of this work for policy and practice. The strengths and limitations of this work are outlined, some further reflections on method are provided, and recommendations for further research are detailed. This chapter ends with some concluding remarks about the work that was undertaken for this thesis.

Due to the Covid-19 pandemic, the anticipated trajectory of this body of work was thrown off course. Lockdown was announced in the week that data collection was to begin for the originally planned study. Unfortunately, the methods that were going to be used in this original study could not be used during the pandemic. In an attempt to save this thesis, a new study was quickly devised and submitted to the ethics committee for review in May 2020. Remote methods of data collection were adopted in place of in person interviews and observations. A replacement for the mapping exercise could not be identified, so this part of the original project was abandoned altogether. The resulting project was certainly not what was originally envisaged; however, it demonstrated that valuable primary qualitative research could be conducted during a time when people could not meet in person.

This thesis outlines the original study before moving on to describe the case study that was ultimately carried out. The first primary aim of the case study was to explore how participation in a programme taking an asset-based approach was experienced by members both prior to and during the pandemic and how participation was related to social inclusion and belonging. The second primary aim was to explore the impact of the Covid-19 pandemic on the programme and its members and the adaptations they made as a result. It was found that the programme taking an asset-based approach, dates-n-mates, promoted the social inclusion and belonging of its members and helped to support members during the pandemic, both of which will be discussed in more detail below. Importantly, this case study added to the research exploring belonging among people with intellectual disabilities, an area that was discovered to be under-researched during the systematic review.

In what follows, I discuss the major findings of this body of work in relation to the literature. In particular, I explore how the findings relate to previous work around asset-based approaches and social inclusion and discuss the relationship between the findings and the Covid-19 pandemic. I then go on to discuss the implications for policy and practice, before moving on to the strengths and limitations of this work. Next, I provide some reflections on conducting remote and repeat interviews, including my recommendations for other researchers. Finally, I make some recommendations for further research, before presenting my concluding remarks.

## **10.1 Asset-based approaches**

### **10.1.1 Asset-based approaches and the capabilities framework**

By providing members with opportunities to use their skills and abilities, dates-n-mates demonstrated that it was not only taking an asset-based approach but also helping members to increase their capability sets. Under the capabilities framework, capabilities are understood to be opportunities to do or be certain things (Burchardt, 2004). The capability set represents all of the things an individual has an opportunity to do or be at any given time (Burchardt, 2004). What an individual actually achieves are referred to as functionings (Mitra, 2006). Freedom of choice and agency are essential to the capabilities framework (Burchardt, 2004; Robeyns, 2005; Trani et al., 2011). It does not matter so much what functionings an individual can achieve but what that individual would like to achieve. Importantly, dates-n-mates provided members with opportunities to undertake roles and participate in activities that they valued and wanted to achieve or do.

For one, it was clear that several participants valued taking on voluntary or paid work. Dates-n-mates provided opportunities for members to fill these valued social roles, thereby increasing the capability sets of these participants. These participants were able to be something that they valued being. The organisation also provided opportunities to participate in a wide range of activities and gave members the ability to input on what activities were offered. This provided members with the capability to do some of the things they wanted to do. Dates-n-mates clearly showed that when barriers were removed and opportunities were created, people with intellectual disabilities could fill a wide range of valued social roles or participate in a wide range of activities. Members were able to realise some of the functionings that they wanted to fulfil and may not have had the opportunity to

achieve prior to their participation in dates-n-mates. Dates-n-mates not only provided these opportunities prior to the pandemic, the organisation also provided opportunities for members to do and be what they wanted to do and be during the pandemic as well.

### **10.1.2 Importance of asset-based approaches during the pandemic**

Organisations taking an asset-based approach had the potential to help people cope with the changes and challenges presented by the Covid-19 pandemic. For one, dates-n-mates provided a platform from which members could develop close relationships prior to the pandemic, which they could then draw on for support during the pandemic. In addition, the group adapted its activities to be carried out online during the pandemic, so members would have a space to interact with others and maintain relationships during this time.

This was important because in Scotland, the pandemic resulted in a lockdown and restrictions that prevented people from meeting with others from different households. These restrictions saw the closure of many workplaces, shops, entertainment venues, healthcare services, and activity centres and limited how many times a person could leave their home each day and how far away from home they could travel. The reduced social contact brought about by these restrictions could cause feelings of loneliness (Tull et al., 2020; van Tilburg et al., 2021) and isolation (Brooks et al., 2020; Tull et al., 2020). Therefore, having social connections and a means to socialise during this time were very important. It was found that having a space to interact with close others online during the pandemic was associated with feelings of social connectedness (Tibbetts et al., 2021). By providing members with opportunities to participate in online activities, dates-n-mates could help members feel connected to others during this time.

In addition to providing social support, dates-n-mates also provided members with practical support during the pandemic. Through the collection of social media data, it became apparent that the group helped people navigate videoconferencing software, held workshops to help people manage stress and anxiety, and distributed accessible information about Covid-19. Interview participants said they appreciated receiving guidance on how to use Zoom and how to safely return to public spaces as restrictions lifted. One participant also remarked that the information dates-n-mates provided about the pandemic was easier to understand than the information she received from news reports.



Through this study, it was clear that groups taking an asset-based approach had the potential to provide a range of support to members during the pandemic. It was vital that these groups were able to continue functioning during this time to help people stay connected, feel less isolated, and access information.

### **10.1.3 Asset-based approaches and social inclusion**

The support provided by groups like dates-n-mates was not limited to the pandemic. Groups taking an asset-based approach had the potential to provide members with social benefits outside of the pandemic as well. Dates-n-mates demonstrated how groups taking an asset-based approach could provide people with opportunities that promote social inclusion. The group gave members a social outlet and a reason to go out to public places, supported the development of close relationships, and created opportunities for members to take on valued social roles. Creating these opportunities for social inclusion is important because, as Boelman and Russell (2013) state, ‘supporting people to have experiences which promote social inclusion is essential and can have a significant impact on wellbeing’ (p. 15).

It was clear through the interviews that the participants largely enjoyed going out to public places with the group prior to the pandemic. Dates-n-mates provided members with a way to have a presence in their communities and take part in activities expected of all adults. It also promoted active participation in community-based activities, which is important because social inclusion involves more than physical presence in the community; it requires participation and engagement as well (Cobigo et al., 2012).

Dates-n-mates also clearly allowed for members to develop close reciprocal relationships. Reciprocity relates to having a sense of ‘connectedness that is shared by the individual and the external referent’ (Mahar et al., 2013, p. 1030). During the interviews, participants spoke about feeling connected to and giving and receiving help from the friends and partners they met through the group. Developing these reciprocal relationships is important because reciprocity is key to social inclusion (S.A. Hall, 2009a) as well as a sense of belonging (Mahar et al., 2013). By helping to build networks that create reciprocity and supportive friendships (GCPH, 2011), groups taking an asset-based approach, like dates-n-mates, have the potential to facilitate social inclusion and foster a sense of belonging.

Reciprocity is also significant because it is ‘an important way to challenge implied dependence’ (Milner & Kelly, 2009, p. 57). People with intellectual disabilities typically rely on others for at least some support (Sandjojo et al., 2019). While needing help is not always viewed as a sign of dependence (Bates & Davis, 2004), through the maintenance of reciprocal relationships, people with intellectual disabilities demonstrate that they can give as well as receive support. By giving in a relationship, people with disabilities may feel that their competencies are recognised and that they are fulfilling a role in the relationship (Bredewold et al., 2016).

In addition, dates-n-mates also clearly recognised members’ skills and abilities and provided opportunities to use them. This is in keeping with the values of asset-based work (Friedli, 2012; Sigerson & Gruer, 2011). Throughout the interviews, dates-n-mates members reported hosting activities and taking on paid and voluntary roles both prior to and during the pandemic. By offering a variety of roles through which people could demonstrate their skills, dates-n-mates showed that it valued the strengths and abilities of its members. This is important because asset-based approaches have the capacity to promote social inclusion by recognising people’s abilities and trusting them to perform valued social roles (Cobigo et al., 2012). In helping members take on valued roles, the group provided a platform through which members could achieve a greater sense of social inclusion.

## **10.2 Social inclusion during the pandemic**

While it was clear that groups taking an asset-based approach had the potential to increase social inclusion before the pandemic, social inclusion could be more difficult for people to fully realise during the pandemic. Drawing on the definition of social inclusion proposed by Cobigo et al. (2012), it was clear that the participants in this study often struggled to feel included during this time, and it was likely that many other people in Scotland faced similar difficulties. According to Cobigo et al. (2012), social inclusion can be defined as:

- (1) a series of complex interactions between environmental factors and personal characteristics that provide opportunities to (2) access public goods and services, (3) experience valued and expected social roles of one’s choosing based on his/her age, gender and culture, (4) be recognized as a competent

individual and trusted to perform social roles in the community, and (5) belonging to a social network within which one receives and contributes support. (p. 82)

This definition of social inclusion was used in a study included in the systematic review by Fulton et al. (2021) and selected to build the categorisation matrices for the analysis of the data in this study. This definition was selected because it was comprehensive and included both belonging and reciprocity.

The components of social inclusion included in this definition would have been difficult for anyone to achieve during the pandemic, but they may have been particularly challenging for people with intellectual disabilities to realise. Because most shops and places offering services, such as hairdressers, were closed during lockdown in Scotland, people often struggled to gain access to basic public goods and services. Many healthcare services essential to people with disabilities were also closed or had reduced capacity, which could make it difficult to access much needed care (Jesus et al., 2021).

In addition, while people may have filled social roles, such as work and voluntary positions, before the pandemic, the closure of many workplaces meant that a lot of people were unable to continue in their roles during this time. Three participants in this study faced workplace closures due to the pandemic. Losing a job during this time could have a significant impact on people with intellectual disabilities because it could further diminish the relatively small and fragile social networks people with intellectual disabilities tended to have prior to the pandemic (Embregts et al., 2022). Two of the participants in this study mentioned that they had missed their co-workers while their workplaces were closed. To compound this problem, people were unable to see other people outside their households in person, which limited people's opportunities to socialise and connect with others. Based on Cobigo et al.'s (2012) definition, it is evident that while lockdown measures may have been necessary to curb the spread of Covid-19, these measures had a negative impact on social inclusion.

Furthermore, while the participants in this study took part in regular social activities throughout the pandemic, this was not the case for many other people. In a study that spanned multiple continents it was found that participants rarely took part in social activities during lockdown, which the authors said put them at risk of social exclusion

(Ammar et al., 2020). Taking part in activities was previously identified as a key component of social inclusion (S.A. Hall, 2009a), so this lack of activity further highlights that many people struggled to attain social inclusion during the pandemic. This lack of activity could also decrease opportunities for encounter, a potential pathway to social inclusion (Bigby & Wiesel, 2011), which will be discussed in the next section.

### 10.3 Encounter

Through the interviews for this study, it was clear that encounter was important to one of the participants. Before the pandemic, he frequented some of his local restaurants and went to the same hairdresser each time he got his hair cut. He said that the people in these places knew his name and that they had friendly chats. He even referred to the staff as friends, and it was evident that he valued these relationships. These more sustained encounters seemed to make him feel like he was a part of his community. His accounts of these encounters illustrated how encounter could lead to social inclusion. They also resonated with findings by Wilton et al. (2018) that showed that repeated service interactions could offer people ‘moments of social connection and recognition’ (p. 18).

According to Bigby and Wiesel (2011), lasting relationships that are forged outside of the family begin with such encounters with strangers. Because of this, they see encounter as ‘an essential inroad’ to social inclusion (Bigby & Wiesel, 2011, p. 261). Put simply, community encounters are ‘meetings between strangers that can be fleeting or more sustained’ (Simplican et al., 2015, p. 25). Bigby and Wiesel (2019) explain that encounters include ‘exchanges between neighbours, consumers, and shopkeepers, passengers and taxi drivers, strangers standing in a queue or sitting in a bar, beggars, and passers-by’ (p. 40). Encounter is important because repeated encounters have the potential to lead to friendship (Bigby & Wiesel, 2019). In addition, the authors argue that encounter should be valued in itself as an ‘essential element of social inclusion’ (Bigby & Wiesel, 2019, p. 41).

However, while there can be positive outcomes from encounter, not all encounters are positive or lead to social inclusion, and they can even be exclusionary (Wiesel et al., 2013). According to Valentine (2008), encounters are shaped by expectations of appropriate behaviour and can ‘represent a tolerance of others in shared space’ (p. 329). She goes on to explain that with tolerance comes ‘an implicit set of power relations’, and that tolerance ‘is a courtesy that a dominant or privileged group has the power to extend to, or withhold

from, others' (Valentine, 2008, p. 329). Therefore, through encounters, people may simply be extending courtesies they feel are expected of them rather than truly being accepting of the person they are interacting with. These interactions may only be superficial and are unlikely to lead to actual inclusion. Furthermore, encounters can even contribute to exclusion when comments or gestures are made to signal someone is not welcome (Wiesel et al., 2013). However, whether positive or negative, encounters with strangers largely ceased during the pandemic as people were confined to their homes and began to connect with others online instead of in person. The participant in this study clearly missed the regular encounters he had with others prior to the pandemic, even if the exchanges could be viewed as superficial.

## **10.4 Moving online during the pandemic**

### **10.4.1 Connecting online**

As opportunities for in-person social interaction and encounter ceased during the pandemic, the participants in this study largely began to socialise online. During this time, the overall use of technology increased (Ammar et al., 2020). From December 2019 to April 2020, the number of Zoom users increased thirtyfold (Hay, 2020). Some organisations took advantage of this communication medium and adapted to lockdown by quickly moving meetings online (Chadwick et al., 2022). For instance, dates-n-mates opted to use Zoom for chats, activities, and events. McFerran et al. (2022) likewise adapted the in-person music groups they held before the pandemic to an online format. The use of video calls provided people with an important way to connect with others during the pandemic. Being able to see others, even if only through a screen, can provide a high degree of social presence (Short et al., 1976). This is important because media with 'a high degree of Social Presence are judged as being warm, personal, sensitive and sociable' (Short et al., 1976, p. 66). Speaking with others using video calls likely helped people to feel more connected to others than they would have using other remote communication methods, such as the telephone, email, and texts.

While the use of videoconferencing software, such as Zoom, can be discussed in relation to social presence, there does not exist a body of literature looking at people's experiences communicating using video calls. This was remarked upon by Hay (2020) in relation to Zoom; although, this paper does little in the way of furthering the discussion. In this case

study, the use of videoconferencing software provided participants with a way to see their friends and a space to feel connected during a time when they were physically apart. Participants liked being able to chat and see their friends' faces. During the calls themselves, dates-n-mates members were engaged in the conversations and activities and chatted with each other openly. They seemed to enjoy their time together, and for some members this simple act of coming together online provided a lifeline during the pandemic. Throughout this study, it became clear that having the ability to connect with people using video calls was hugely important to participants' sense of wellbeing.

While they likely did not provide the same level of social connection as Zoom, participants in this study also reported using social media to communicate during the pandemic. According to Shpigelman (2018), interacting on Facebook through 'likes' and posts can also give people a sense of social presence that can help make up for physical distance. Furthermore, they found that having visibility and popularity on Facebook could create a sense of belonging and community (Shpigelman, 2018). However, J.A. Hall (2018) notes that interacting on social media is rarely considered by users to be social interaction. Very little time spent on social media is used to chat with others or post on others' walls (J.A. Hall, 2018). It is possible that this may have changed during the pandemic; although, given that social media interactions tend to be asynchronous, it is unlikely that they held the same importance, or provided the same degree of social presence, as video calls. This point was illustrated by a participant in this study who said he preferred speaking by video call because he liked to speak to others 'face-to-face'. It was clear through the interviews that having access to more synchronous methods of online communication where the speakers were visible to each other could have been very important to some people during the pandemic.

#### **10.4.2 Benefits of moving groups online**

Through the interviews for this study, it was clear that when groups moved online during the pandemic, they not only allowed people to see each other and experience a high degree of social presence, but they also provided people with a meaningful way to spend their time and socialise with others. Many participants spoke about how they would have experienced additional boredom or loneliness without the online chats and activities held by dates-n-mates. They also enjoyed having opportunities to meet new people through online activities. McFerran et al. (2022) likewise found that their online music groups

helped build a sense of community and allowed participants to meet new people during the pandemic. It was clearly important to people that they were provided with opportunities to socialise and connect with others during this time.

In addition to providing people with a meaningful way to socialise and spend their time, online groups could also provide routine. By providing regularly scheduled activities, groups such as dates-n-mates could help establish routine in participants' lives. This could provide structure to people's days and, as evidenced by one participant in this study, give people a reason to keep a healthy sleep routine. This is important because many people with intellectual disabilities lost their daily routines during the pandemic (Kim et al., 2021). A loss of routine could be distressing to people during this time (Brooks et al., 2020). Scheffers et al. (2021) found that routine was important to people during the pandemic because it could provide feelings of safety and a sense of control. However, while there are clear benefits to participating in online groups, evidence suggests that some people may have experienced difficulties accessing these groups and that there was a preference for face-to-face communication.

### **10.4.3 The downside of online interactions**

While most of the participants in this study seemed to appreciate having online activities during the pandemic, they consistently said they would prefer to see people in person. Chadwick et al. (2022) similarly found that carers, professionals, and people with intellectual disabilities felt that online communication was not the same as meeting in person, and that they sometimes expressed an eagerness to return to face-to-face communication. In addition, two of the participants in this study expressed a strong desire to be able to give their friends and family members hugs. This is in line with findings by Embregts et al. (2022) who found that people could miss the physical contact that could only come from meeting in person.

In addition, some of the participants in this study reduced their engagement in online activities over time and were looking forward to a return to in-person meetings. Furthermore, one participant found it difficult to engage with others through video calls. While it has been found that social interaction through any medium helps create feelings of relatedness and develop closeness (J.A. Hall, 2018), many people find that online communication is not an adequate substitute for face-to-face communication (E. Hall,

2021). The participant in this study, for instance, found that he was unable to make friends through online chats and activities and found it difficult to follow conversations online. It has also been found that online support from carers cannot completely replace in-person support due to the shortcomings of this medium, such as not being able to fully read non-verbal communication (Scheffers et al., 2021). Online interactions have also been found to be associated with more stress and negative affect (Tibbetts et al., 2021).

The frequent use of video calls during the pandemic could also lead to ‘Zoom fatigue’ (Wiederhold, 2020; Williams, 2021). The term ‘Zoom fatigue’ came into use in 2020 to describe the fatigue and impaired wellbeing people were experiencing due to the excessive use of video calls to communicate (Williams, 2021). Communicating by video call is more psychologically demanding than communicating in person (Williams, 2021). This is due to a number of reasons, such as, an increased need for concentration, a reduced ability to read body language, difficulty detecting humour and relaxing into conversation, and a lack of complete synchrony (Wiederhold, 2020; Williams, 2021). Overall, it is clear that interacting in person is typically more desirable than interacting online and that online interactions cannot fully replace in person communication. While moving interactions online may have been of great benefit to many people during the pandemic, there should be caution when moving in person activities online going forward.

## **10.5 Challenges since the pandemic**

While this research took place at the height of the pandemic in 2020, at the time of writing, restrictions have now ceased, and people have largely returned to their pre-pandemic lives. Unfortunately, the experiences and knowledge gained during the pandemic do not appear to have created beneficial change in the lives of people with intellectual disabilities. For instance, despite the newfound awareness of the importance of being able to access the internet, there does not appear to be much initiative to eliminate digital exclusion and make sure people with intellectual disabilities can get online (Chadwick et al., 2022), a point which will be discussed in more detail below.

In addition, many voluntary organisations that provided opportunities for people with disabilities ceased to operate during the pandemic and have found it difficult to restart activities since restrictions lifted (E. Hall, 2021). This was not the case for dates-n-mates, but it was evident that had the group been unable to operate, it would have had a



detrimental effect on members' lives. However, even when there were opportunities to return to in-person activities, it could cause anxiety and stress (Silence et al., 2021). Participants reported that they could find it difficult to adjust to new guidelines in public places and expressed anxiety over seeing friends they had not seen for many months. This resonated with work by Silence et al. (2021), who found that over 70% of respondents felt anxious or stressed about a return to face-to-face activities. While people seemed to welcome the relaxing of restrictions and looked forward to an end to the pandemic, it was clear that a return to pre-pandemic life could come with its own set of difficulties.

## **10.6 Support during the pandemic**

### **10.6.1 Breakdown of networks of support**

One of the largest difficulties people with disabilities faced during the pandemic was a breakdown in networks of support. In this study, one participant went without necessary care and support for several months during the pandemic. His case clearly illustrated the negative impacts that a lack of care could have on the lives of people who depend on support for activities of daily living and to leave their homes. Unfortunately, his experience was not unique. The pandemic exacerbated the disparities people with disabilities experienced in health status, health outcomes, and healthcare access (Jesus et al., 2021) and 'exposed and magnified the existing frailties in social care' (Pearson et al., 2022, p. 12).

Furthermore, like the participant in this study, people who relied on personal assistance or caregiving often found that their care was reduced, interrupted, or discontinued as a result of the pandemic (E. Hall, 2021; Jesus et al., 2021; Pearson et al., 2022). It was found that, in Spain, over half of the people with intellectual and developmental disabilities surveyed indicated that they did not have access to the services and professional supports that they needed (Navas et al., 2021). Similarly, in the UK, it was found that many people with intellectual disabilities used support services less frequently or not at all during the pandemic (Flynn et al., 2021). Care workers themselves were often under strain during this time and sometimes had to isolate because either they or their family members had an underlying health condition that necessitated it, which could leave people without support (Pearson et al., 2022).

Even when people did have access to services, the quality of care could be affected by the pandemic. Professional carers reported that the quality of contact they had with the people they supported decreased significantly during the pandemic, which was largely due to the reliance on remote methods of support (Scheffers et al., 2021). Two of the participants in this study mentioned that they had been in contact with support workers by video call. They did not remark on the quality of this care, but it was evident that one of the participants missed being able to see her support worker in person. It also became apparent that a lack of professional support networks during this time could lead to an increased reliance on family support.

### **10.6.2 The role of family**

Four of the six participants in this study lived with their parents during the time of the interviews and relied on them for support. During the pandemic, the restrictions could result in an over-reliance on family support (Redquest et al., 2021). A study conducted in Spain by Navas et al. (2021) revealed that family was the main support for nearly 73% of the people with intellectual and developmental disabilities surveyed. This reliance on family was likely intensified by the fact that many people with intellectual disabilities were unable to access their usual sources of formal support during the pandemic (Flynn et al., 2021).

Many families also decided to move their relative with an intellectual disability home during the pandemic to allow for them to maintain contact or provide a continuity of care. One of the participants in this study had lived independently prior to the pandemic but moved home when the first lockdown was announced. Her parents were concerned that they would not be permitted to see each other during the pandemic due to the social distancing guidelines prohibiting the mixing of households, which would have left her without support. She and her parents worried that she would not have been able to cope on her own, so despite the fact that she wished to live in her own flat, a return to her parents' home was considered to be the better option. There was clearly tension created between her desire for independence and her need for support during the pandemic, and she often expressed frustration that she was living with her parents.

This participant's situation was not unusual. For instance, it was found that some mothers moved their children home from residential facilities at the onset of the pandemic because

they were afraid of being separated from their children (Vereijken et al., 2021). These mothers found that they could have difficulties balancing their wishes with those of their children and their children's autonomy during this time (Vereijken et al., 2021). However, this move was often deemed essential for practical reasons. Access to family members with intellectual and developmental disabilities who did not live at home could be restricted or even prohibited by services during the pandemic (Rose et al., 2022).

Providing continual support could be extremely demanding on families, particularly when it was being carried out alongside work commitments (Rose et al., 2022). A study reported by Hatton et al. (2023) found that the self-reported general health of family caregivers in the UK decreased during the pandemic. In addition, one participant in this study expressed concern over the demands his care placed on his mother. Kim et al. (2021) similarly found that people with intellectual disabilities could feel they placed an increased caregiving burden on their families during the pandemic. However, even when professional support was available, some families opted not to receive this support because they wanted to minimise their risk of being exposed to Covid-19 (Hughes & Anderson, 2022; Pearson et al., 2022). It was clear that most caregiving fell to families because other options either separated people from their family members, posed a risk, or were simply unavailable.

The importance of family for providing support during this time is readily apparent. However, some people with intellectual disabilities did not have access to family support or did not receive enough support during this time. This was clearly illustrated by one participant in this study. This individual lived alone several miles away from his family, and he was also shielding. Because he lived on his own during this time, he had to take responsibility for his basic needs and knowledge surrounding the pandemic. He was left feeling vulnerable, and his difficulties caring for himself and connecting with others during the pandemic had a negative impact on his mental health. Other people likely faced similar situations. Nearly a third of people with intellectual and developmental disabilities surveyed in Spain reported that they did not receive more frequent support or contact from family during the pandemic (Navas et al., 2021). The social distancing guidelines and restrictions on movement could make it difficult for family to provide support to their family member with intellectual disabilities if that individual lived in another household. Overall, it is clear that there could be major repercussions for both individuals and families when people were unable to access the care and support they needed during the pandemic.

## 10.7 Impact of pandemic on health and wellbeing

The Covid-19 pandemic had a massive impact on people's health and sense of wellbeing. As discussed in the previous sections, it could lead to a reduction in care and support. In addition, it could lead to an increase in negative emotions. One participant in this study likened the confinement and isolation he felt during lockdown to being in prison and another said that it felt like being in a cage. All but one of the participants mentioned feeling bored during the pandemic, and most had experienced loneliness. Furthermore, for the participant living on his own during the pandemic, it was clear that the confinement and isolation of lockdown had decreased his mood significantly and left him with feelings of helplessness. This is in keeping with findings by Brooks et al. (2020) who found that during pandemics, being confined, losing routine, and having less social and physical contact with others could cause frustration, boredom, and feelings of isolation.

In addition, Covid-19 could have a direct impact on the people's physical health. In Scotland, adults with intellectual disabilities were found to be more likely to become infected with Covid-19 and to develop severe illness than the rest of the population (Henderson et al., 2022). This could further increase experiences of negative emotions. People with intellectual and developmental disabilities could recognise their vulnerability to Covid-19 and live with increased anxiety as a result (Hughes & Anderson, 2022). Two participants in this study were clearly very frightened of contracting Covid-19. According to Usher et al. (2020), this fear is a common response to infectious disease outbreaks. Being in lockdown has also been found to be associated with greater health anxiety (Tull et al., 2020). It is clear that the circulation of a potential deadly virus and the resulting restrictions caused people a considerable amount of anxiety. This anxiety could then be exacerbated by a lack of clear and consistent messaging about the pandemic (Usher et al., 2020).

According to Usher et al. (2020), people may have perceived that they were given mixed messages from the government about the pandemic, which could cause confusion, uncertainty, and fear. In addition, misinformation and disinformation also spread, which could make it difficult to fully understand what was happening during the pandemic (Xie et al., 2020). Furthermore, news reports could be inaccessible for people with intellectual disabilities, which could further increase anxiety (Fudge Schormans et al., 2021). One

participant in this study mentioned that the information about the pandemic could be confusing.

## 10.8 Breaking the rules of the pandemic

Even when people had access to adequate information about the pandemic, they sometimes decided to disregard the guidelines. Two participants in this study mentioned that they had gone against the social distancing guidelines. One of the participants was clearly struggling with boredom and loneliness during the pandemic and was desperate to socialise with others. He visited with his cousins during a time when households were not permitted to mix. Another participant wanted physical intimacy with his partner. He knowingly went against the guidelines because he felt that if other people were breaking the rules, he should be able to break the rules as well. In both cases, the participants appeared to be going against the guidelines in an attempt to meet their emotional needs.

During the early stages of the Covid-19 pandemic in the UK, most people complied with the government guidelines (Clarke & Barnett, 2022). Non-compliance was found to be associated with gender and age, with men and younger people reporting that they broke the restrictions more often than women and older people (Rosha et al., 2021). A proneness to boredom was also found to be associated with non-compliance (Boylan et al., 2021; Drody et al., 2022). Compliance, on the other hand, was associated with a person's surroundings and resources (Leather et al., 2022). Having access to cars, video conferencing software, delivery slots, and uncrowded spaces were found to help people stay home and adhere to social distancing guidelines (Leather et al., 2022).

While the guidelines were in place to stop the spread of Covid-19 and keep people safe and physically healthy, complying with the restrictions could have negative impacts on people's mental health. For instance, compliance was found to be associated with increased loneliness among women (Wright et al. 2021). In addition, some people may have felt they could not continue to distance from loved ones because it caused mental distress (Leather et al., 2022). It was found that during the pandemic, people often sought to reduce risk to themselves and others by following the guidelines, but at the same time, they sometimes decided to take risks (Clarke & Barnett, 2022). Risk-taking could be justified and deemed acceptable or essential for a number of reasons, including for one's wellbeing (Clarke & Barnett, 2022). This appeared to be the case for the two participants in this study.

It is also important to point out that some people simply may not have been able to follow the guidelines as they were originally set out. Social distancing is not always possible for people with intellectual disabilities (Goggin & Ellis, 2020). As evidenced by this study, people may need support with daily tasks that require close proximity to personal assistants or carers. In addition, it could be difficult for people with intellectual disabilities to understand the abrupt end to physical interaction (Goggin & Ellis, 2020). It is clear that there were instances where following the guidelines was not possible or caused a significant amount of distress.

## **10.9 Implications for policy and practice**

Now that key findings have been discussed in relation to topics surrounding asset-based approaches, social inclusion, and the pandemic, I will turn to a discussion of some of the implications these findings have for policy and practice.

### **10.9.1 Should there be support for asset-based approaches?**

It is clear that if dates-n-mates were to cease operations, members would be without a vital platform through which they can form close reciprocal relationships, socialise, participate in a range of community-based activities, and fill valued social roles. In short, its closure would have a negative impact on members' social inclusion. Dates-n-mates continued to receive adequate funding to operate throughout the duration of this study; however, projects taking an asset-based approach often struggle to get funding (McLean & McNeice, 2012). A lack of funding can cause these projects to cease, which can then leave people unable to access activities they enjoyed (Boelman & Russell, 2013). Based on the findings from this study, the benefits that these programmes can offer participants highlight the importance of continuing to fund groups like dates-n-mates. However, despite these benefits, asset-based approaches are not immune from criticism.

Asset-based approaches have gained momentum in recent years in response to state spending cuts (Macleod & Emejulu, 2014). As Friedli (2012) states, they are 'part of efforts to reduce "unaffordable demand," to achieve public spending cuts and to promote a DIY response to loss of services and loss of benefits' (p. 8). According to Macleod and Emejulu (2014), 'ABCD [Asset-Based Community Development] is neoliberalism with a

community face, meaning that logic of free market relations and a hostility to state-sponsored social welfare is the central unacknowledged value embedded within this theory and practice' (p. 446).

It does appear that the recent proliferation of asset-based approaches in Scotland may be in response to funding cuts that demand that people make up for where the state is failing. It is easy to critique asset-based approaches for furthering a neo-liberal agenda. However, while this critique should not be ignored, without asset-based approaches, people would be left lacking vital opportunities and resources. We cannot do nothing. The burden should not be placed on voluntary organisations taking an asset-based approach to provide for their communities, but these organisations should be supported to operate. They should not be used as a substitute for state funding, and they should be nurtured and valued for what they can bring to people's lives. Policy should support the creation and continuation of asset-based approaches and advocate for the funding of programmes like dates-n-mates to ensure that people have access to groups that provide them with opportunities to feel valued and included in their communities.

### **10.9.2 Addressing the digital divide**

Organisations taking an asset-based approach can also play a role in helping to bridge the digital divide. All of the participants in this study were able to access the internet and take part in online activities with dates-n-mates during the pandemic. When conducting the interviews, it was clear that the participants were largely familiar with their devices and navigating Zoom. During the pandemic, dates-n-mates provided workshops to members on topics such as the technical aspects of using Zoom and staying safe online. The pandemic highlighted the need for people with intellectual disabilities to be able to access the internet, and dates-n-mates showed that with the right support, many people with intellectual disabilities could learn to navigate the internet safely.

Prior to the pandemic, it was found that people with intellectual disabilities were not accessing the internet to the same extent as the rest of the population (Chadwick et al., 2013), and this situation continued for many people during the pandemic. This was due to several reasons, such as a lack of access to appropriate devices and adequate support, an inability to pay for internet service or data, and unreliable internet service (Fudge Schormans et al., 2021; Seale, 2022). Having adequate support has been found to be

particularly important for people with intellectual disabilities to be able to access the internet and experience digital inclusion (Alfredsson Ågren et al., 2020; Barlott et al., 2020). However, the people supporting people with intellectual disabilities to access the internet could also place restrictions on its use, which could constrain digital inclusion (Barlott et al., 2020). Supporters could also withhold assistance because they felt that people with intellectual disabilities were too vulnerable and needed to be protected from the risks related to going online (Seale, 2022). According to Chadwick et al. (2013), prior to the pandemic, there was a need to raise awareness of the benefits of internet use among supporters.

The digital divide is concerning because having access to the internet can bring benefits to people with intellectual disabilities, such as allowing for social connection and access to information and providing independence (Glencross et al., 2021). During the pandemic, service providers, educational, health, and social care professionals, and caregivers were made aware of the digital exclusion faced by people with intellectual disabilities (Chadwick et al., 2022). However, they often ‘underestimated people's ability to use ICT [information and communications technology]; were unwilling to provide the effort to train and support ICT use; and were often not adequately trained (digitally competent/literate) themselves’ (Chadwick et al., 2022, p. 252).

During the pandemic, it became clear why it was important for people with intellectual disabilities to know how to use ICTs (Seale, 2022). People with intellectual disabilities, like the rest of the population, were unable to interact with people from other households in person. Thus, the need for online social interaction was readily apparent. This study illustrated how important having online interactions could be for people with intellectual disabilities during this time. They helped participants maintain valuable connections with their friends, ward off the boredom of lockdown, and create a supportive community. The importance of the internet to maintain connections with others was recognised by the government during this time.

The Scottish Government launched a programme during the pandemic called Connecting Scotland to help people on low incomes access the internet. This programme provided digital devices and practical support to people who were digitally excluded (Scottish Government, 2022a). Some people with intellectual disabilities may have benefited from this programme; however, it does not address all of the specific barriers faced by people



with intellectual disabilities when trying to access the internet. In addition, not all people with intellectual disabilities would have been eligible to participate in this programme due to their income or been aware that this support was available. Similar programmes could be launched to help support people with intellectual disabilities specifically and help to bridge the digital divide.

### **10.9.3 Families need more support**

Throughout the interviews it also became clear that the families of people with intellectual disabilities need more support. It was found that most people with intellectual and developmental disabilities received support from their families during the pandemic (Navas et al., 2021), including the majority of participants in this study. According to Scherer et al. (2022), there was an expectation from service providers and governments that families would become the primary care providers during this time. There could also be an over-reliance on family because many people with intellectual disabilities could no longer carry out their usual routines that included spending time out of the home and with other people (Redquest et al., 2021). In addition, the pandemic could compound the typical stressors encountered by family caregivers (Rose et al., 2020). It was found that mothers caring for a child during the pandemic could have little time to themselves (Embregts et al., 2021) and that informal carers had high levels of mental health problems during this time (Willner et al., 2020). Furthermore, the majority of family caregivers reported that they experienced tiredness, feelings of stress, and sleep disturbances during the pandemic (Hatton et al., 2023).

According to Willner et al. (2020), the pandemic demonstrated that it is families that provide the safety net when the system shuts down, and they argue that family carers need consistent long-term support. As mentioned previously, four out of six of the participants in this study lived with their parents during the pandemic. Three of these participants typically received help from support workers or personal assistants. However, these sources of professional support largely ceased during lockdown. While the parents were not interviewed as a part of this study, it was clear through the interviews with their children that they were providing crucial support during this time in addition to juggling work. In line with what Willner et al. (2020) found, it was evident that families needed a more robust system of support. While the Scottish Government published advice for unpaid carers during the pandemic (Scottish Government, 2023), policy did not reflect the

enormous challenges faced by carers during this time or lead to the support that family carers were in need of. Moving forward, policy must be aimed at providing unpaid carers with more support.

#### **10.9.4 Difficulties making informed decisions**

Whether people had access to family support or not, it became apparent through the interviews that it was important for participants to be able to access clear and reliable information about the pandemic. Dates-n-mates helped its members access information about the pandemic by providing it in multiple formats. For instance, they produced easy read information about Covid-19 and the changes to the guidelines during the pandemic that they shared via social media. They also held online workshops for members to learn how to safely return to the community as restrictions began to ease.

Other organisations attempted to develop accessible resources about Covid-19 and the pandemic. Easy read information about Covid-19 and how to keep safe were created by organisations such as Photosymbols and the National Health Service (NHS). It was clear that producing and distributing accessible information about the pandemic could be accomplished relatively easily if organisations made the decision to do so. Producing accessible information is important. A study of the experiences of people with mild intellectual disabilities during the Covid-19 pandemic found that participants felt responsible for their health and the health of others (Embregts et al., 2022). In order to act responsibly during this time people needed to have access to reliable and trustworthy sources of information about the pandemic and Covid-19.

However, Chadwick et al. (2022) noted that when accessible material was published online, people with intellectual disabilities could struggle to find it and that at times, there could actually be too much easy read information, which could cause confusion. The difficulties people could experience in finding clear information about the pandemic is concerning because this (lack of) information could lead to people making decisions that could potentially put their health and the health of others at risk. The pandemic highlighted the importance of disseminating accurate information in both a timely and easily accessible way. In the future, more efforts should be made to increase the accessibility and reliability of vital health related information. Making this information available should become common practice.

## 10.10 Study strengths and limitations

After providing a detailed discussion of the findings and illustrating some of the implications for policy and practice, it is important to point out that this body of work had some strengths as well as several limitations.

One strength of this study was that it was designed to allow for qualitative research to take place during the pandemic when in-person research activities were prohibited. Interviews were conducted over Zoom and by telephone, which eliminated the need for in-person contact. These remote methods were found to be effective, as discussed in Chapter 9. In addition, in-person observations were substituted with online observations and the collection of social media data. These did not provide as much information as in-person observations would have, but they did allow for the remote collection of some observational data and gave a sense of members' participation and engagement in online activities. Overall, this study showed that qualitative research could be successfully carried out during the pandemic.

Another strength of this work was that interview participants were followed up over time. Five of the six participants were interviewed seven times over a period of three months. As will be discussed in more detail below, this captured changes that had occurred in participants' lives during the pandemic and showed how their interactions with other people and the community evolved as the restrictions in Scotland changed. This allowed for a clearer picture to develop about participants' lives and their interactions with dates-and-mates during this time. If only single interviews had been conducted, it would not have been possible to capture the participants' responses to unfolding events.

In addition to its strengths, this work also had limitations. First of all, this project did not allow for a complete exploration of participants' social inclusion. The original study had been designed to capture participants' physical presence, community participation, and belonging and to situate inclusion within participants' daily lives. Due to the pandemic, this was no longer feasible. People did not have a presence in their communities and did not participate in community-based activities during this time. Belonging was also difficult to explore during the pandemic because people were largely separated from the groups to which they felt they belonged. Therefore, while the current study does explore social

inclusion, this research was not carried out in the anticipated context or using the innovative approaches that had been planned.

In addition, all of the interview participants had internet access during the pandemic. Internet access was not required for the study; people were invited to participate by telephone if they chose, and participant packs were posted to participants' homes. However, all participants who agreed to take part in the study had internet in their homes and were able to join the online activities with dates-n-mates over Zoom. It is important to point out that not all dates-n-mates members had internet access during this time. It is possible that these members would have felt differently with respect to their social inclusion and sense of belonging than the members who were able to access the online activities. Unfortunately, the views of people without internet access were not included in this work.

All of the participants had mild to moderate intellectual disabilities. No one with severe or profound intellectual disabilities volunteered for the study, so the views of these groups are not represented by the results. All participants were also able to engage fully with the interview process and articulate their views. Most participants also had family and financial resources that may not be typical of all people with intellectual disabilities. Four participants lived at home with at least one parent during the pandemic, and a further participant, who lived in his own flat, had regular support from his family. Only one participant was left without regular family support; however, he mentioned having a close relationship and regular telephone contact with his mother. No participants lived in supported housing, with flatmates, or with partners. The views in this study reflected those of people who lived in the family home or had close relationships with their families. All participants also had the financial resources to afford membership with dates-n-mates and to participate in regular activities. The experiences of the pandemic for people without these family and financial resources would have likely been much different from those represented by the results of this study.

Furthermore, while multiple methods of data collection were used to inform the larger case study, only interview data were used to inform the embedded cases. It may have been useful to see photographs from participants' daily lives, for instance, or to have more information about their engagement with the dates-n-mates activities through additional observations. The larger case study would also have benefited from additional data

collection. It would have been useful to get the views from dates-n-mates staff about what it was like to run the group during this time. However, the data had to be collected and analysed within a reasonable timeframe given it formed part of a PhD. Including additional methods of data collection would have enriched the study, but it also would have made it unmanageable to complete in the required timeframe.

While one of the strengths of this study was the use of several follow-up interviews with each participant, these follow-ups spanned a relatively short period of time. The interviews all took place during a period in which the lockdown measures were easing in Scotland. Only one participant was interviewed after additional restrictions were introduced on the 23rd of September 2020. The study would have offered additional insight into peoples' experiences during the pandemic had the participants been followed up through the second lockdown that went into effect in Scotland on the 4th of January 2021. It would have been interesting to explore participants' views on the second lockdown and get a sense of how this lockdown was experienced in relation to the first. However, at the time that the study was designed, it was not known how long the pandemic would last, and the study parameters had to be defined when seeking ethical approval. As mentioned above, this work also formed part of a PhD and needed to be manageable within the time allotted for the degree programme.

Finally, this study only included six participants. This number was deemed suitable for an embedded case study that was longitudinal in nature. A lot of data were generated through the 37 interviews conducted with these six participants. Interviewing additional participants may have resulted in an unmanageable amount of data. While many of the participants' stories resembled each other, they continued to offer unique experiences and perspectives. Having additional participants would have likely added insights and observations that were missed by this research.

## **10.11 Reflections on method**

After detailing some of the strengths and limitations of this body of work, I will now provide some reflections on conducting remote and repeat interviews, as well as outlining some recommendations for other researchers who may be considering remote methods of interviewing. I will also reflect on the usefulness of conducting the embedded case studies

and how developing the individual narratives allowed me to have deeper insights into the key concepts explored in this thesis.

### **10.11.1 Online interviews**

Although it may have been preferable to speak to people in person, it was not possible to meet face-to-face to conduct interviews during the pandemic. However, there could be some benefits to conducting remote interviews during this time. For one, people were often bored and isolated and welcomed the distraction that interviews could bring (Wahl-Jorgensen, 2021). In addition, Zoom interviews could feel more comfortable and relaxed than in-person interviews because both the interviewer and the participant could choose their environment and control their self-presentation (Wahl-Jorgensen, 2021). Remote interviews also allowed for participants to be interviewed from across Scotland. The original project consisting of in-person interviews was only going to be carried out in Glasgow, where I am based, due to time and financial constraints.

Online interviews have also been found to be just as long as in-person interviews and to allow for personable exchanges (Howlett, 2022). Additionally, during the pandemic, they invited the participant into the interviewer's environment by allowing them to see into the interviewer's home, which could then lead to a more equal power dynamic (Howlett, 2022). Finally, by moving interviews online, it allowed for primary qualitative research to be carried out during the pandemic. While online interviews do not allow the interviewer to have a fully immersive experience (Howlett, 2022), this study showed that they can be used to connect with participants and collect rich data. The participants in this study engaged well with the interviews and were nearly always ready and waiting to take part in each follow-up. Like taking part in online groups, participating in online interviews seemed to provide people with a meaningful way to spend their time and interact with others despite the social distancing guidelines. Overall, the use of remote interviews in this study was not found to have had an impact on the quality of the data collected, and it showed that online interviews could be used successfully with participants with intellectual disabilities when they had basic IT skills.

### 10.11.2 Recommendations for remote interviews

There were several things that I found useful when conducting remote interviews or would recommend to other researchers thinking about using remote methods of interviewing. First of all, researchers should make sure they find a quiet place where they can carry out the interviews without interruptions or distractions. It is impossible to eliminate all distractions, but mobile phones should be put on silent and email notifications should be turned off, and if there are other people in the building, they should be instructed not to disturb the researcher. The researcher should suggest that the participant likewise find a quiet place to talk and free themselves from distraction (Johnson et al., 2019; Lobe et al., 2020). This helps maintain the flow of the conversation and keeps both parties engaged. It also serves the practical purpose of helping ensure the audio-recording will be of good quality.

The researcher should also offer the participants options for the medium used for the interviews, if possible. It should not be assumed that all participants will have stable internet access, an appropriate device, or the ability to navigate video-conferencing software (Salmons, 2015). Allowing participants to use the telephone for interviews makes the study more inclusive and allows people to take part even if they do not have reliable internet access or adequate support to use videoconferencing software. Even if all the participants regularly use the internet and make video calls, they may prefer one platform over another. By offering participants some choice, a medium can be agreed upon that each participant is comfortable using. This has the potential to help the interviews go more smoothly and also helps ensure the participants will be able to access the interview at the scheduled time.

It may also be helpful to ask participants if they would like to receive a reminder about the interview. Because online interviews do not require participants to actively go somewhere or wait for a researcher to call or show up at their homes, they are easily forgotten about. In addition, people with intellectual disabilities have been found to have difficulties with prospective memory, which can make it more challenging to prepare for and perform future activities (Levén et al., 2011). One of my participants opted to have text reminders sent to him an hour before the interview to make sure he was awake and prepared for the interview. This same participant also appreciated having an email with the Zoom link re-sent to him the evening before each interview to make sure it was not buried in his inbox.

When interviewing participants online, the researcher may also want to provide the participants with some instructions to help make the most out of the interviews (Lobe et al., 2020). I did not do this myself, but there are some clear benefits to providing instruction. For instance, it may be helpful to tell participants to try to make sure their full face and shoulders are in view of the camera. This will allow the researcher to see facial expressions and some gestures. The researcher may also want to request that participants sit during the interviews. One of my participants walked in circles. I did not try to prevent this, but I did find it distracting and dizzying.

### **10.11.3 Repeat interviews**

Conducting research during the pandemic not only led to my adoption of remote interviews, but it also influenced the number of interviews I carried out with each participant. Because the context in which the interviews were conducted presented a lot of change, repeat interviews were carried out with each of the participants. Repeat interviews can be beneficial when trying to understand change over time (Read, 2018; Vincent, 2013). By interviewing participants multiple times during the pandemic, I learned how they were impacted by the changing government guidelines. I also gained insight into how they perceived the pandemic and changing guidelines over time. For instance, in the early interviews, one participant said that he always followed the rules and was angered by those who did not. However, by the later interviews, he had made the decision to break the social distancing rules, so he could hug his partner. Had a single interview been conducted, this shift in attitude would not have been captured.

There are some other benefits to conducting repeat interviews. They allow for familiarity and trust to develop over time (Read, 2018). By conducting multiple interviews, I began to learn the names of some of the important people and places in participants' lives and developed a more in-depth understanding of their daily lives, which led to deeper conversations. I also found that participants became more talkative and eager to provide updates and share different aspects of their lives as the weeks went on. In addition, repeat interviews allow for the researcher to probe key topics multiple times to cross-check information (Read, 2018) and to listen to and reflect on previous interviews so that new questions can be developed (Roos, 2021). After each interview for this study, I listened to the audio-recording and typically transcribed the interview before conducting the next



follow-up with that participant. A tailored interview topic guide was made for each of the follow-up interviews with questions designed to elicit more details about topics that were previously discussed, follow up on ongoing issues, or ask questions that had been missed.

I found the use of repeat interviews incredibly useful when trying to gain an understanding of participants' experiences during the pandemic. Had single interviews been conducted, I would not have known how participants' lives changed over time in response to the pandemic or been able to gain as much detail about important topics. The use of repeat interviews allowed me to better answer the research questions and really gain an understanding of participants' lives during this time. However, while they were helpful for this study, repeat interviews likely would have been unnecessary in the original study given the aims of that research. This study showed that the use of repeat interviews can help build rapport and greatly increase the richness and completeness of the data collected through qualitative research with people with intellectual disabilities. The use of repeat interviews also allowed for me to develop an in-depth narrative about each participant's life.

#### **10.11.4 Use of individual narratives**

By conducting an embedded case study and producing individual narratives for each participant, I was able to gain greater insight into each participant's life and capture change over time. I learned the daily rhythms of participants' lives and developed an understanding of what was important to each participant. In addition, I was able to get a sense of the challenges each participant faced and the strategies they employed to overcome those difficulties. In analysing each participant's interviews separately, I was able to provide a deeper reflection on their lives during the pandemic and tell their individual stories in a sensitive and thoughtful way. It allowed me to focus my attention on each participant in turn, so I could take into account their individual communication styles as I interpreted and developed in-depth analyses of their personal narratives.

While each participant's experience was unique, there were marked similarities between their stories. The narratives revealed the sense of isolation, loneliness, and boredom that participants often experienced during the pandemic. This is in keeping with previous research. As mentioned above, the restrictions put in place during pandemics could lead to feelings of isolation and boredom (Brooks et al., 2020). It was clear through the interviews

that dates-n-mates helped its members cope with these feelings by providing them with social activities. This is important because taking part in activities is a key component of social inclusion (S.A. Hall, 2009a).

Furthermore, dates-n-mates provided a platform through which members could connect with their friends, maintain reciprocal relationships, and develop a sense of belonging during the pandemic. Through the regular online chats held by the organisation, members were able to feel as if they were a part of a community. Participants clearly had a sense of ‘familiarity, comfort, security, and emotional attachment’ to this community, in keeping with Antonsich’s notion of ‘place-belongingness’ (Antonsich, 2010, p. 646). The narratives clearly revealed the ways in which dates-n-mates helped participants overcome their feelings of isolation and boredom and promoted members’ social inclusion and sense of belonging during the pandemic.

The narratives also allowed for examples of participants’ agency, resilience, and resourcefulness to emerge. Participants demonstrated control over their lives despite the circumstances. They regularly made decisions about their health and safety and pursued the activities they wanted to engage in. Agency features strongly in asset-based work (GCPH, 2012; McLean & McNeice, 2012). By providing members with key information about the pandemic, social distancing guidelines, internet safety, and the use of Zoom, dates-n-mates helped participants to make considered decisions about their lives.

The use of the individual narratives allowed in-depth explorations of participants’ lives, which provided insight into the challenges participants faced, the coping strategies they relied on, and the support they received from dates-n-mates during the pandemic. The social connections that participants maintained through dates-n-mates featured prominently in the individual narratives. This is important because social inclusion is central to asset-based approaches and what they aim to achieve (Boelman & Russell, 2013; GCPH, 2012; McLean & McNeice, 2012).

## **10.12 Recommendations for further research**

After reflecting on this body of work, I developed some recommendations for further research. As mentioned previously, the original study would have provided a more rigorous exploration of social inclusion by combining questionnaires and interview questions to capture community presence, community participation, and belonging. It also

would have situated feelings of inclusion / exclusion and belonging in participants' daily lives through the use of a photo mapping exercise. This study could provide a much more comprehensive picture of social inclusion in the lives of people with intellectual disabilities attending a group taking an asset-based approach, and now that restrictions have lifted, it is possible to carry this research out.

In addition to conducting more rigorous research on social inclusion, more research should be carried out to explore belonging and reciprocity. As evidenced by the systematic review by Fulton et al. (2021), there has been little empirical work focused explicitly on belonging and reciprocity in the lives of people with intellectual disabilities. Although, with respect to belonging, this has begun to change in the time since this systematic review was conducted (see, for example, Kaley et al., 2021; Robinson et al., 2020). However, there is still a need for additional research. This work is important because belonging and reciprocity are key components of social inclusion, and through further research, it can be better understood how they are experienced by people with intellectual disabilities and how the overall social inclusion of people with intellectual disabilities can be better supported.

More research should also be conducted on asset-based approaches. Very little research has been carried out with a focus on asset-based approaches in the lives of people with intellectual disabilities (McNeish et al., 2016). McNeish et al. (2016) also pointed out that most of the work that has been done has adopted a case study design. This work likewise took a case study design; however, other study designs could also be used to explore asset-based approaches and their outcomes. Further work should move beyond case studies to attempt to get a clearer sense of how asset-based approaches operate and impact on the lives of people with intellectual disabilities. For instance, it would help provide evidence of the potential benefits of asset-based approaches if a larger number of people were followed up with over time.

If conducting further case studies, it would be useful to adopt a multiple-case design (Yin, 2018). This would allow for multiple programmes to be analysed and for a cross-case synthesis to be conducted. This would help illustrate a range of experiences and outcomes that could be had from programmes taking an asset-based approach. Finally, when researching programmes taking an asset-based approach, different outcomes aside from social inclusion should also be explored. While the current research focused on social inclusion, there are many potential benefits of asset-based approaches that are worthy of

exploration. There could be a more in-depth exploration of participants' social networks or social capital, for instance, or a look at the health outcomes related to being a member of these types of organisations.

## **10.13 Concluding remarks**

Through this work, I aimed to explore how one organisation taking an asset-based approach supported people with intellectual disabilities both before and during the Covid-19 pandemic. I also intended to add to the literature on asset-based approaches in the lives of people with intellectual disabilities. It was found that dates-n-mates, a friendship and dating agency that embodies the principles of asset-based work, supported its members to develop independence and agency. Asset-based approaches focus on strengths and capabilities, and it was clearly evident that dates-n-mates strove to celebrate and build upon its members skills and abilities. The organisation provided accessible information, helping to support its members to make decisions about their lives. In contrast to the findings from much of the research with participants with disabilities during the pandemic (Embregts et al., 2022; Fudge Schormans et al., 2021; Hughes & Anderson, 2022; Kim et al., 2021; Pearson et al., 2022), the participants in this study demonstrated agency through their ability to adapt to and deal with many of the challenges posed by the pandemic. Belonging to dates-and mates appeared to validate participants' sense of personhood, increasing their resilience in the face of difficult circumstances. In taking an asset-based approach, dates-n-mates showed a commitment to valuing the contributions that people with intellectual disabilities can make to their communities and helping members experience personal growth.

When undertaking this work, I had anticipated meeting with participants face-to-face and witnessing their interactions with other people and their environment. However, the Covid-19 pandemic caused this thesis to go in a slightly different direction. By conducting research during the pandemic, I was unable to utilise the data collection methods I had intended to use, and I could not fully explore participants' typical experiences of social inclusion and belonging. While some concessions had to be made, carrying out qualitative research during the pandemic helped to expose some of the persistent inequalities faced by people with intellectual disabilities and their resilience and agency in the face of the changes and challenges posed by this situation. This research also showed that dates-n-

mates as an organisation had an incredible ability to adapt during this time and find innovative ways to help its members stay connected and informed.

The case study highlighted that social interaction and connection are necessities and essential for people's sense of wellbeing. However, unfortunately, it has been found that following the lifting of the government restrictions, people with intellectual disabilities still are not participating in community-based activities or leaving their homes with personal assistants or social workers as much as they had prior to the pandemic (Hatton et al., 2023). The pandemic has undoubtedly had a long-term negative impact on the social inclusion of people with intellectual disabilities. The fact that dates-n-mates has persisted throughout this time is hugely important. It was third sector organisations, like dates-n-mates, that 'stepped in when services closed' (Scherer et al., 2022. p. 15) and provided emergency support (Pearson et al., 2022), and as shown by the interviews, there are many people who rely on the group to form meaningful relationships and participate in community-based activities. It is crucial that groups like dates-n-mates continue to receive support to operate. They provide vital support and opportunities to the people who participate in them and help members feel a sense of belonging. As one participant stated, 'They care about a lot of folk. They definitely do.'

# Appendices

## **Appendix A: Belonging and reciprocity amongst people with intellectual disabilities: a systematic methodological review**

### **Overview**

This paper was previously published on 15 March 2021 in the *Journal of Applied Research in Intellectual Disabilities* (Fulton et al., 2021; copyright: Wiley). It was written by the first author, but the last author assisted with screening titles, abstracts, and full text articles, and both the second and last authors had input on the drafted manuscript. This work has been reproduced in accordance with the Creative Commons Attribution 4.0 International Public License (<https://creativecommons.org/licenses/by/4.0/legalcode>).

### **Introduction**

This methodological review compiles and assesses the approaches that have been taken to explore frequently overlooked or difficult to measure aspects of social inclusion. The specific focus is on how the concepts of belonging and reciprocity have been discussed and examined in the lives of people with intellectual disabilities. However, before describing the current review, it is necessary to situate it within a wider literature on social inclusion.

Social inclusion takes on a multitude of meanings in the literature (Bates & Davis, 2004; Brown et al., 2015; Cobigo et al., 2012; Simplican et al., 2015), which has resulted in researchers approaching the topic from a variety of different angles and employing a wide range of methods (Simplican et al., 2015). While quantitative measures, such as the number and frequency of social contacts and community-based activities, can be useful indicators of opportunities to establish connections in the community (Merrells et al., 2017a) and levels of community involvement (Simplican et al., 2015), they tell us little about social inclusion unless combined with an exploration of individuals' preferences (Bigby, 2012).

Cobigo et al. (2012) argue that such objective measures should be accompanied by an investigation of subjective feelings of belonging to gain a full and meaningful understanding of social inclusion. "Without targeting this subjective element," state Cobigo et al. (2012), "strategies aiming to improve social inclusion, integration and

participation are likely to only achieve social exposure, or the mere physical presence in the community” (p. 80). While people with intellectual disabilities often have difficulty expressing these subjective feelings, it is crucial that efforts are made to help enable people to communicate their views.

The focus of this methodological review is on two elements that are often central to discussions of social inclusion—belonging and reciprocity—both of which require the exploration of peoples’ perceptions of inclusion. This paper examines the qualitative and mixed methods approaches researchers have taken to explore these concepts. This will expose the shortcomings and strengths of the methods used in previous research and provide a clearer sense of how belonging and reciprocity can be examined in a more comprehensive or rigorous fashion in future studies. However, before describing the methods adopted in this systematic review, it is important to have a basic understanding of how belonging and reciprocity fit within the broader discussion of social inclusion.

## **Defining belonging and reciprocity**

Social inclusion has often been viewed in relation to employment and independent living (E. Hall, 2005). While achieving these life goals might lead to greater physical presence in the community, definitions of social inclusion should account for relationships, membership, and belonging (S.A. Hall, 2017, p. 861). As Power (2013) states, belonging:

takes the concept of social inclusion beyond narrow understandings and identifies it as not simply the promotion of the increased presence of marginalised persons in society, but rather that such people return to or begin to occupy valued social roles within society and community life. (p. 68)

In their review of the literature on belonging and people with disabilities, Mahar et al. (2013) found that most definitions of belonging included feelings of being “needed, important, integral, valued, respected, or feeling in harmony with a group or system” (p. 1029). At its core, the cultivation of a sense of belonging is not about where people participate, but how they participate (Milner & Kelly, 2009).

In addition to general feelings of being valued and respected, the development of reciprocal relationships is important to fostering a sense of belonging (Mahar et al., 2013; Milner & Kelly, 2009), and the concept of reciprocity is included in many definitions of

social inclusion. Overmars-Marx et al. (2014), for instance, describe inclusion as a “reciprocal process” that involves the participation and commitment of everyone involved (p. 269), and S.A. Hall (2009a) concluded that the maintenance of reciprocal relationships was a core element of social inclusion.

Reciprocity is also a key component of how friendship is often conceptualised by people with intellectual disabilities (Callus, 2017; Bates & Davis, 2004) and has been found to act “as an important way to challenge implied dependence” (Milner & Kelly, 2009, p. 56). However, while reciprocity is often found to be an important theme in studies on social inclusion, very little work has focused on reciprocity specifically. An exception to this is a study by Bredewold et al. (2016), which found that reciprocal relationships can develop between people with and without disabilities, but the common notion of what constitutes balanced reciprocity may need to be expanded to include different or seemingly smaller return gifts, such as “happy smiles” (p. 547) or “expanded horizons” (p.545).

Belonging and reciprocity are central to discussions of social inclusion, yet often remain unexplored in their own right. An important starting point is to examine how these concepts have been defined and operationalised in previous research. This review will seek to answer the following questions: i) How have belonging and reciprocity been defined in studies exploring these concepts in the lives of people with intellectual disabilities? ii) What qualitative or mixed methods approaches have been used in these studies? and iii) What were the strengths and weaknesses of the approaches adopted?

## **Method**

### **Study design**

This review took a systematic approach to identify and evaluate relevant papers, following the approach taken by Fryer et al. (2012) to conducting a methodological systematic review.

### **Search strategy**

The database search was intended to return papers focused on the social inclusion or community participation of people with intellectual disabilities. During the screening process this initial pool of resources was narrowed down to studies looking specifically at



belonging or reciprocity. The search was deliberately kept quite broad to make certain all relevant studies were returned. Guidance was sought from a university librarian to help refine the search strategy and ensure best practice was adhered to.

### *Databases*

Ten databases were searched as shown in Figure 1. The initial search was conducted in February 2018, and an additional search was carried out in October 2018 to identify any subsequently published papers. A hand search of three key journals (Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual & Developmental Disability, and Journal of Intellectual Disability Research) and reference lists of included papers was also conducted to identify any additional relevant studies.

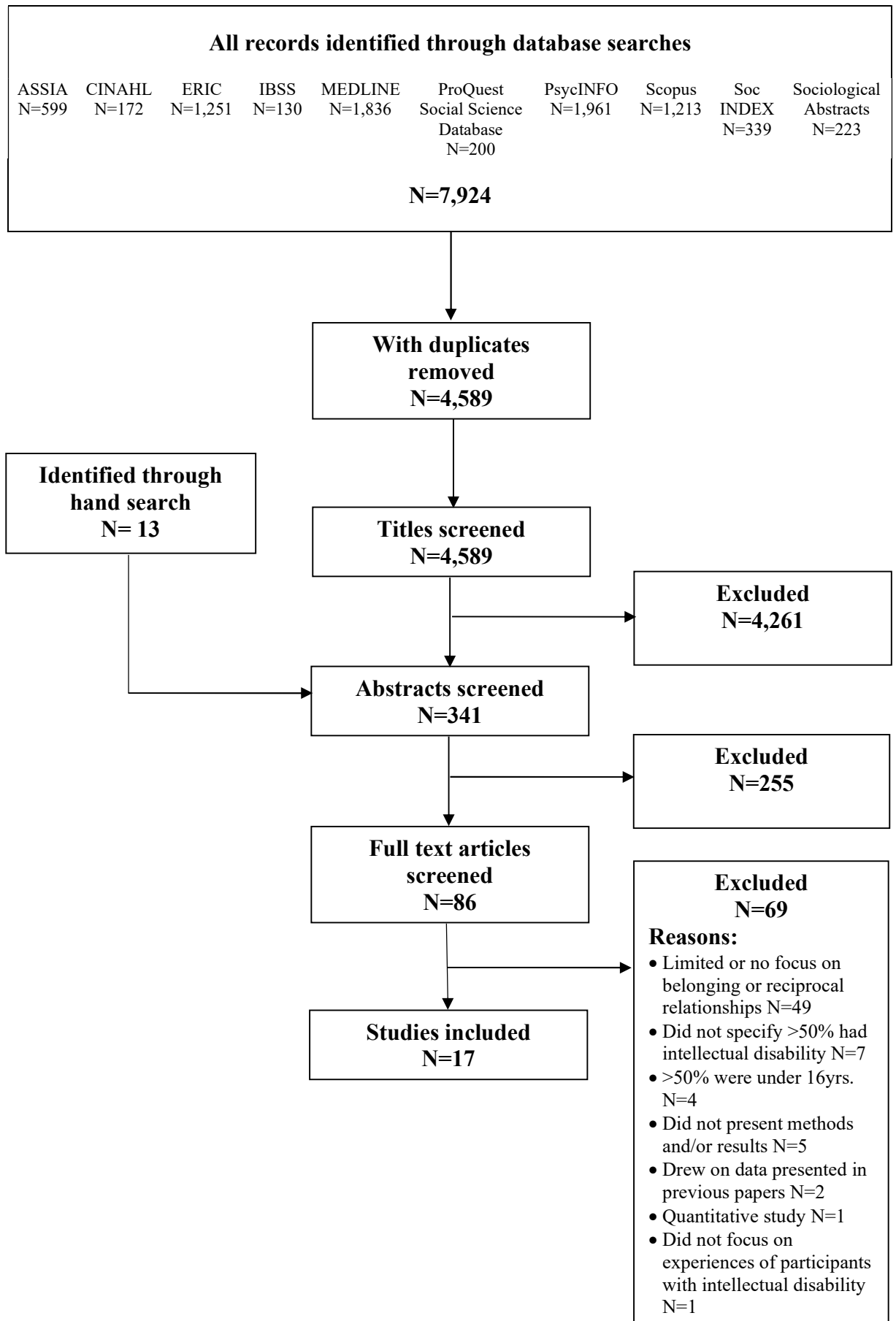
### **Search terms**

Search terms were identified through a careful read of the literature and preliminary searches of the databases. It was not anticipated that belonging or reciprocity would be the primary focus of all included studies, so search terms were designed to encompass a broad range of concepts related to social inclusion more generally.

Inclusion-related search terms were: belonging\*, reciprocity, “reciprocal relationship\*”, affiliation, acceptance, friendship\*, “social\* connect\*”, “social bond\*”, “interpersonal relationship\*”, “peer relationship\*”, “social support”, “social network\*”, “community membership”, “social inclusion”, “community inclusion”, “social participation”, “community participation”, “social\* engage\*”, “community engagement”, “social\* involve\*”, “community involvement”, “social\* integrat\*”, “community integration”, “social\* activ\*”, “community activit\*”, “community based activit\*”, and “active citizenship”.

Population specific search terms were: "learning disab\*", "intellectual\* disab\*", "developmental\* disab\*", "mental\* retard\*", "mental\* disab\*", "intellectual\* impair\*", "mental\* defici\*".

Relevant database-specific, phrase-indexed subject headings were also searched in all databases except Scopus, which does not provide a thesaurus. Search results were limited to peer reviewed journal articles published since 2000 in English.



**Figure 1:** Flow diagram of results

## **Selection process**

Search results were exported to EndNote, where duplicates were removed. Titles and abstracts were screened against the initial list of inclusion and exclusion criteria. Selected papers were then read in their entirety, and the full inclusion and exclusion criteria were applied.

The following inclusion and exclusion criteria were developed to identify empirical papers focused on how belonging and reciprocity were experienced by people with intellectual disabilities in settings and opportunities available upon exiting the school system:

### **Inclusion criteria:**

1. Primary research
2. Focuses on social inclusion or related concepts as they apply to people with intellectual disabilities
3. Is a peer reviewed journal article published in 2000 or later in English
4. Focuses on adults or young people aged 16 and over
5. Uses qualitative or mixed methods

For full text screening, the following inclusion criterion was added:

6. Attempts to measure or describe experiences of (not) belonging or (a lack of) reciprocal relationships

### **Exclusion criteria:**

1. Is a review, conceptual, or opinion piece, or otherwise fails to describe methods
2. Has a primary focus on the participation or inclusion of family members or supporters and experiences of people with intellectual disabilities are disregarded
3. Focuses on the training of supporters or clinicians or on the provision or evaluation of services
4. Focuses on an intervention that does not have increasing social inclusion or participation as a primary aim
5. Focuses on people's opinions or feelings about including people with intellectual disabilities in mainstream or community settings
6. Is clearly focused on other disabilities with a low likelihood that half of participants would have intellectual disabilities, unless otherwise specified

7. Focuses on policy or policy implementation
8. Focuses on inclusion within primary or secondary school classrooms

For full text screening, the following exclusion criterion was added:

9. It is not specified that at least half the primary participants have intellectual disability

Titles, abstracts, and full text articles were screened independently by two researchers, and conflicts were discussed until agreement was reached in each instance.

### **Quality appraisal and data extraction**

Quality appraisal was carried out to provide a comprehensive overview of the conduct of the studies and the level of description provided in the papers. As the function of the quality appraisal was to provide discussion points rather than eliminate papers from this review, papers were not scored. Because quality appraisal was conducted purely for descriptive purposes, the process allowed for the development of a quality appraisal checklist combining elements from three frequently used quality appraisal tools.

The CASP Qualitative Checklist (Critical Appraisal Skills Programme [CASP], 2018) was used as the starting point. Question 2, pertaining to the appropriateness of qualitative methods, was removed because only studies for which qualitative methods would be appropriate were included in the review. Three questions adapted from the QualSyst Checklist for Assessing the Quality of Qualitative Studies (Kmet et al., 2004) and the JBI Critical Appraisal Checklist for Qualitative Research (Joanna Briggs Institute [JBI], 2017) were then added to address gaps in the CASP checklist, resulting in the 12 quality appraisal items shown in Table 2.1.

Quality appraisal ratings were completed independently by two reviewers. All conflicts were discussed until agreement was reached. Data were then extracted to compile detailed descriptions of the theories and procedures used in each of the studies.

## **Results**

Search results are presented in Figure 1, and results from the quality appraisal are shown in Table 1(a-c). An overview of the 17 papers selected for inclusion is provided in Table 2(a-c), and additional study characteristics are provided in Table 3(a-c). Overall, the selected

studies encompassed a wide range of research aims and study designs. Each of the papers discussed belonging or reciprocity at some point; however, as a group, they rarely had a primary focus on these concepts or the intent to explore them from the outset of the research. All studies were conducted in high-income countries.

The 17 selected papers were grouped into three broad categories based on how reciprocity and belonging featured in the research, each of which will be presented in turn: (1) reciprocity in relationships and social interactions; (2) belonging within a specific setting; and (3) experiences of belonging in the wider community. Within each of these categories, a summary of how belonging or reciprocity was incorporated will be presented, followed by a description of the methods adopted. After this, the paper will turn to a more critical discussion of the strengths and weaknesses found across this body of research.

### **1) Reciprocity in relationships and social interactions**

Five papers explored the interpersonal relationships and social interactions of people with intellectual disabilities and are presented in Table 2a (Johnson et al., 2010; Johnson et al., 2012; Lafferty et al., 2013; McVilly et al., 2006; Pottie & Sumarah, 2004). Each of these papers included some discussion about the reciprocal nature of the relationships or interactions under study. Two of these papers (Johnson et al., 2010; Johnson et al., 2012) came from the same study, meaning four unique studies were identified.

Three of these five papers spoke explicitly of reciprocity. Pottie and Sumarah (2004) framed their research within the Aristotelian concept of friendship. They understood reciprocity to be an essential component of friendship and demonstrated how reciprocity operated in the relationships observed during the study. Johnson et al. (2010) described reciprocal relationships as relationships in which both giving and receiving existed, though not necessarily to an equal extent (p. 176). Their results and discussion highlight some elements of reciprocity uncovered in relationships between the primary participant and people in her social network. Lafferty et al. (2013) explored close relationships and clearly featured the concept of reciprocity in their results and discussion.

The two remaining papers did not use the term reciprocity specifically but instead spoke of ideas and exchanges that implied reciprocity. Johnson et al. (2012) focused on social interactions that were mutually rewarding for participants and appeared to serve no

obvious purpose. While reciprocity was not mentioned explicitly, interactions were described as being “mutually enjoyable” (p. 338) or “resulting in mutual fun” (p. 332). Inherent in this mutuality are the notions of giving and receiving essential to reciprocal relationships. McVilly et al. (2006) talked about notions of reciprocity in a similar way when describing their exploration of loneliness. When detailing what friendship meant to participants, they spoke of shared activities, mutual trust and affinity, and “the opportunity to exchange thoughts and ideas” (p.198).

### *Methods adopted*

A grounded theory approach was taken in studies by Johnson et al. (2010; 2012) and Lafferty et al. (2013). A further study adopted a mixed methods approach (McVilly et al., 2006) and used the constant comparative method to analyse qualitative data. The final study (Pottie & Sumarah, 2004), stated that qualitative field research was employed. The presentation of data in this paper was suggestive of a narrative approach. Four of the five papers mentioned the use of methods that allowed the researchers to observe participants’ relationships or interactions with others. This was accomplished through jointly conducted dyadic interviews and extensive observation.

According to Morgan et al. (2013), dyadic interviews promote interaction between participants, which allows for the stimulation of ideas that may be overlooked in individual interviews. In studies described by Lafferty et al. (2013) and Pottie and Sumarah (2004), dyadic interviews allowed for a more in-depth understanding of participants’ relationships, which perhaps enabled the reciprocal nature of these relationships to emerge and be explored. However, Lafferty et al. (2013) did note that one partner tended to dominate the interview, an issue that has been raised in previous critiques of this approach (Booth & Booth, 1994). To help counteract this, individual follow-up interviews were also carried out to gain the perspective of each partner on their own (Lafferty et al., 2013).

**Table 1:** Results from quality appraisal

Year	Author	Research aims clearly stated?	Research design appropriate to address research aims?	Connection made to existing body of knowledge?†	Recruitment strategy clear and appropriate?	Context clearly described?†	Data collected in way to address research issue?	Relationship between researcher and participants considered?	Ethical issues taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings and discussion of credibility?	Conclusions clearly supported by results?‡	Is the research valuable?
<b>a. Reciprocity in relationships and social interactions</b>													
2004	Pottie & Sumarah	y	y	y	not fully addressed	n	y	n	not fully addressed	not fully addressed	y	y	y
2006	McVilly et al.	y	y	y	not fully addressed	n	y	n	not fully addressed	y	y	y	y
2010	Johnson et al.	y	y	y	y	y	y	n	y	y	y	y	y
2012	Johnson et al.	y	not fully addressed	y	y	y	y	n	y	y	y	y	y
2013	Lafferty et al.	y	not fully addressed	y	y	n	y	n	y	not fully addressed	n	y	y
<b>b. Belonging within a specific setting</b>													
2009	Cramm et al.	y	y	y	y	n	y	n	not fully addressed	not fully addressed	not fully addressed	y	y
2015	Frawley & Bigby	y	y	y	not fully addressed	y	y	n	y	y	y	y	y
2017	Lysaght et al.	y	not fully addressed	y	y	n	y	n	y	not fully addressed	y	y	y
2017	Werner & Hochman	y	not fully addressed	y	not fully addressed	y	y	n	y	y	y	y	y
2017	Wilson et al.	y	y	y	not fully addressed	n	y	y	y	y	y	y	y

<b>c. Experiences of belonging in the wider community</b>													
2004	E. Hall	y	y	y	not fully addressed	n	y	n	not fully addressed	not fully addressed	n	y	y
2009	S.A. Hall	y	y	y	not fully addressed	n	y	n	y	y	y	y	y
2011	Umb-Carlsson & Lindstedt	y	y	y	y	y	y	n	y	y	y	y	y
2013	Schleien et al.	y	y	y	not fully addressed	y	y	y	y	y	y	y	y
2017	Merrells et al.	y	y	y	y	n	y	y	y	y	y	y	y
2018	Strnadová et al.	y	y	y	not fully addressed	n	y	n	y	y	y	y	y
2018	Wilton et al.	y	not fully addressed	y	not fully addressed	n	y	n	not fully addressed	y	y	y	y
† Question adapted from QualSyst Checklist for Assessing the Quality of Qualitative Studies (Kmet et al., 2004)													
‡ Question adapted from JBI Critical Appraisal Checklist for Qualitative Research (JBI, 2017) and QualSyst Checklist for Assessing the Quality of Qualitative Studies (Kmet et al., 2004)													



**Table 2:** Overview of included papers

<b>a. Reciprocity in relationships and social interactions</b>							
<b>Year</b>	<b>Author</b>	<b>Country</b>	<b>Objective</b>	<b>Design</b>	<b>Methods</b>	<b>Participants</b>	<b>Results</b>
2004	Pottie & Sumarah	Canada	to describe friendships between individuals with and without developmental disabilities and identify factors that can nurture or impede these friendships	qualitative field work	dyadic interviews, observation	4 friendship dyads (8 individuals: 4 females and 4 males aged 28-49 years) from a L'Arche community in which one friend had intellectual disability and one did not; 1 key informant included to facilitate understanding of nonverbal communication of participant with severe intellectual disability	three categories were identified: 1) contours of friendship, 2) facilitating friendship, and 3) L'Arche--a community context; friendships between people with and without developmental disabilities occur and can be meaningful and reciprocal
2006	McVilly et al.	Australia	to explore 'loneliness' as experienced by people with intellectual disabilities in post-secondary education and employment	mixed methods	questionnaires, interviews with primary participants	51 adults with intellectual disabilities and intermittent to limited support needs (29 females and 22 males aged 16-52 years), 12 of whom participated in interviews (6 females, 6 males); parents, teachers, and work supervisors completed questionnaires	the modified Loneliness Scale was found to be reliable and valid; interviews revealed distinct differences in the experiences of the 'most lonely' and 'least lonely' participants, including: how the groups described their friendships; the expectations they had of their friends; and their experiences establishing, negotiating, and maintaining friendships
2010	Johnson et al.	Australia	to describe the social interactions of a woman with severe intellectual disabilities	grounded theory	observation, interviews with informants	central participant was a 20-year-old female with severe intellectual disability; 14 of the central participants' social network members were interviewed (4 family members, 8 support workers, and 2 peers with intellectual disabilities)	the participant's social interactions could be summarised by 3 primary roles (lioness, anxious child, and entertainer); aside from family, her social network was primarily made up of paid and domain-specific relationships; she could be difficult to interact with, but people valued their interactions with her

2012	Johnson et al.	Australia	to identify and detail the nature of social interactions between people with severe intellectual disabilities and those with whom they have positive relationships	grounded theory	observation, interviews with informants	6 central participants with intellectual disabilities who communicated at a symbolic, non-linguistic level (3 females and 3 males aged 20-44 years); 57 people who had a positive relationship with a central participant (22 family members, 29 paid workers, and 6 peers), 51 of whom were interviewed	social interactions were situated within a shared moment; two themes characterised interactions in shared moments: 1) having fun and 2) hanging out
2013	Lafferty et al.	Northern Ireland	to uncover the experiences of people with intellectual disabilities in close personal relationships, the nature of the relationships, and the meanings given to relationships	grounded theory	dyadic interviews	8 heterosexual couples (16 individuals: 8 females and 8 males aged 26-65 years) where both members of the relationship had intellectual disabilities	close personal relationships provided many benefits to participants; five themes were identified: 1) comradeship--being together is what matters, 2) the experience of happiness and contentment, 3) mutual support and complementary reciprocation, 4) coping with the ups and downs of relationships, and 5) continuation and commitment
<b>b. Belonging within a specific setting</b>							
Year	Author	Country	Objective	Design	Methods	Participants	Results
2009	Cramm et al.	Netherlands	to investigate supported employees' views of employment, with focus on factors that contribute to social integration	Q methodology	Q sort, interviews with primary participants	18 adults with mild intellectual disabilities who had worked 3 days/week at the same workplace for at least 6 months (7 females and 11 males aged 21-56 years)	factor analysis revealed two primary views on work and social integration: 1) work as participation and 2) work as structure; interviews revealed that supported employment contributed to self-development and was preferred over placements in day centres
2015	Frawley & Bigby	Australia	to explore the meanings of self-advocacy for people with intellectual disabilities and how membership in a self-advocacy group has influenced members' social inclusion	exploratory qualitative approach, inclusive research	interviews with primary participants	12 adults with intellectual disabilities who were involved in a self-advocacy group (all but one aged 55 years and over)	three main themes were identified: 1) a sense of belonging, 2) social connections, and 3) doing things that matter; involvement in self-advocacy groups can help further the social inclusion of people with intellectual disabilities

2017	Lysaght et al.	Canada	to find out what inclusion at work looks like for people with intellectual and developmental disabilities and what aspects of work promote inclusion	grounded theory	interviews with primary participants and informants	74 primary participants with intellectual disabilities from 3 regions of Ontario, Canada (30 females and 44 males aged 21-59 years); 60 people who supported a primary participant were also interviewed	benefits of both paid and volunteer work included: enjoyment, a sense of belonging, and feelings of making a contribution; inclusion was promoted in the workplace through frequent and ongoing contact with others, shared workplace experiences and overlapping routines, and having the sense that someone in the workplace would provide a listening ear
2017	Werner & Hochman	Israel	to examine the meaning of inclusive military service to the social inclusion of people with intellectual disabilities	phenomenology	interviews with primary participants and informants, focus group	31 adults with intellectual disabilities enlisted in military service (12 females and 19 males aged 21-30 years); 36 family members (primarily parents); 28 military commanders or career soldiers in charge of participants with intellectual disabilities	level of inclusion varied; four social network groups were identified that varied in closeness and reciprocity, each of which played an important role in the social inclusion of participants; relationships were often formed but tended to be limited to the base
2017	Wilson et al.	Australia	to explore and understand the experiences of adults with intellectual disabilities who participated in a structured social group	phenomenology	interviews with primary participants	10 adults with moderate intellectual disabilities (3 females and 7 males aged 19-48 years) who were members of a social group	two core themes were identified: 1) supported engagement fosters wellbeing and 2) developing social belonging and connectedness; the social group helped counter loneliness, expand friendship circles and social life, provide a greater sense of wellbeing, and reverse a largely sedentary and isolated lifestyle
<b>c. Experiences of belonging in the wider community</b>							
Year	Author	Country	Objective	Design	Methods	Participants	Results
2004	E. Hall	Scotland	to produce an account of social exclusion with the experiences of people with intellectual disabilities at its centre	narrative approach	group interviews with primary participants	21 adults with intellectual disabilities from five locations in Scotland	social inclusion as it is conceptualised in policy does not fully recognise the rejection people often face in inclusive spaces or take into account individual preferences; people with intellectual disabilities have responded to discrimination by self-excluding and actively creating safe spaces

2009b	S.A. Hall	USA	to describe social inclusion as experienced by young adults with intellectual disabilities and identify what limits and facilitates their social inclusion	phenomenology	interviews with primary participants	14 young adults with mild or moderate intellectual disabilities (7 females and 7 males aged 22-35 years)	seven themes were identified: 1) living accommodations and transportation, 2) work and volunteer experiences, 3) involvement in activities, 4) relationships and interactions, 5) sense of belonging, 6) social roles, 7) influential factors; participants had varied experiences of social inclusion which were attributed to a range of factors
2011	Umb-Carlsson & Lindstedt	Sweden	to understand the lived meanings of quality of life for adults with intellectual disabilities	phenomenology	interviews with primary participants	21 adults with mild or moderate intellectual disabilities from one county in Sweden (11 females and 10 males aged 33-48 years)	quality of life is characterised by subjective well-being; the experience of well-being consisted of five themes: 1) social adult status, 2) control of life, 3) personal safety, 4) social belonging, and 5) self-chosen solitude
2013	Schleien et al.	USA	to give people with intellectual and developmental disabilities a voice regarding their access, participation, and inclusion in the community and to try to create change in the community by sharing their voices	participatory action research	photovoice, surveys	7 central participants with mild or moderate intellectual disabilities who were members of an organisation that supported people with intellectual disabilities (aged 21-48 years); 74 attendees of the community photovoice exhibition completed surveys	six themes were identified, the first two of which were discussed at length: 1) a desire for community membership and to achieve a sense of belonging and 2) a desire for independence and to live independently; a survey of the community photovoice exhibition attendees provided positive feedback, but nearly half of respondents were friends or family of participants
2017b	Merrells et al.	Australia	to describe how young adults with intellectual disabilities who had experienced long-term community-based coordination spent their time, formed relationships, and felt included and to explore their lived experiences of social inclusion	phenomenology	interviews with primary participants	10 young adults with intellectual disabilities (5 females and 5 males aged 19-24 years) who had experienced long-term community-based coordination and services	two main themes were identified: 1) segregated, excluded, and treated like an outcast in my community; and 2) challenges in experiencing, initiating, and maintaining peer friendships

2018	Strnadová et al.	Australia	to better understand the meaning of belonging and the barriers to a sense of belonging for some people with intellectual disabilities	not stated	focus groups with primary participants	24 adults with intellectual disabilities (9 females and 15 males aged 20-61 years) who were involved in a self-advocacy organisation	two main themes and six subthemes were identified: 1) meaning of belonging: i) belonging in relation to place, ii) belonging as being part of a community, iii) belonging as having relationships and iv) belonging as identity; 2) barriers to belonging: : i) prejudice and ii) bullying
2018	Wilton et al.	Canada	to examine the role organisations and places associated with consumption have in the lives of people with intellectual disabilities	participatory research	go-along interviews with primary participants, mapping, photography, workshops	12 adults with intellectual disabilities (4 females and 8 males aged early 20s to late 50s) associated with self-advocacy groups and community organisations in Toronto, Canada	three major themes were identified: 1) going shopping--negotiating autonomy and responsibility; 2) shopping and sociability; and 3) presence, participation, and belonging; shopping was a key activity in participants' weekly routines and created opportunities for autonomy and encounters with others

The papers by Johnson et al. (2010; 2012) presented findings from a study focused on the social interactions of people with severe intellectual disabilities. The primary participants in this study had complex communication needs, so unlike the previous studies, no interviews were conducted with the primary participants themselves. Instead, a combination of extensive observation and interviews with primary participants' social network members was used. The authors explained that while interviews with family members or supporters can provide valuable insight into the interactions of people who may have difficulty expressing their own views, observations could perhaps provide a deeper understanding of relationships. This was illustrated particularly well through fieldnotes depicting an exchange between two people in a close relationship whose communication did not depend on words (Johnson et al., 2011, p. 268).

The final study to touch upon reciprocity (McVilly et al., 2006) began by piloting a quantitative scale of loneliness. Subsequent interviews explored how loneliness was experienced by the least and most lonely survey respondents. This was the only study in this group that relied entirely on participants' self-reports of relationships.

As illustrated by Table 3a, only one paper mentioned providing accessible study information to participants at the outset. It was also notable that three papers did not fully describe the contexts (sites, settings, and timeframes) in which data were collected, and none fully explained the relationship between researchers and participants (see Table 1a). However, it should be clarified, that an omission of these details in the text does not mean that the researchers did not address these points; it simply means that the information was not presented in the paper.

**Table 3:** Additional study characteristics

Year	Author	Process of obtaining consent described?	Accessible study information provided to participants?	Supporter present during interviews?	At least one person with intellectual disability interviewed as part of data collection process?	Primary participant with intellectual disability interviewed as part of data collection process?	Explains how data collection process was adapted for participants with intellectual disability?	Interview schedules piloted?
<b>a. Reciprocity in relationships and social interactions</b>								
2004	Pottie & Sumarah	not addressed	not addressed	N/A	y	y	y	not addressed
2006	McVilly et al.	not addressed	not addressed	not addressed	y	y	y	not addressed
2010	Johnson et al.	y	not addressed	not fully addressed	y	n	y	not addressed
2012	Johnson et al.	y	not addressed	not fully addressed	y	n	y	not addressed
2013	Lafferty et al.	y	y	not addressed	y	y	y	not addressed
<b>b. Belonging within a specific setting</b>								
2009	Cramm et al.	not addressed	not addressed	not addressed	y	y	y	y
2015	Frawley & Bigby	not fully addressed	not addressed	not addressed	y	y	y	not addressed
2017	Lysaght et al.	not fully addressed	not addressed	optional	y	y	not fully addressed	not addressed
2017	Werner & Hochman	y	not fully addressed	optional	y	y	not fully addressed	not addressed
2017	Wilson et al.	y	y	optional	y	y	not fully addressed	not addressed
<b>c. Experiences of belonging in the wider community</b>								
2004	E. Hall	not addressed	not addressed	y	y	y	y	not addressed
2009	S.A. Hall	y	not addressed	not addressed	y	y	y	y
2011	Umb-Carlsson & Lindstedt	not fully addressed	not addressed	not addressed	y	y	not fully addressed	not addressed

2013	Schleien et al.	not fully addressed	not fully addressed	y	y	y	y	not addressed
2017	Merrells et al.	y	not fully addressed	optional	y	y	y	y
2018	Strnadová et al.	y	y	not addressed	y	y	y	not addressed
2018	Wilton et al.	y	y	optional	y	y	not fully addressed	not addressed



## 2) Belonging within a specific setting

Belonging was mentioned in reference to a specific context—such as a workplace or social group—in five studies (Cramm et al., 2009; Frawley & Bigby, 2015; Lysaght et al., 2017; Werner & Hochman, 2017; Wilson et al., 2017). The details of these studies are shown in Table 2b. While each paper spoke overtly of belonging, none provided a framework from which to explore the concept. Despite this omission, three papers did provide clear models of social inclusion used to guide the research (Lysaght et al., 2017; Werner & Hochman, 2017; Wilson et al., 2017).

Lysaght et al. (2017) adopted Cobigo et al.'s (2012) model of social inclusion. The diagram the authors used to illustrate this model clearly incorporates a sense of belonging (Lysaght et al., 2017, p. 924), and participants' feelings of belonging were outlined in the results. Frawley and Bigby (2015) also identified a sense of belonging as an important component of social inclusion. In analysing their data, the authors found that belonging was central to discussions of what membership in a self-advocacy group meant to members.

Two papers (Werner & Hochman, 2017; Wilson et al., 2017) utilised Simplican et al.'s (2015) model of social inclusion which consists of two domains, interpersonal relationships and community participation. While this model pointedly does not incorporate belonging as a component of social inclusion, Werner and Hochman (2017) spoke to the importance of belonging from the outset of their paper, and Wilson et al. (2017) found “that many of the participants wished to connect and belong socially” and could, with adequate social support, develop a sense of belonging to a structured social group (Wilson et al., 2017, p. 854). Unlike the previous papers, the paper by Cramm et al. (2009) did not address belonging until after analyses revealed that many participants placed value on belonging within supported employment environments.

### *Methods adopted*

A phenomenological approach was taken in two studies (Werner & Hochman, 2017; Wilson et al., 2017), Q methodology was used in a third (Cramm et al., 2009), and a fourth paper (Lysaght et al., 2017) stated that a grounded theory approach was used. The final

study (Frawley & Bigby, 2015) was described as ‘inclusive research’ and adopted an exploratory qualitative approach.

The study by Cramm et al. (2009) took a very different approach than the other studies in this review. The researchers utilised Q methodology, which according to McKeown and Thomas (2013), “brings qualitative research into the quantitative realm” (p. 2). Participants were first asked to complete a Q-sort, whereby they rank-ordered a series of 22 statements derived from the literature on social integration as it pertained to the workplace. The Q-sort was followed by individual interviews; however, the authors provided very little discussion of these interviews and did not describe how the data were analysed.

Two studies used a combination of interviews with primary participants and additional informants. Lysaght et al. (2017) conducted a total of 114 interviews with people with intellectual disabilities and supporters to gain insight into primary participants’ experiences of (not) working. Fourteen interviews were conducted with primary participants alone, 20 with supporters alone, and 40 with both. Werner and Hochman (2017) explored experiences of people with intellectual disabilities conscripted for military service. They conducted semi-structured interviews with 31 project participants, 36 family members, and 28 military commanders or career soldiers in charge of participants.

The final two papers in this group used interviews with participants with intellectual disabilities as the sole means of data collection. Wilson et al. (2017) explored the experiences of people who participated in a structured social group using individual interviews with group members. Frawley and Bigby (2015) adopted “a collaborative group method of inclusive research” (p. 256), in which self-advocates with intellectual disabilities made active contributions to the study throughout the research process (see Bigby et al., 2014 for further information). Data collection for this study consisted of in-depth interviews with other self-advocacy group members.

As shown by Table 3b, only one of the five papers mentioned that accessible study information was provided to participants. It was also found that just two papers in this group fully described the contexts in which data were collected, and only one adequately considered the relationship between researchers and participants (see Table 1b). Furthermore, two papers did not describe the qualitative data analysis in enough detail to demonstrate that it was sufficiently rigorous.

### 3) Experiences of belonging in the wider community

A more general discussion of belonging within the wider community was presented in the seven papers shown in Table 2c (E. Hall, 2004; S.A. Hall, 2009b; Merrells et al., 2017b; Schleien et al., 2013; Strnadová et al., 2018; Umb-Carlsson & Lindstedt, 2011; Wilton et al., 2018).

Two of these studies drew from the framework of belonging posited by Antonsich (2010), in which belonging is organised:

around two major analytical dimensions: belonging as a personal, intimate, feeling of being ‘at home’ in a place (place-belongingness) and belonging as a discursive resource which constructs, claims, justifies, or resists forms of socio-spatial inclusion / exclusion (politics of belonging). (p. 645)

Strnadová et al. (2018) used this definition as the foundation for their expanded framework of belonging which incorporated ideas from a wider reading of the literature. Wilton et al. (2018) combined this framework of belonging with Simplican et al.’s (2015) model of social inclusion. This was done with the intention of holding “the concepts of social inclusion and belonging in productive tension, suggesting that both offer important analytical insight on the social geographies of people with intellectual disabilities” (Wilton et al., 2018, p. 248).

The study by S.A. Hall (2009b) used the author’s own conceptualisation of social inclusion, which emerged from a qualitative meta-analysis (S.A. Hall, 2009a). Social inclusion was defined as “being involved in activities, developing and maintaining reciprocal relationships, and having a sense of belonging” (S.A. Hall, 2009b, p. 25). A sense of belonging was subsequently identified as a major theme when describing how social inclusion was experienced by young adults with intellectual disabilities.

A further two papers featured belonging in the results. The study by Umb-Carlsson and Lindstedt (2011), found a sense of social belonging to be a major component of quality of life from the perspectives of people with intellectual disabilities. Through their photovoice

project, Schleien et al. (2013) found that participants desired a sense of belonging, which was evidenced by participants speaking of the places they felt welcomed or accepted.

The two remaining papers did not feature belonging as prominently. One of these (Merrells et al., 2017b) briefly mentioned a sense of belonging in both the introduction and results sections, but the authors never defined the concept or discussed it in any detail. The final paper (E. Hall, 2004) offered a critique of existing definitions of social inclusion and social exclusion to contextualise the research. While the concept of belonging was never discussed explicitly in this paper, many participants' narratives touched on topics related to feeling accepted or welcomed.

### *Methods adopted*

Three of these studies adopted a phenomenological approach (S.A. Hall, 2009b; Merrells et al., 2017b; Umb-Carlsson & Lindstedt, 2011), two utilised participatory approaches (Schleien et al., 2013; Wilton et al., 2018), and one used a narrative approach (E. Hall, 2004). The remaining paper (Strnadová et al., 2018) failed to describe a specific study design, but stated that inductive content analysis was used to analyse the data.

All seven papers incorporated either individual or group interviews with primary participants with intellectual disabilities as part of the data collection process. E. Hall (2004) reported that he used group interviews to provide participants with a supportive environment, reduce the risk of participant compliance, and recognise that people live social lives and often have collective narratives (p. 300). Strnadová et al. (2018) used focus groups to help participants feel relaxed and to elicit the various meanings of belonging held by participants (p. 3).

The final two studies adopted more participatory approaches. Schleien et al. (2013) used photovoice, which has been described as “a creative form of participatory action research” (Brake et al., 2012, p. 45). This method uses photography and group discussion to promote critical reflection and conversation about the strengths and concerns within a community (Wang & Burris, 1997, p.370). In their project, Schleien et al. (2013) utilised individual photography assignments, individual interviews, group discussions, and a community exhibition featuring participants' photographs. The second participatory study (Wilton et al., 2018) used a combination of go-along interviews, visual maps created using

photography and GPS technology, and participant workshops. The authors noted that their study design fell short of participatory action research, but they still strove to actively involve participants throughout much of the research process.

Only two of these studies stated that participants were provided with accessible study information as shown by Table 3c. In addition, only two fully described the context in which data collection took place, and only two adequately considered the relationship between the researcher and participants (see Table 1c).

## **Discussion**

### **Conceptualisations of belonging and reciprocity**

While each of the papers in this review contained some discussion of belonging or reciprocity, these concepts were rarely explored from the outset or defined. The relative omission of belonging and reciprocity from the literature is problematic because they have both been identified as key components of social inclusion (S.A. Hall, 2009a; Overmars-Marx et al., 2014), making them important constructs to examine. Furthermore, of those papers that did strongly feature belonging and reciprocity, almost none provided clear definitions for these terms, leaving the reader to infer what was meant by the authors. While it is recognised that authors cannot be expected to define every concept mentioned in the text, the general lack of clear conceptualisations of belonging and reciprocity across this literature was striking.

A coherent conceptualisation of belonging was only adopted in two papers (Strnadová et al., 2018; Wilton et al., 2018). An additional five papers included belonging within the major research themes yet failed to provide a clear definition of the concept. This is perhaps unsurprising, as Mee and Wright (2009) pointed out: “Sometimes, belonging is at the centre of the analysis but, more often, it is used in a way that implies a common understanding of what belonging is and why belonging is important” (p. 772), to which they added, “no such common understanding exists” (p. 772).

The papers that defined belonging both drew from the framework developed by Antonsich (2010). In the remaining papers, belonging tended to be described in relation to being welcomed, accepted, or appreciated, which certainly resonates with Antonsich’s

framework. However, by providing very little in the way of definition, these papers generally assumed readers had a common notion of what belonging was.

Across this body of work, belonging was mentioned in relation to specific settings, such as a workplace or social group, as well as to more general contexts, such as a neighbourhood or community. Through their scoping review of literature on sense of belonging and disability, Mahar et al. (2013) similarly found that the scale and context to which belonging was ascribed varied widely. This led the authors to emphasise the importance of specifying the “external referent that serves to ground the individuals’ subjective perceptions” (Mahar et al., 2013, p. 1030).

Mahar et al. (2013) argued that “because of the possibility that a sense of belonging may be multifaceted and conflicting, depending on the external referent, a global measure will not have practical applications and may be misleading” (p. 1030). Belonging is highly context dependent and can only be understood in reference to a specific group, time, and place. For instance, belonging is likely to mean something very different in relation to a specific structured social group with regular attendees, such as that described by Wilson et al. (2017), than it is to the community as a whole, where the meaning of belonging may draw from experiences in a range of places and interactions with a wide variety of people. This stresses the importance of providing comprehensive descriptions of the contexts in which such research is carried out. While most of the studies in this review provided an adequate description of the research site, many failed to mention the timeframe in which the research was conducted. This omission may disregard information important to the understanding of participants’ experiences of belonging.

While at least some attempts were made to explore and conceptualise belonging, there was a marked lack of research conducted on reciprocity, and limited attempts were made to define the concept. This is a critical oversight considering that reciprocity has been found to be central to descriptions of friendship by people with disabilities (Bates & Davis, 2004; Callus, 2017; Milner & Kelly, 2009) and a key component of both social inclusion (S.A. Hall, 2009b; Lysaght et al., 2017) and belonging (Mahar et al., 2013). Across these studies, the concept of reciprocity tended to arise through discussions of interpersonal relationships or social interactions, and studies describing reciprocity often made mention of mutual enjoyment or exchanges.

While only one paper mentioned that reciprocity should not be contingent upon equal exchanges (Johnson et al., 2010), it is important to reiterate that point here. As bell hooks (2009) argued:

With reciprocity all things do not need to be equal in order for acceptance and mutuality to thrive. If equality is evoked as the only standard by which it is deemed acceptable for people to meet across boundaries and create community, then there is little hope. (p.87)

In their participatory action research project, Milner and Kelly (2009) pointed out that there is often a failure to recognise the subtle ways people may benefit from social connections, including a passing exchange or a shared moment of fun. The benefits of such fleeting moments of connection and conviviality and their ability to lead to the greater social inclusion of people with intellectual disabilities have been further illustrated through the literature on encounter (e.g. Bigby & Wiesel 2011; Bigby & Wiesel, 2019; Wiesel & Bigby, 2014; Wiesel & Bigby, 2016). Researchers should, therefore, be challenged to expand their notions of reciprocity to recognise the value of seemingly brief or unequal exchanges and to rethink what reciprocal relationships can look like. This might be particularly important when people lack the practical resources to ensure an equal exchange with others.

### **Methods used across this research**

The number of qualitative studies in intellectual disability research has been shown to be increasing over time (Beail & Williams, 2014). However, between 2009 and 2011, it was found that the range of research methods employed in these studies was limited, with most studies relying on semi-structured interviews (Beail & Williams, 2014). Across the 17 papers in this review, individual interviews were likewise identified as the primary means of data collection. This heavy reliance on participants' abilities to express themselves may have excluded many people from taking part in this research and contributed to the fact that only two studies in this review included participants with severe intellectual disability (Johnson et al., 2010; 2012; Pottie & Sumarah, 2004).

Despite the extensive use of individual interviews, the range of methods adopted by researchers did appear to be diversifying in recent years, with four papers mentioning the

use of group interviews, three including participant observation, two making explicit use of dyadic interviews, two employing photographic methods, and one using go-along interviews. Studies using observation and dyadic interviews allowed researchers to witness exchanges between primary participants and their close social contacts, which was particularly important to the exploration of reciprocity. Through direct observation, researchers could document the subtle or often seemingly unremarkable reciprocal actions of participants.

The studies using photography (Schleien et al., 2013; Wilton et al., 2018) enabled participants to play an active role in documenting their everyday experiences. When the photographs were used as a stimulus for interviews and group discussion, they helped to provide an in-depth understanding of participants' sense of inclusion and exclusion that it would have been difficult to achieve through interviews alone. Similarly, the go-along interviews utilised by Wilton et al. (2018) meant that participants were able to provide an immediate commentary on locations in their communities and aspects of their daily lives that mattered to them. These more participatory methods appear particularly useful to research committed to capturing participants' subjective experiences of belonging.

However, regardless of methods adopted, some issues and omissions relating to recruitment and data collection procedures were identified across these 17 papers. Before discussing these shortcomings, it is important to reiterate that omissions may be due to constraints imposed by word limits. Furthermore, some authors do provide additional details about the conduct of their studies in other papers. For instance, Johnson et al. (2011) provide information about how the research was communicated to participants in Johnson et al. (2010; 2012), and further discussion of the relationships between participants and researchers was provided in Bigby et al. (2014) for the study described in Frawley and Bigby (2015) and in Fudge Schormans et al. (2018) for the study in Wilton et al. (2018). While it is recognised that many of these studies were of high quality, the absence of key information across the papers included in this review is notable and warrants discussion.

Of the 16 studies to conduct group or individual interviews with participants with intellectual disabilities, only seven papers indicated whether a supporter was, or could be, present during interviews. The importance of providing this information should not be overlooked. Jointly conducted interviews have been found to allow ideas and topics to



surface that may not emerge otherwise (Booth & Booth, 1994), and supporters have been included in group interviews to help build trust and help participants express themselves (E. Hall, 2004). However, the relative power of supporters can influence what participants say (Llewellyn, 2009), and there may be a tendency for some supporters to dominate interviews (Booth & Booth, 1994). Therefore, the presence or absence of others should be clarified as it is likely to have an impact on the data collected.

Researchers should also detail the steps taken to make the research accessible to participants. It has been recommended that people with intellectual disabilities be provided with study information in advance, giving them plenty of time to develop questions and discuss it with others, and that study information be provided in formats accessible to potential participants (Andre-Barron et al., 2008). Only four papers in this review described how study information was made accessible. Without this detail it is impossible to assess the degree to which participants were truly informed about the studies in which they took part. This is not to say that research should only attempt to include participants who are able to provide informed consent on their own behalf, but that care should be taken to explain studies to all potential participants and involve them in the process of consent as fully as possible.

Across these papers, it was also found that the contexts in which data were collected and relationships between researchers and participants were seldom fully explained. By omitting this information, the authors failed to provide the reader with a complete understanding of the data or demonstrate how the researchers acted as valid and reliable tools of data collection. As Booth and Booth (1994) stated in their reflections on conducting interviews with people with intellectual disabilities: “ultimately, in this type of research the validity of the data is the stuff of the relationship between the interviewer and the informant” (p. 421).

## **Limitations**

This systematic review has several limitations. The search was limited to papers published in English between January 2000 and October 2018, and grey literature was not searched. This may have resulted in the omission of some relevant studies. Also, given the lack of clarity surrounding definitions of social inclusion, belonging, and reciprocity, the search and selection processes relied on the authors’ own understandings of these concepts. To

help mitigate some of this bias, two researchers screened all papers independently, and the search was conducted using a large range of terms derived from a wide reading of the literature. Ideas of what constituted social inclusion, belonging, and reciprocity were kept similarly flexible and inclusive during the selection process. However, it is recognised that the researchers' perceptions of these concepts will have impacted on the studies included.

## **Conclusion**

While each of the 17 papers in this review touched on belonging or reciprocity, very few defined these concepts or explored them in much depth. The papers also frequently omitted important details concerning recruitment and data collection. These shortcomings should be addressed in future research to reveal more fully how belonging and reciprocity are experienced by people with intellectual disabilities and produce a sound and robust literature on these concepts. This work is vital given how prominently belonging and reciprocity feature in discussions of social inclusion and could lead to communal and societal level changes that enable people with intellectual disabilities to lead fuller lives.

## Appendix B: Approval letter from MVLS ethics committee for original study



29<sup>th</sup> July 2019

**MVLS College Ethics Committee**

***Project Title: Assessing the role of asset-based approaches in fostering belonging and facilitating the wider community participation of adults with intellectual disabilities***  
***Project No: 200180110***

Dear Prof Jahoda,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: End February 2022
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:  
[http://www.gla.ac.uk/media/media\\_227599\\_en.pdf](http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson  
 MD, BSc (Hons), FRCP, FESO  
 Professor of Stroke Medicine  
 Consultant Physician  
 Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion  
 Chair MVLS Research Ethics Committee

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 G51 4TF

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## Appendix C: Approval letter from MVLS ethics committee for updated study



14<sup>th</sup> May 2020

**MVLS College Ethics Committee**

***Project Title: Assessing the role of asset-based approaches in the lives of adults with intellectual disabilities during the COVID-19 pandemic***

***Project No: 200190157***

Dear Prof Jahoda,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: As stated in application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: ([http://www.gla.ac.uk/media/media\\_227599\\_en.pdf](http://www.gla.ac.uk/media/media_227599_en.pdf))
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson  
 MD, BSc (Hons), FRCP, FESO  
 Professor of Stroke Medicine  
 Consultant Physician  
 Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion  
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## Appendix D: Interview topic guide

Introduction: No right or wrong answers. You can take a break whenever you want.

Can ask them to share a bit about themselves. Can share a bit about myself as well.  
Can you tell me how you found out about dates-n-mates?

Who told you about the group? Was it your idea to go? What was it like the first time you ever went? How did you feel about going?

1. General experience of taking part
  - a. Length of time involved in group
  - b. Activities involved in with dates-n-mates prior to lockdown
  - c. Likes/dislikes
  - d. Thoughts/feelings about the group and taking part`
2. Impact group has had on life
  - a. Difference dates-n-mates has made to life
  - b. Changes to self
  - c. Friends, reconnections (inside and outside structured group activities)
3. Impact of COVID-19 and role group has had in life
  - a. How they have been doing generally during lockdown
  - b. Contact with dates-n-mates/group members during lockdown
  - c. Activities involved in during lockdown
  - d. Likes/dislikes about activities
  - e. Satisfaction with levels/modes of contact
  - f. Satisfaction with support dates-n-mates has offered (practical, social)
  - g. Most missed aspects of dates-n-mates prior to lockdown
  - h. Any benefits/setbacks to online communication
4. Participation in other activities
  - a. Other activities involved in prior to lockdown
  - b. Current contact with groups/friends outside of dates-n-mates
  - c. Previous and current online participation (social media, video-conferencing, gaming)
  - d. Things not done but interested in trying (during and outside of lockdown)

Closing: Is there anything else you would like for me to know?

Leave opening to come back with follow-up questions.  
-Make arrangements for first follow-up interview.

## Appendix E: Follow-up interview topic guide

Check still happy to take part.

Check recording is okay.

Recap last conversation.

Can you tell me about how things have been for you over the past week/fortnight? Has anything changed?

### 5. Impact of COVID-19 and role group has had in life

- a. Have you spoken to people from <name of group> over the last week/fortnight? How did that go?
- b. Can you tell me about some activities you have done with <name of group> over the past week/fortnight? How have these worked? What did/didn't you like about these?

### 6. Participation in other activities

- a. Can you tell me about any other activities you have taken part in over the past week/fortnight? Have you taken part in any other clubs or groups in the past week/fortnight? Can you tell me a bit about these?
- b. Have you tried any new activities over the past week/fortnight? How did they go?

## Appendix F: Study information leaflet



### Do you take part in dates-n-mates? We want to know what you think!



#### What is this study about?

We want to know what it's like to take part in groups like dates-n-mates.

We also want to know what things have been like for people during the coronavirus outbreak.



OR



#### What will happen if I take part?

You will speak to a researcher on the phone or online. This will happen a few times.

The researcher will ask you questions about what it's like to take part in dates-n-mates. They will also ask about the activities you have been doing during the coronavirus outbreak.

### It is up to you if you take part!



#### How can I find out more?

Please contact the researcher. She can send you study information. This will give you details about taking part.

She would also be happy to answer any questions you have.



Lauren Fulton

Tel: 07745 796047

Email: [l.fulton.1@research.gla.ac.uk](mailto:l.fulton.1@research.gla.ac.uk)



## Appendix G: Participant information sheet



### Participant Information Sheet

**Exploring the experiences of adults with learning disabilities who take part in an organised group during the coronavirus (COVID-19) outbreak**



Please read this information sheet.



You can ask someone to read it with you.

You can talk it over with someone you trust.

#### **What is this study about?**

This study is looking at what it's like to take part in groups like dates-n-mates.

We also want to know what has changed for people because of the coronavirus.

We want to find out how groups like dates-n-mates have helped people stay connected and stay busy.



This can help us learn ways to help other people during this time.

We want to know what you think!

### **Why do you want me to take part?**

I am asking you because you take part in dates-n-mates.



### **Do I have to take part?**

No. You get to decide if you take part.

It is OK to say 'no'.



If you say 'yes' but change your mind later, it is OK.

You don't have to say why you stopped taking part.



### **What will happen if I take part?**

You will speak to a researcher.

This can be on the phone or online. It's your choice.



You can ask the researcher any questions you have.



The researcher will ask you some questions to make sure you are happy to take part.



There are 3 parts to this study.

### Part 1: First interview



The researcher will ask you some questions about yourself.

Next, they will talk to you about what it's like to take part in dates-n-mates.

They will also ask you about what has changed for you because of coronavirus.



A recorder will be used to record the interview.

This will help the researcher remember what you say.



This interview will likely take about 1 to 1 ½ hours.

If this is too long, you can finish this meeting on another day.



You can also take breaks if you want to.

## Part 2: Short interviews

The researcher will want to speak a few more times.

This is to talk about how things have changed for you.



These short interviews will take place once a fortnight.

They will happen over 3 months.



These interviews will also be recorded.

This will help the researcher remember what you say.



These interviews will take about 20 minutes each.

## Part 3: Online observations

The researcher will want to see some of the things dates-n-mates has been doing online.

This includes things like Facebook posts and online social events.

You do not have to do anything different for this part.



The researcher will take some notes about what happens online.

### **Will anything bad happen if I take part?**

You will have to give up some of your time.

It is unlikely that anything bad will happen to you as a result of taking part.



### **Are there any good things about taking part?**

People who have taken part in other studies thought it was interesting.

### **Will other people find out what I say?**

Everything you say will be kept private.

The researcher will only talk to another person about you if they are worried about you or someone else.

Your information will be kept safely on a computer and in locked cabinets.



### **What will happen to what I say?**

The researcher will write a report about what they found out.

Other people will be able to read this report.

Some of the things you say may be in this report.





Your name will not be in the report.

No one will be able to tell what you said.



Your information will be kept safely for 10 years.

After 10 years, your information will be destroyed.

This will be done in a way so no one else can see it.

### How can I take part?



Contact the researcher by phone or email if you are interested in taking part.

### Who can I contact if I have questions about the study?



My name is Lauren. I am studying at the University of Glasgow.

I will be the researcher for this study. You can contact me if you have any questions.



Tel: XXXXX XXXXXX



Email: [I.fulton.1@research.gla.ac.uk](mailto:I.fulton.1@research.gla.ac.uk)

**Thank you for taking time to read about this study!**

## Appendix H: Consent form



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

Project Number: 200190157

Participant Identification Number:

Title of research study:

**Exploring the experiences of adults with learning disabilities who take part in an organised group during the coronavirus (COVID-19) outbreak**

Name of Researchers:




Lauren Fulton, PhD student

Professor Andrew Jahoda, Professor of Learning Disabilities

Dr Deborah Kinnear, Senior Lecturer

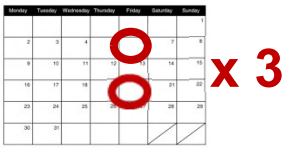





### Participant Consent From

Please **circle** if you agree  or disagree

	<p>I have seen the study information sheet.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I understand what the information sheet told me.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I have seen the privacy notice.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

	I understand what the privacy notice told me.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	I have been able to ask questions if I wanted to.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	I understand that I get to decide if I take part.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	I know I can change my mind and stop taking part at any time.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	I understand that information about me will be kept secret.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	I understand that information about me will be kept for 10 years.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	I agree to take part in an interview about dates-n-mates.	<input checked="" type="checkbox"/>	<input type="checkbox"/>



<p>Month</p> 	<p>I agree to take part in a short interview once a fortnight.</p> <p>I understand these will take place over 3 months.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I agree to be included in notes about what happens with dates-n-mates online.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I agree that meetings can be recorded.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I understand the researcher will type out what I say.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I understand that a report will be written about the study.</p> <p>I understand that some of the things I say may be in the report.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I know my name will not be in the report.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<p>I would like to take part in the study.</p>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

---

**Name of participant**

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**Date**

---

**Signature**

---

**Researcher**

---

**Date**

---

**Signature**

(1 copy for participant; 1 copy for researcher)

## Appendix I: Privacy notice

### Privacy notice for the research study:

Exploring the experiences of adults with learning disabilities who take part in an organised group during the coronavirus (COVID-19) outbreak

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#### Your information



This research study will ask for some personal information about you.



The University of Glasgow will be what's called the 'Data Controller' of your information.

A data controller decides what information to collect and how to use that information.



This sheet explains what the University of Glasgow will do with your information.

#### What personal information will we ask for?

We will ask for things like your:

- Name
- Age
- Address

Name	_____
Address	_____ _____ _____
Phone Number	_____



- Telephone number
- Gender

We will also ask about:

- Who you live with
- Any work you do



We will also ask for a bit of very private information. This is called 'special category' data.

This will include:

- Information about your health

### What does the law say?



There are laws to protect your personal information.



These laws say we must have a reason for asking for your information.

The reason we will ask for your information is for research.

This research may be able to help other people or researchers.



We must always ask your permission to use your information.



You can say 'no' at any time.

You never have to share any information with us that you don't want to.

### **What do we do with your information?**



Your personal information will be used by researchers at the University of Glasgow.



We will keep your information private.



Paper forms with your information will be kept in locked cabinets.



The researcher will type out some of your information.

This information will be kept on a secure computer with a password.



We will use your information to learn about what helps people stay connected during the coronavirus outbreak.



Your information will also be used to help us write a report.

Other people will be able to see this report.



Things like your name, address, and telephone number will not be in the report.



We will always ask your permission before using information that could tell people who you are.

### How long do we keep it?



Recordings of interviews will be deleted after the researcher types out what was said.



We will keep the rest of your information for 10 years.



After 10 years, your information will be destroyed.

This will be done in a way to keep your information private.



## What are your rights?

You can ask to see the information we have about you.



You can ask for a copy of this information.

If the information is wrong, you can ask to have it changed.



You can say 'no' if you don't want to share your information.



If you want to use your rights, please email [dp@gla.ac.uk](mailto:dp@gla.ac.uk).

Or fill in the online form:

<https://www.gla.ac.uk/myglasgow/dpfoioffice/gdpr/gdprrequests/>



## What if I'm not happy with how my information is used?

You have the right to complain if you are unhappy with how your information was stored or used.

If you want to complain, you can contact the University Data Protection Office.



You can contact them by sending an email to [dataprotectionofficer@glasgow.ac.uk](mailto:dataprotectionofficer@glasgow.ac.uk).



If you are unhappy with how the university responds, you can complain to the Information Commissioner's Office.



Their information can be found online: <https://ico.org.uk/>



**Who do I contact if I have questions?**

Lauren Fulton

Institute of Health & Wellbeing

University of Glasgow



Tel: XXXXX XXXXXX





Email: [I.fulton.1@research.gla.ac.uk](mailto:I.fulton.1@research.gla.ac.uk)

## Appendix J: Coding example from transcript in NVivo

P2: You know, I just, I don't know. Um, last week, during the coronavirus I get confirmation about the football, and that might start back up again.

L: Oh nice.

P2: But, it's like, it's like 3 games in 6 days.

L: Mm hmm.

P2: So, you're like, I need, I need to get a personal assistant in to do that.

L: Right.

P2: Because, I think, I think to ask my mum to do 3 games in like 6 days would maybe be a bit much.

L: That is a lot. Do you know when that would happen? The games?

P2: So, eh, the 3 games in 6 days will be October.

L: October. Okay.

P2: So, so definite October.

L: Mm hmm.

P2: It's trying, trying to ram it all in on the calendar. But, but, if you go, because of coronavirus, you go and say to somebody, 'Oh, I've got a ball to do on this day in October, I've got 3 games on this day in October'. Their, their first wage. See when we get them in in October?

L: Mm hmm.

P2: Their first wage is gonna be huge.

L: Yeah.

P2: Um, because, because we will have done that much. I mean, do you, do you know what I think will happen?

L: What?

P2: This is why I'm curious about doing the social distancing.

L: Mm hmm.

P2: 'Cause I think they will put us through the social distancing training, she'll come out, and she'll lift everything.

L: Yeah.

P2: And I'm like, I'm like, I can't—I can wear a mask.

L: Yeah.

P2: If they want me to put gloves on, I'm like, no, no, not really.

L: Yeah.

P2: 'Cause I just, I just think it affects the inability to work.

L: So, would you rather just wait until everything is lifted before you go out and do stuff?

P2: Well, well, in terms of that, I think so.

L: Mm hmm.

P2: Whereas, whereas, if I go and see [partner], I go and see dates-n-mates, I can do that as social distancing.

L: Right.

P2: And if I, and if I'm away doing the football, I could do, I could do that as social distancing. I could put a visor or something on.

L: Mm hmm.

P2: So, so, there's ways around about that at my Friday group. It's just the, it's just the drama, I'm no...

L: Yeah.

P2: I'm not, I'm not keen on it, and I'm not, um, I'm not too keen on, what, they're doing the gala dinner as social distancing.

L: Right.

P2: Because then, because then, that effectively is a waste of money if you can't dance, do you know what I mean?

L: Yeah.

Not having someone to take him out  
 Taking risks and bending rules  
 Experiencing loss  
 Considering impact on mother  
 Concerns surrounding scheduling  
 Unwanted contact during the pandemic  
 Frustration with others' reactions to the pandemic  
 Resuming dates-n-mates activities during the pandemic  
 Negative impact on activities  
 Online activities with dates-n-mates  
 Concerns about scheduling conflicts, cancellations, and transportation  
 Feelings about and relationships with staff members  
 Wanting to see partner  
 Afraid of loss and bad things happening  
 Resuming activities during the pandemic  
 Ability to cope during the pandemic  
 Frustration with people not following the rules  
 Other activities  
 Looking forward to activities and getting out again  
 Supporting his partner during the pandemic  
 Caring about the health and wellbeing of partner  
 Difficulties with restrictions and guidelines

Not having someone to take him out  
 Taking risks and bending rules  
 Experiencing loss  
 Considering impact on mother  
 Concerns surrounding scheduling  
 Unwanted contact during the pandemic  
 Frustration with others' reactions to the pandemic  
 Resuming dates-n-mates activities during the pandemic  
 Negative impact on activities  
 Online activities with dates-n-mates  
 Concerns about scheduling conflicts, cancellations, and transportation  
 Feelings about and relationships with staff members  
 Wanting to see partner  
 Afraid of loss and bad things happening  
 Resuming activities during the pandemic  
 Ability to cope during the pandemic  
 Frustration with people not following the rules  
 Other activities  
 Looking forward to activities and getting out again  
 Supporting his partner during the pandemic  
 Caring about the health and wellbeing of partner  
 Difficulties with restrictions and guidelines

Participant 2		0	0
Getting help and giving back		0	0
Having a sense of value to others		0	0
Caring about the health and wellbeing of partner		5	19
Experience of valued and expected social roles of one's choosing		0	0
Supporting his partner during the pandemic		7	13
Hosting a Zoom event		2	3
Receiving support from partner		5	7
Thinking about others		0	0
Considering impact on mother		5	8
Getting out when nothing seems normal		0	0
Dealing with uncertainty		0	0
Concerns surrounding scheduling		5	8
Feeling he has to start over		2	4
Frustration with others' reactions to the pandemic		3	4
Impact of the pandemic on dates-n-mates		0	0
Cancelled and rescheduled dates-n-mates activities		3	7
Resuming dates-n-mates activities during the pandemic		6	12
Negative impact on activities		5	11
Reaction to the pandemic and easing restrictions		4	7
Resuming activities during the pandemic		6	28
Concerns about scheduling conflicts, cancellations, and transportati		5	10
Prioritising activities		5	28
Unwanted contact during the pandemic		3	3

<input type="checkbox"/>	<input type="radio"/> Longing for connection			0	0
	<input type="radio"/> Difficulties with restrictions and guidelines			7	44
	<input type="radio"/> Emotional reunions			2	3
	<input type="radio"/> Feelings about and relationships with staff members			5	7
	<input type="radio"/> Frustration with dates-n-mates			1	6
	<input type="radio"/> Frustration with people not following the rules			5	7
	<input type="radio"/> Hope that restrictions would lift			1	1
	<input type="radio"/> Looking forward to meeting with dates-n-mates in person			3	3
	<input type="radio"/> Staying in touch and meeting up with friends			3	5
	<input type="radio"/> Staying in touch and meeting up with partner			6	10
	<input type="radio"/> Taking risks and bending rules			4	7
	<input type="radio"/> Wanting to see partner			6	15
<input type="checkbox"/>	<input type="radio"/> Regaining independence			0	0
	<input type="checkbox"/> <input type="radio"/> Access to goods and services			0	0
<input type="checkbox"/>	<input type="radio"/> It's tough but I'm managing			0	0
	<input type="checkbox"/> <input type="radio"/> Experiencing loss and difficult emotions			0	0
	<input type="radio"/> Afraid of loss and bad things happening			4	10
	<input type="radio"/> Difficulty trusting others			1	2
	<input type="radio"/> Experiencing difficult emotions			3	6
	<input type="radio"/> Experiencing loss			5	8
	<input type="radio"/> Feeling let down by potential PAs			4	11
	<input type="radio"/> Not wanting to seem different			1	2
<input type="checkbox"/>	<input type="radio"/> Feeling confined			0	0
	<input type="radio"/> Concerns about finding activities to do with a personal assistant			4	9
	<input type="radio"/> Lack of meaningful activity			3	9
	<input type="radio"/> Looking forward to activities and getting out again			6	25
	<input type="radio"/> Needing to get out of the house			5	12
	<input type="radio"/> Not having someone to take him out			2	5
<input type="checkbox"/>	<input type="radio"/> Keeping going			0	0
	<input type="checkbox"/> <input type="radio"/> Keeping busy			0	0
	<input type="checkbox"/> <input type="radio"/> Managing to keep going			0	0

## Appendix K: Coding example from social media data in Excel

Post ID	Account	Date of post	Description			Categories				
			Primary topic (e.g. former events, upcoming activities, Covid-19)	Activities held	Date activities held	Other	Online activities	Number of unique online activities held	Return of in-person activities	Health, wellness, and human rights related activities and information (inc help for abuse and info about relationships)
T280420-1	dates-n-mates twitter	28-Apr-20	Easy-read news; Covid-19 coverage							
T280420-2	dates-n-mates twitter	28-Apr-20	Members' socially distanced walks							
T280420-3	dates-n-mates twitter	28-Apr-20	At home activity idea							
T290420-1	dates-n-mates twitter	29-Apr-20	Virtual music and dance p	Music and dance party	29-Apr-20			1	1	
T300420-1	dates-n-mates twitter	30-Apr-20	E-newsletter							
T300420-2	dates-n-mates twitter	30-Apr-20	Virtual music and dance p	Music and dance party	29-Apr-20			1		
T010520-1	dates-n-mates twitter	01-May-20	Virtual quiz	Disney themed quiz	01-May-20			1		
T020520-1	dates-n-mates twitter	02-May-20	Online activities	Games night	06-May-20			1	1	
				General knowledge quiz	08-May-20				1	
				Daily video chats						
T040520-2	dates-n-mates twitter	04-May-20	Help with feeling stressed							1
T040520-3	dates-n-mates twitter	04-May-20	Video chats	Daily video chats	Every weekday, Monday through Friday at 2pm			1		
T060520-2	dates-n-mates twitter	06-May-20	Games night	Games night	06-May-20			1		
T070520-2	dates-n-mates twitter	07-May-20	Help with feeling stressed							1
T080520-1	dates-n-mates twitter	08-May-20	Virtual events	Karaoke and dance party	13-May-20			1	1	
				General knowledge quiz	15-May-20				1	
T080520-2	dates-n-mates twitter	08-May-20	Virtual quiz	Virtual quiz	08-May-20			1		
T090520-1	dates-n-mates twitter	09-May-20	At home activities							



	Research question driven			Based on Cobigo et al's (2012) definition of social inclusion						
	Impact of Covid-19 pandemic	Adaptations made due to Covid-19 pandemic	Providing support during pandemic to members	Access to goods and services		Experience of valued and expected social roles of one's choosing		Experience of being recognised as a competent individual trusted to perform social roles in the community		Experience where supported as a resource as a socio-belonging
Member, family, and director feedback/interviews				pre-pandemic	during pandemic	pre-pandemic	during pandemic	pre-pandemic	during pandemic	pre-pandemic
			shared source of easy-read daily news							
			shared activity idea							
			provided link to access e-newsletter and sign up to receive subsequent newsletters							
			provided online activity to members							
			provided online activities to members							
			shared technique for coping with stress							
			provided online activity to members							
			shared link for tips for coping with stress						stress tips were developed by one of the directors	
			provided online activities to members							
			provided online activity for members							
			shared link to at home activity ideas							

		Based on Antonsich's (2010) framework for belonging									
Experience of belonging to a social network where support is given and received/Belonging as a resource in discourses and practices of socio-spatial In/exclusion ('politics of belonging'; belonging to a group of people)		Belonging as feeling 'at home' (place-belongingness)		Other		Notes					
pre-pandemic	during pandemic	pre-pandemic	during pandemic								
	encouraged members to share what they had been doing			shared photos members submitted of their walks outdoors							
	members participated in virtual activity together			music and dance party was requested by members							
	members 'really got stuck in' and 'cheered each other on'										
	members participated in a virtual activity together			Disney themed quiz was requested by members							
	members participated in virtual activities together										
	members given space to connect and chat with other members										
	members participated in a virtual activity together										
3 directors										members had been 'chatting, laughing, [and] sharing entertainment ideas '	
	members participated in virtual activities together									this had originally been posted on the dates-n-mates website before lockdown	
	members participated in a virtual activity together									this was their first karaoke night	



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