Views and Experiences of Parents of Adults with Intellectual Disabilities, Service Providers and People with Intellectual Disabilities Around Care and Social Networks in Times of Austerity

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Abstract

Background

People with intellectual disabilities can benefit from having meaningful relationships with people in their social networks. These networks can include family, friends and professionals, and can be vital for providing support and maintaining and improving wellbeing. Since the introduction of austerity measures in 2008, funding for care, welfare, services and support systems in the U.K. has been reduced. There is little U.K. research which explores the views and experiences of parents of adults with intellectual disabilities, service providers and people with intellectual disabilities regarding their care, relationships and social networks in times of austerity. As a result, this thesis aimed to explore these experiences in order to better understand the ways in which austerity may be perceived to impact individuals' lives from their own perspectives, and to make suggestions for future research, policy and practice.

Methodology

A systematic literature review and synthesis was carried out in order to analyse previous literature regarding the social networks of people with intellectual disabilities (Chapter Two). Mixed methods research approaches were then used to undertake three empirical studies. Chapter Four presents the findings and conclusions regarding interviews with ten parents of adult children with intellectual disabilities. Chapter Five considers the responses of nine professionals who provide services to adults with intellectual disabilities. Finally, analysis of the responses of 150 people with intellectual disabilities are presented in Chapter Six.

Results

Theories of stigma, normalisation and care ethics were used to better understand reported experiences and effects of austerity. The experiences of parents, service providers and people with intellectual disabilities suggested that austerity was felt to negatively impact on relationships, care and social networks. Under austerity, distance was experienced in relationships with Local

Authorities and their workers. Systems were felt to have been designed to create and maintain this distance. Participants in each study reported feeling misunderstood and uncared about, and that their lives, identities and wellbeing were all negatively impacted by the effects of austerity. Relationships with Local Authorities and their workers were experienced as having become (more) adversarial, with each group of participants reporting feeling the need to fight against cuts, against being given stigmatised identities and against false assumptions being made about them. Loss was experienced around relationships. The care and social networks both of people with intellectual disabilities and of parents were felt to be being diminished. Improvements under earlier policies based on normalisation principles were felt to have been lost; practice and attitudes were instead felt to be regressing to historically poor levels. Under austerity the purpose, experiences and effects of reassessment were all experienced as disabling people with intellectual disabilities.

Conclusion

This study makes suggestions for improvements in policy, practice and research. An evaluation of the financial and emotional impacts of austerity is recommended in order that governments and Local Authorities can better understand the impacts of their decisions. Policy being written in partnership with people with intellectual disabilities, parents and service providers could promote a care ethics approach. This could be strengthened by a promise from governments that appropriate support will be funded and provided to people with intellectual disabilities throughout their lifetimes. Training of government and Local Authority staff by people with intellectual disabilities, parents and service providers could challenge stigma and aid the development of policies and practices which understand and meet the needs of people with intellectual disabilities and those who support them. A care advocacy collective could also be instrumental in promoting these changes. Longitudinal research which includes the experiences of people with significant intellectual impairments, those who have experienced no deterioration in their relationships with Local Authority workers and importantly, the experiences of assessors making judgements about eligibility for care would add to our understandings of the ways in which experiences of care and social networks could be improved.

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Chapter One Introduction and Overview

In 2008 the Global Financial Crisis, which was labelled “The Great Recession” and was considered to be “the most severe since the Great Depression of the 1930s” (Burton, 2016, p. 1) led to political and fiscal choices being made by successive U.K. governments. The resulting austerity policies, which were designed to adjust the economy “through the reduction of wages, prices, and public spending to restore competitiveness”, were undertaken in the hope that national finances would more quickly rebalance (Blyth, 2015, p. 2). These policies resulted in significant cuts to welfare and social care budgets. Austerity impacted on all those receiving care and support, including those with intellectual disabilities, and continued reductions in government funding coincided with more people requesting support (The King’s Fund, 2021). More recent increases in government funding since the Covid-19 outbreak were not considered adequate to fill previous or current social care funding gaps (NHS Digital, 2022; The King’s Fund, 2023). The little research already undertaken to assess the impacts of cuts on people with intellectual disabilities has found that austerity had negative impacts on wellbeing (Malli et al., 2018; UN Committee on the Rights of Persons with Disabilities, 2016). However, the effects of austerity measures on experiences of care and social networks for people with intellectual disabilities and their parents, and for people providing services in times of austerity has yet to be fully researched.

This first chapter presents a very brief overview of some past and current issues relating to austerity and the care and social networks of people with intellectual disabilities, their parents and the people who provide their services. It will define key terms and include prevalence rates and the types of accommodation in which people live. It will then provide information regarding what life is like for some people with intellectual disabilities with a focus on some of the particular issues that affect them: activities, social networks and health inequalities. Relevant policies and the concept of eligibility will then be presented particularly in relation to *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health (DoH), 2001) (introduced pre-austerity) and The Care Act (DoH, 2014), introduced during austerity. Relevant philosophies which relate to understanding approaches to people with intellectual disabilities will be presented; these are normalisation and care ethics. The concept of stigma, which both Goffman (1990b) and Link and Phelan (2001) explain can be understood in terms of the ways in which power can be used in relationships, is also presented and applied to findings.

This introductory chapter will conclude with a brief background and overview of this research study. This will include the context for this research on the experiences of people with intellectual disabilities, parents and service providers during austerity, and the initial research aims. An overview of the thesis will then be presented.

Definitions

'Intellectual Disabilities'

The term 'Intellectual Disabilities' is one of many in a long history of labels given to a diverse group of individuals with a wide range of strengths, attributes and support needs. The term 'learning disabilities' is also often used interchangeably with this and other similar terms. Different terms and definitions highlight the diversity of available approaches to understanding this group of people collectively and as individuals, which include medical, social and biopsychosocial models and may focus on perceived deficits or on perceived strengths. Abilities in terms of social functioning and relationships are inherent within many definitions. 'Disorders of intellectual development' for example are defined by the World Health Organization (WHO, 2023) as a permanent:

> significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

The British Institute of Learning Disabilities (2011) acknowledge definitions of deficit but also point out the role people with intellectual disabilities can have within relationships:

> Individuals who have the label of a learning disability/difficulty can and should be described in many other ways including, friend, neighbour, relative, colleague, community member, partner, employee, parent. A label describes one aspect of a person but does not capture the whole person.

Approximately 1.5 million people in the U.K. have intellectual disabilities which equates to around 2.16% of the population (Mencap, 2023a).

'Social Networks'

Social networks have been defined in different ways. Social networks can be defined as "opportunity structures" which may or may not provide support (Forrester-Jones & Grant, 1997, p. 2) or as positive interpersonal relationships (Sullivan et al., 2016). They also may include people who are critical of our actions and those we find actively unhelpful. Although the word 'social' suggests network members are known only within a social sphere, Hill and Dunbar (2003) and Dunbar (2015, 2021) are clear that social networks can include close and extended family members, friends, workers and a range of health and other professionals who may be seen or interacted with regularly or only very rarely. Age, location and level of support needs may influence how many people one considers to be in one's network. Similarly, whether people with intellectual disabilities themselves are asked directly, or whether staff or family are asked about the networks of people with intellectual disabilities may also influence the nature and membership of reported networks. The ways in which researchers define who is part of one's social network and how researchers define 'contact' with network members may also have an influence on the size and nature of networks. Measures can include a diverse range of suggested network members, such as in the *Social Network and Employment Scale* (SONES) (Forrester-Jones et al., 2006) which includes prompts for people with intellectual disabilities to consider shopkeepers, social acquaintances and health staff for example and defines ‘contact’ as face to face engagement (including virtual face to face contact) but not emails or texts. Social networks can also be defined in less diverse ways, such as Dagnan and Ruddick’s study (2014) of older people with intellectual disabilities for example, which considers family members, people with intellectual disabilities and ‘others’ which includes advocates and friends without intellectual disabilities. Despite their definitions of ‘contact’ with networks members being wider than Forrester-Jones et al. and including letters, phone calls and visits, 8% of Dagnan and Ruddick’s sample had no-one in their social network. There are then a wide range of ways in which social networks and contact with members of networks can be defined in the academic literature.

‘Accommodation for People with Intellectual Disabilities’

Housing options are limited by Local Authority (L.A.) funding but typically consist of residential care homes (where people with intellectual disabilities live with many other people with intellectual disabilities with 24-hour support), Supported Living (where people with intellectual disabilities live in small homes alone or with a small number of other people with intellectual disabilities with some part-time support), or Shared Lives (where people with intellectual disabilities rent a room in a family home and are supported by one or more adults in that home). Hatton et al. (2022) found that in 2020/2021, 14% (18,515) of working age adults with intellectual disabilities were living in residential care and 23% (31,070) were living in Supported Living accommodation. Shared Lives Plus (2023) reported that in 2021/22 of 8491 people who lived in Shared Lives accommodation, 6007 (71%) had intellectual disabilities. This was an increase of 4% over the previous year. While the type of accommodation in which a person with intellectual disabilities lives can impact on their care and social networks, with smaller services generally having better outcomes than larger residential institutional settings, there are a large number of factors which can influence people’s lives beyond accommodation type. These can include intrinsic factors such as the abilities of the person with intellectual disabilities, and extrinsic factors, including the location of the service, the ethos of the service and levels of staffing and staff training, all of which can affect the relationship and social network opportunities open to people (Dagnan & Ruddick, 1997; Emerson et al., 2000; Perry et al., 2011; Robertson et al., 2001).

At least half of people with intellectual disabilities in the U.K. however live at home with parents (Foundation for People with Learning Disabilities, 2023). The Foundation for People with Learning Disabilities (2023) also state that 29,000 adults with intellectual disabilities live with parents (aged 70 or over). Care by family in the family home is the cheapest option for L.A.s, which can mean that a range of accommodation options and support options are not presented to people with intellectual disabilities or their families (Borsay, 2004; Power, 2008; Webb, 2013). Families have reported high levels of stress regarding the difficulties they can experience when working with L.A.s to try to get support for themselves and their family member with intellectual disabilities. Parents have also stated that the social care system functions in ways which do not support them or their families (Power, 2008) and can feel the need to fight for any service at all for their children with intellectual disabilities (Walmsley et al., 2017). The transition from child to adult services can be equally stressful and adversarial (Jacobs et al., 2018; Roos & Søndenaa, 2020), and this can continue through to relationships with adult services (Power, 2008). Parents have also reported a lack of understanding by professionals regarding parents' needs and the needs of their family members, including the need for relationships and social network development and maintenance (Forrester-Jones, 2021). For parents of adult sons/daughters with intellectual disabilities, there are additional issues related to ageing and caring.

'Parents of adults with intellectual disabilities'

Parents of adults with intellectual disabilities have been broadly defined as being from 40 years old (Burke et al., 2018) to over 75 years old (Weeks et al., 2009). These parents are often missing from academic literature, which can instead focus on younger parents of young children with intellectual disabilities (Mahon et al., 2019). Some of the key issues for parents of adults with intellectual disabilities are reported as a sense of anxiety about the level of care which services will/do provide, increased levels of stress regarding lack of information about services and systems, lack of future planning, lack of trust in services and policy and related feelings of fear regarding who will care for their sons/daughters when they as parents die and can no longer advocate for their adult child (Brennan et al., 2020; Lee & Burke, 2020; Pryce et al., 2017; Weeks et al., 2009). The financial and emotional 'burden' that parents can experience when caring for sons/daughters can be overlooked by L.A.s and society more widely (Bauer & Sousa-Poza, 2015; Egan & Dalton, 2019). Relationships between parents and L.A.s and associated services have been reported as being poor, often adversarial and as systems-led rather than person-centred (Power, 2008; Walmsley et al., 2017).

'Service Providers'

Like parents, service providers too can find themselves in difficult relationships with funders (Harris & Roulstone, 2011; Mansell, 1996). Service providers can include those who provide any form of support to people with intellectual disabilities and/or parents, which can encompass, but are not limited to, different types of accommodation, physical and emotional support, personal care, advice, day services, advocacy groups, support to access local facilities, welfare support and on-call support. Key difficulties for service providers can include how to provide basic services in times of cuts (Bradshaw et al., 2018) and feelings of powerlessness related to high levels of stress and 'burn-out' more frequently attributed to frontline staff (as in Stevens et al. (2021) and Thomas and Rose (2010) for example).

What Life is Like for People with Intellectual Disabilities

Key issues for people with intellectual disabilities often revolve around the desire to live 'ordinary' lives, have 'ordinary' identities and 'ordinary' relationships, and take part in 'ordinary' activities alongside non-disabled people as part of 'ordinary' social networks (Harrison et al., 2021). Ordinariness was related to having relationships with a range of different people, taking part in activities which give a sense of purpose to one's life, being in work, having time for leisure activities, building and using skills, and following one's interests. These are all aspects of life to which many people with intellectual disabilities have long aspired (Gregory et al., 2001; Head et al., 2018; Hulbert-Williams et al., 2011; Jahoda et al., 1990). Typically for people with intellectual disabilities, long-term supportive relationships and social networks will be required in order to achieve these 'ordinary' goals (Edgerton, 1993; Wolfensberger et al., 1972).

Lack of Activities

Lack of meaningful activity is an important issue for people with intellectual disabilities (Murphy et al., 2017). If organised activities do exist and are accessible to people with intellectual disabilities, they tend to be in specialist day services with others who have intellectual disabilities or involve undertaking simple household tasks with a staff member as part of a group (Bhardwaj et al., 2018; Cooper, 1998; Lippold & Burns, 2009). The Foundation for People with Learning Disabilities (2023) suggest 58,000 people with intellectual disabilities are supported to undertake activities in day centres or similar day opportunities services but are clear this does not mean that others beyond these 58,000 are supported to undertake activities. Authors also argue that engagement with activities in these settings and in one's local area requires full and proactive support from staff and/or families (Emerson et al., 2001; Emerson &McVilly, 2004; Jahoda et al., 1990; Perry et al., 2011). Boredom is common when cuts are made to activities, welfare and staffing support, which can then negatively impact identities (Hamilton et al., 2017; The Money Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). The ability to undertake activities then is fundamentally linked to one's social networks.

Lack of Social Networks

Research regarding the lives of people with intellectual disabilities suggests that social networks are key to social identity (Heyman et al., 1997); while Bhardwaj et al. (2018) explain the ways in which they are vital for social functioning, self-esteem and quality of life. Social networks are also associated with happiness, self-confidence, mental health, and leisure activities (Forrester-Jones et al., 2006) and are deemed crucial for facilitating social inclusion (van Asselt-Goverts et al., 2013).

Dunbar has undertaken extensive research on the numbers of people within social networks. For people without intellectual disabilities, a social network size of 150 people is typical. He suggests for people with intellectual disabilities social network size is more likely to be 25-30 people (Dunbar, 2015). A recent literature review (Harrison et al., 2021) found the average reported in academic literature was just 12 members, with a range of between 0 and 42 members. Lower numbers of people in one's social network reduces the numbers of people with whom one has the opportunities to interact, form long-term bonds and engage in relationships. It also reduces the numbers of people on whom one can rely for meaningful support (Dunbar, 2015). When social networks and associated relationships are diminished, the business of daily living (paying bills, reading letters, shopping, accessing food banks and budgeting for example) gets harder (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012) and the importance of being assessed as eligible for the support one needs can come into sharp focus. Social networks are also important for tackling the health inequalities which people with intellectual disabilities can face.

Greater Health Inequalities

Health issues are also important when considering the needs of people with intellectual disabilities, who can experience greater levels of health inequalities than the general population (Bollard et al., 2018) and greater levels of avoidable deaths (Truesdale et al., 2021). These health inequalities came into sharper focus during the Covid-19 pandemic where people with intellectual disabilities were at higher risk of hospitalisation and death than the general population (Heslop et al., 2021; Mencap, 2021). People with intellectual disabilities need relationships and social networks with knowledgeable people in their lives who can support them with accessing healthcare (Flynn et al., 2021; Heslop et al., 2021) and support them to understand and make informed choices about healthy lifestyles (Cooper et al., 2015). Without this support, policies which aim to positively influence the health and wellbeing of people with intellectual disabilities may continue to have mixed levels of efficacy (Javaid et al., 2020). The effectiveness of policies which relate to people with intellectual disabilities should then be considered.

Policy

Progress has been made in changing policy in the U.K. to move from institutional care to community-based care. This was in part based on the assumption that living in a community will enable people with intellectual disabilities to be part of those communities and have relationships with a range of non-disabled people as part of diverse social networks (Forrester-Jones et al., 2006; Perry et al., 2011).

In England, The Care Act (2014) was introduced in order to address the perceived unfairness of previous policies under which eligibility for services was felt to have relied on a 'postcode lottery' dependent on L.A. funding levels and decisions (Newton & Browne, 2008; Newton et al., 2006; Slasberg & Beresford, 2017). The Care Act was designed to consider the needs of people with intellectual disabilities and their carers (usually parents).

This Act was introduced in times of austerity and L.A.s were tasked with bringing in this Act whilst simultaneously saving money. Under The Care Act, eligibility for support requires assessment to be made about whether a person's needs arise from a physical or mental impairment or illness; whether their needs mean they are unable to achieve two or more specified outcomes and whether there is a consequential likelihood of significant impact on wellbeing. Eligibility under The Care Act is not dependent on membership of a labelled group, instead criteria for eligibility are based on promoting wellbeing and preventing crisis.

Eligibility for care is though closely linked to the level of finances which governments and L.A.s feel they can commit to meeting people's care needs (Slasberg & Beresford, 2017). Eligibility has long been inextricably linked with the concept of assessing a person as deserving or undeserving of collective forms of support. In 1388 the Statute of Cambridge for example required local officials to label people as either ‘deserving poor’ in order to be eligible for help from their parish and church or as ‘undeserving poor’ and therefore not eligible for support (Middleton, 1997; Stewart, 2016). The ways in which policy definitions can still be linked to considerations of eligibility for services can be seen in The Department of Health White Paper *‘Valuing People: A New Strategy for Learning Disability for the 21st Century’* (2001) and in The Care Act 2014 (DoH, 2014). In the *Valuing People* White Paper, the Department of Health considered definitions in terms of eligibility for services and were clear that IQ score alone should not automatically equate to eligibility. The Care Act takes a similar approach. As such, having learning disabilities:

> is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need.
> (Department of Health, 2001, p.14)

For the purposes of this thesis the relevant eligibility outcomes within The Care Act are developing and maintaining family or other personal relationships; accessing and engaging in work, training, education or volunteering; and making use of necessary facilities or services in the local community including public transport, and recreational facilities or services.

The impacts of austerity in relation to the purpose, effects and experiences of reassessment under this Act and to issues of care and social networks are therefore worthy of investigation. Appropriate theories can be helpful in providing perspectives on these impacts.

Theories

Theories regarding stigma, normalisation and care ethics will be used in this thesis in order to add depth to findings. These theories are dominant in the discourse around different ways of understanding the lives and experiences of people with intellectual disabilities, their families and those who support them. They also have been, and can continue to be, used to consider and create opportunities for positive change for individuals, communities and societies in both policy and practice (Bogdan & Taylor, 1987; Rogers, 2016; Scior et al., 2020; Scior et al., 2022; Tronto, 2013).

Stigma

People with intellectual disabilities and those who support them are often subject to negative assumptions of deviance. Goffman (1990b, p. 15) labelled this approach as *stigma*, which he defined as “an attribute that is deeply discrediting”. Goffman (1990a, 1990b, 1991) critiqued a range of institutions as centres of control for the powerful over the powerless, including people with intellectual disabilities. Goffman highlighted the ways in which the policy of institutionalisation of people with intellectual disabilities and other stigmatised individuals made the desire for the measurement of socially constructed deviance a reality. The Mental Deficiency Act of 1913 for the first time separated out in legislation the perceived differences between people who had what may now be termed intellectual disabilities and those with mental health conditions. Negative perceptions of difference and associated stigma continued in this Act as it created new categories of human being each of which had negative connotations linked to assumptions about morality, sexuality and threat. The concept of stigma has been widely applied but is not without critique. Bogdan and Taylor (1987) argued that the act of labelling a person as ‘mentally retarded’ or indeed any of the terms considered first appropriate then inappropriate over time, is infused with power. They claimed that the concept of labelling a person creates a new form of ‘mentally retarded’ person and a new form of knowledge about this group, which determines self-definition and moral agency not just for those labelled, but also for those who are not. Bogdan and Taylor (1987) went on to argue that challenging the effects of stigma requires closer examination and greater development of the ways in which supportive and reciprocal relationships between disabled and non-disabled people can develop and be maintained within social networks. Scior et al. (2020) and Scior et al. (2022) suggest that challenging this stigma is a global issue which needs local, effective solutions which can enable and support people with intellectual disabilities to challenge stigma for themselves and for others. It is this stigma which normalisation aimed to address.

Normalisation

This philosophical approach to understanding people with intellectual disabilities as people with rights who have the potential to be ordinary members of communities came to influence service policies in the U.K. in the 1980s and 1990s after a long history of institutionalisation of people with intellectual disabilities (Atkinson et al., 1997). Bank-Mikkelson first described normalisation principles in 1959, focusing on a rights-based approach to understanding the lives and needs of people with intellectual disabilities. This concept was elaborated in literature by Nirje in 1969 who considered the ways in which the lives of people with intellectual disabilities should echo as closely as possible the ordinary lives of non-disabled people. Wolfensberger et al. (1972) reported the circumstances in which normalisation could be applied to supporting people with intellectual disabilities to enjoy meaningful roles in society. Although there are a number of critiques of normalisation as a concept and in practice (Chappell, 1992; Culham & Nind, 2003; Williams & Nind, 1999) it did mark a shift in policymaking regarding the ways in which people with intellectual disabilities could be viewed and supported, which could be seen in the positive effects of *Valuing People* for example (Shakespeare, 2013) and The Care Act, both of which included the importance of having relationships, friends and a social life. The concept of care ethics takes these ideals and applies them to relationships at all levels.

Care Ethics

Care ethics is a way of approaching the purpose and structure of societies which considers acts of care and caring to be paramount organising factors (Rogers, 2016; Tronto, 2013). Care ethics has its basis in feminist philosophy. Feminism is a belief in the social, economic, and political equality of the sexes. Care ethics writers have challenged the traditional notion that the public sphere of existence (which includes economic, political, moral, and rational philosophical dominance) should be reserved for men while the private, home and less powerful ‘caring’ sphere should be the domain of women (Noddings, 2013; Tronto, 2013).

Nel Noddings (2013) for example was one of the first authors to provide a comprehensive theory of care. In her work on the relationships between mothers and their children, she was clear that unconditional love and reciprocal relationships should not be assumed, highlighting that some mothers could feel ambivalence towards their children. She suggested though that in the act of caring, the ‘one-caring’ and the ‘cared-for’ could enter a reciprocal relationship which could lead to the growth of one other’s wellbeing. Care ethics then is an approach which understands human existence to be universal, contextual, and grounded in often complex mutual interdependence.

In terms of ethical and moral thinking, Gilligan (1993) and Held (2006) both suggested that care and responsibility to others could be equated with a feminist understanding of ethics, while individual rights and justice fit more closely with a male-gendered understanding. Held argued for the need to adopt a more compassionate (rather than seemingly objective) basis for human interaction based on feminist understanding of ethics as a relational activity. Care ethics is then embedded in the practical nature of how women make sense of their realities and relationships. Gilligan (1993) too argued that the traditionally male understanding that the application of general ethical principles as the peak of moral development had resulted in girls and women being perceived to be less capable of moral thought than their male counterparts. Instead, she argued, the application of care ethics could be used to guide both men and women to understand their thoughts and actions in a more nuanced, embodied and context-dependent way.

These and other authors challenged the ways in which reality could be understood and knowledge could be created, challenging the notion of ‘objectivity’ in ethics as a beneficial way to understand human experience. Care ethics authors suggest that the traditionally male-dominated realm of economic activity encouraged an ethical approach of competition and domination which were in opposition to the ethics of women’s experiences (Held, 2006). With care ethics, knowledge production could be linked to the value of people's relationships rather than to the following of limited abstract moral rules.

Other authors such as Tronto (2013) and Kittay (1990) then argued that this ethic of care could and should be expanded on a global scale throughout political, social, and economic structures. Tronto particularly noted the intersectional nature of care, feminist theory, and political thinking. Rogers (2016) related this expansion specifically to the ways in which understanding caring relationships with people with intellectual disabilities could be developed. These authors suggested that care ethics should be at the heart of ethical decision-making on these wider scales, where policies, laws, social norms, systems, structures, and organisations could all be examined in terms of how caring they are and how they could be changed to have care ethics embedded within them.

Care ethics can therefore be understood as an interwoven "complex life sustaining web" (Tronto, 2013, p. 3) in personal, political, and social spheres and as such can offer a lens through which to consider the ways in which social networks could be understood and improved. Forrester-Jones and Grant (1997) for example suggest that social networks may or may not provide support. This links with Noddings' ideas that care is not necessarily straightforward and may involve complex emotions. If the social networks of people with intellectual disabilities and those who are in relationships with them were to be considered in terms of care ethics approaches, both individual and wider political and social solutions to meeting the needs of everyone within these groups may be revealed. The opportunity for social networks to be life-sustaining webs on individual and wider social scales is therefore worthy of study.

Summary

There is very little global or U.K.-based research regarding the impact of austerity on people with intellectual disabilities and their families (Malli et al., 2018). There is even less research on the experiences of service providers and their relationships in times of austerity (see Bradshaw et al., 2018). Research which does exists suggests that austerity has negative impacts on the wellbeing of people with intellectual disabilities and their families, and that managers of services can find the demands of austerity make it increasingly difficult to provide support to meet even basic needs. The extent to which austerity affects the care, social networks and relationships of people in these groups is in need of wider research. A background and overview to this research project and the ways in which it aims to explore these issues is therefore presented below.

Background and Overview of This Research

This research was undertaken whilst I was registered as a PhD student at the Tizard Centre, University of Kent. I was working as a Senior Lecturer in Health and Wellbeing at the University of Winchester. I had previously worked for three charities supporting people with intellectual disabilities. My post previous to working at Winchester University was as a Registered Manager of a residential care home in Hampshire. The home supported 23 people with dual diagnosis of intellectual disabilities and a range of mental health needs/physical impairments. I also mentored other Registered Managers in services offered by the charity. During this time, it became clear to me that the ways in which relationships and social networks could impact the wellbeing of people with intellectual disabilities, parents, staff and myself, were intertwined. I also realised that both the people I supported, and their parents had very different views regarding what they wanted for themselves and their loved ones, and that as a charity there was not enough L.A. funding to meet even the basic costs of the service. Significant fundraising was needed just to balance the finances, let alone offer a service which included ‘additional’ services such as activities. When the opportunity to undertake a PhD became available, as part of a wider Tizard Centre research project on the effects of austerity on people with intellectual disabilities, I took it. This enabled me to investigate my interests in the experiences of people with intellectual disabilities, parents and service providers regarding care, social networks and relationships under austerity and this became the topic of my PhD.

The initial aims of my PhD study were to investigate the views and experiences of parents of adults with intellectual disabilities and people with intellectual disabilities around care and social networks in times of austerity. For my study, effects of austerity were defined as cuts to services, care, support and/or welfare which affected people with intellectual disabilities or parents. However, as the research process began, service providers came forward asking to be interviewed regarding their experiences. The research question was therefore expanded to include their perspectives and to add another dimension to the ways in which austerity may be experienced.

My research question therefore was:

What are the views and experiences of parents of adults with intellectual disabilities, service providers and people with intellectual disabilities around care and social networks in times of austerity?

I was keen to ensure that people with intellectual disabilities were asked both quantitative and qualitative questions regarding their lives, as often research about the lives and social networks of people with intellectual disabilities relies on the views of others, which may or may not accurately reflect the views of people with intellectual disabilities (Harrison et al., 2021). Parents often feel they do not have the opportunity to tell their own stories and be heard by professionals (Power, 2008; Walmsley et al., 2017). It was therefore important to ensure this research was undertaken in a way which would value them and their experiences. This also applied to service providers.

Structure of the Thesis and Chapter Descriptions

Chapter Two: Literature Review and Synthesis (Harrison et al., 2021)

This chapter will consider and analyse available academic literature regarding the social networks of people with intellectual disabilities. As this study centres on the effects of austerity in the U.K., this is the geographical area of focus in order that any effects of U.K. Community Care policies could be included. The concepts of normalisation and stigma will be applied to the findings. This chapter will conclude that there is a lack of published literature regarding social networks of people with intellectual disabilities which includes the experiences of people with intellectual disabilities, families and/or carers. It will also conclude that people with intellectual disabilities dream of an 'ordinary' life, with 'ordinary' relationships, activities and social networks, and that this dream is often thwarted. Suggestions will also be made regarding interventions which may be used to tackle the issues which are found to affect people with intellectual disabilities.

Chapter Three: Methodology

In this chapter I will discuss the various methodologies and methods which were considered for use in this thesis. I will explain the approaches used for data collection and analysis and justify these choices. I will also describe the ways in which participants were selected and the processes which were followed throughout the course of the research. Investigation of the research question requires mixed methods approaches in order to explore both qualitative 'meanings' that people were making (Willig, 2022) and to gain quantitative data which can be statistically analysed. Critical realism (Bhaskar, 2008) is used as it is an established way to recognise the value of mixed methods approaches within a realist-relativist spectrum of understanding reality.

Chapter Four: Parent Interviews

In this chapter I will report and analyse the results of semi-structured interviews with parents of adult sons/daughters with intellectual disabilities regarding care and social networks. Although parents of children with intellectual disabilities are included in academic research (Ryan & Runswick-Cole, 2008; Walmsley et al., 2017), the experiences of parents of adults with intellectual disabilities is an under-researched area (Brennan et al., 2020; Mahon et al., 2019). I will demonstrate the importance and place of care, relationships and social networks throughout this chapter and the ways in which austerity was felt to affect these. I will argue that parents felt their lives had become harder as a result of austerity, that austerity as a concept had failed them, and that false assumptions were felt to have been made about them and their sons/daughters which negatively affected their sense of identity. I will also suggest that parents felt they and their sons/daughters had been both strategically and practically distanced in their relationships with professionals. Concepts of stigma and normalisation will be applied to illuminate interpretations of the data and current related literature. Possible ways in which these issues could be addressed will also be presented.

Chapter Five: Service Provider Interviews

In this chapter I will report the findings of semi-structured interviews with service providers. Published academic literature researching views and experiences of service providers regarding the effects of austerity on themselves and on the care and social networks of people with intellectual disabilities is rare (Humphreys et al., 2022; Ryan et al., 2021). Frontline staff who support people with intellectual disabilities often report issues of stress which relate to organisational cultures and their relationships with managers and with people with intellectual disabilities (Gray & Muramatsu, 2013). Managers have highlighted difficulties trying to meet basic needs in times of cuts to funding (Bradshaw et al., 2018). I will report on the ways in which service providers felt austerity had changed their relationships with funders and changed funders' understandings of the concept of care. I will present themes relating to the ways in which service providers felt their relationships with funders were being distanced, the ways in which they felt their identities were being changed, their feelings of powerlessness, and the emotional and physical pain they felt they, and the people they supported, were experiencing. The ways in which policy and legislation were felt to be being misused will also be presented. I will demonstrate the ways in which academic literature can be used to consider these findings and the ways in which this study builds on this literature. The concept of care ethics will also be considered. This study will conclude with suggestions regarding improved future policy and practice based on the development of meaningful relationships.

Chapter Six: Interviews With People With Intellectual Disabilities

This chapter will be used to report the findings and analysis of interviews using five mixed methods measures with 150 people with intellectual disabilities. Despite the importance of the views of people with intellectual disabilities and the importance of social networks for many aspects of health and wellbeing, there is a lack of academic literature which uses the responses of people with intellectual disabilities themselves regarding the impacts of cuts on their social networks (Harrison et al., 2021). Relevant literature which does exist will be related to the findings proposed in this chapter. Statistical analysis of quantitative findings and additional qualitative comments will be offered, which will illuminate the effects of cuts on people with intellectual disabilities in terms of their social network opportunities, the importance and nature of the activities they undertake, their family relationships, their relationships with professionals, their health, and their use of welfare systems. Suggestions for ways in which relationships and social networks could be enhanced in order to tackle the negative impacts of cuts on health and wellbeing will be made.

Chapter Seven: Discussion

In this chapter I will discuss the research findings with reference to the review and synthesis of literature. I will also consider the broader implications of the study and make suggestions for future research.

Chapter Eight: Conclusion

In this chapter I will present a brief conclusion to this thesis.

Chapter Two Study One: Literature Review (Harrison et al., 2021)

A systematic review and synthesis was completed in order to inform the research direction and questions of this PhD study. This enabled an understanding of what was known about austerity and the lives and social networks of people with intellectual disabilities. This was completed in November 2019 and published in 2021 (Harrison et al., 2021). This chapter will report the systematic literature search, the quantitative and qualitative analyses and will discuss findings. Quantitative findings relate to the nature, characteristics and factors reported to be possible influences on social network creation, maintenance and size. Results from the qualitative studies were used to identify the ways in which opportunities for people with intellectual disabilities to gain and maintain ‘ordinary’ relationships with others were often thwarted. The discussion includes the application of Goffman’s (1990b, p. 15) theory of stigma, which he defined as “an attribute that is deeply discrediting”. Wolfensberger et al.’s (1972) theory of normalisation is also applied to the findings of this literature review and synthesis. Stigma and normalisation are both concepts which relate to understandings of the self and of social relationships. The ways in which these concepts interact are relevant to this study as “it should be seen that a language of relationships, not attributes, is really needed” when considering the ways in which the self, social networks and social ‘norms’ are understood (Goffman, 1990b, p.15).

The research question for this literature review was ‘*How do people with intellectual disabilities experience their social networks?’.*

Background

A range of authors highlight the numerous ways in which social networks, defined as “opportunity structures” which may or may not provide support (Forrester-Jones & Grant, 1997, p. 2) or positive interpersonal relationships (Sullivan et al., 2016) are important to people with intellectual disabilities. They are key to social identity, social functioning, self-esteem and quality of life (Bhardwaj et al., 2018; Heyman et al., 1997). Social networks are also associated with happiness, self-confidence, mental health, and leisure activities (Forrester-Jones et al., 2006), and are deemed crucial for facilitating social inclusion (van Asselt-Goverts et al., 2013).

Understanding more about social networks is important for several reasons and ignoring them comes at a human and financial cost. Strong, supportive social networks can build people’s skills and positively impact on the identities of people with intellectual disabilities (Beadle-Brown et al., 2016; Bradshaw & Goldbart, 2013). However, people with intellectual disabilities on average have less diverse networks (Kamstra et al., 2015), which are more depleted and impoverished with an average size of 22 members (Forrester-Jones et al., 2006) when compared to ‘ordinary’ population samples where networks of 150 people in a wider range of areas of life have been reported (Dunbar, 2015;

Hill & Dunbar, 2003). People can find their relationships are enhanced through much-needed supportive networks (Hall & Kramer, 2009) in diverse situations such as: living on locked wards (Fish, 2016); being mothers (Stenfert Kroese et al., 2002); or experiences of older age (McCausland et al., 2018). They can also combat loneliness (Callus, 2017), which itself can have a detrimental effect on health and wellbeing. For people with intellectual disabilities and their families, the importance of social networks for positive health, wellbeing, social inclusion and tackling disadvantage across the life-course, therefore, cannot be understated (Bele & Kvalsund, 2016).

The ways in which people with intellectual disabilities understand themselves is affected by the ways in which they feel they are perceived by others, including ‘ordinary’ people in ‘ordinary’ relationships. Little though is known about their social networks from their own perspective (Craig & Bigby, 2015). This study aims to provide new data and analysis to aid understanding of this topic.

Method

Search Strategy and Eligibility Criteria

This review took place in November 2019. The method used for review aligns with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). Databases used were Scopus, Web of Science (Social Sciences Science citation index), International Bibliography of the Social Sciences (IBSS) and PsycINFO. Inclusion criteria were that articles must have been published in peer-reviewed academic journals; been written in English; been empirical using the responses of adults with intellectual disabilities, their families or formal care providers; had adults with intellectual disabilities as the focus; were carried out in the U.K.; and were focused on the social networks of adults with intellectual disabilities. No start date was set; the earliest study was published in 1990 and the last in November 2019. U.K.-only studies were included in order to identify those which took account of shifts in U.K. policy such as community rather than institutional care, and more recently, policies of austerity unique to the U.K.. Due to the wide timeframe, some early papers did not include specific information regarding their study's ethical procedures. Where findings formed part of a larger study, sometimes ethical reviews had already been reported in allied publications and so were absent in the reviewed article. Studies were excluded if they did not differentiate between children, young people and adults with intellectual disabilities; if they included autistic participants or those with mental health conditions without intellectual disabilities as their focus; or were undertaken outside of the U.K.. Keywords used in the electronic search were as follows:

- (Social networ*) OR (Social support networ*) AND
- (Intellectual and Developmental Disabilit*) OR (learning disabilit*)

  OR (mental retardation) OR (subnorma*) OR (mental handicap) OR

  (developmental disabilit*) AND
- (famil*) OR (family support) OR (informal support)
- OR (identity)
- OR (friend*)
- OR (relationship*)

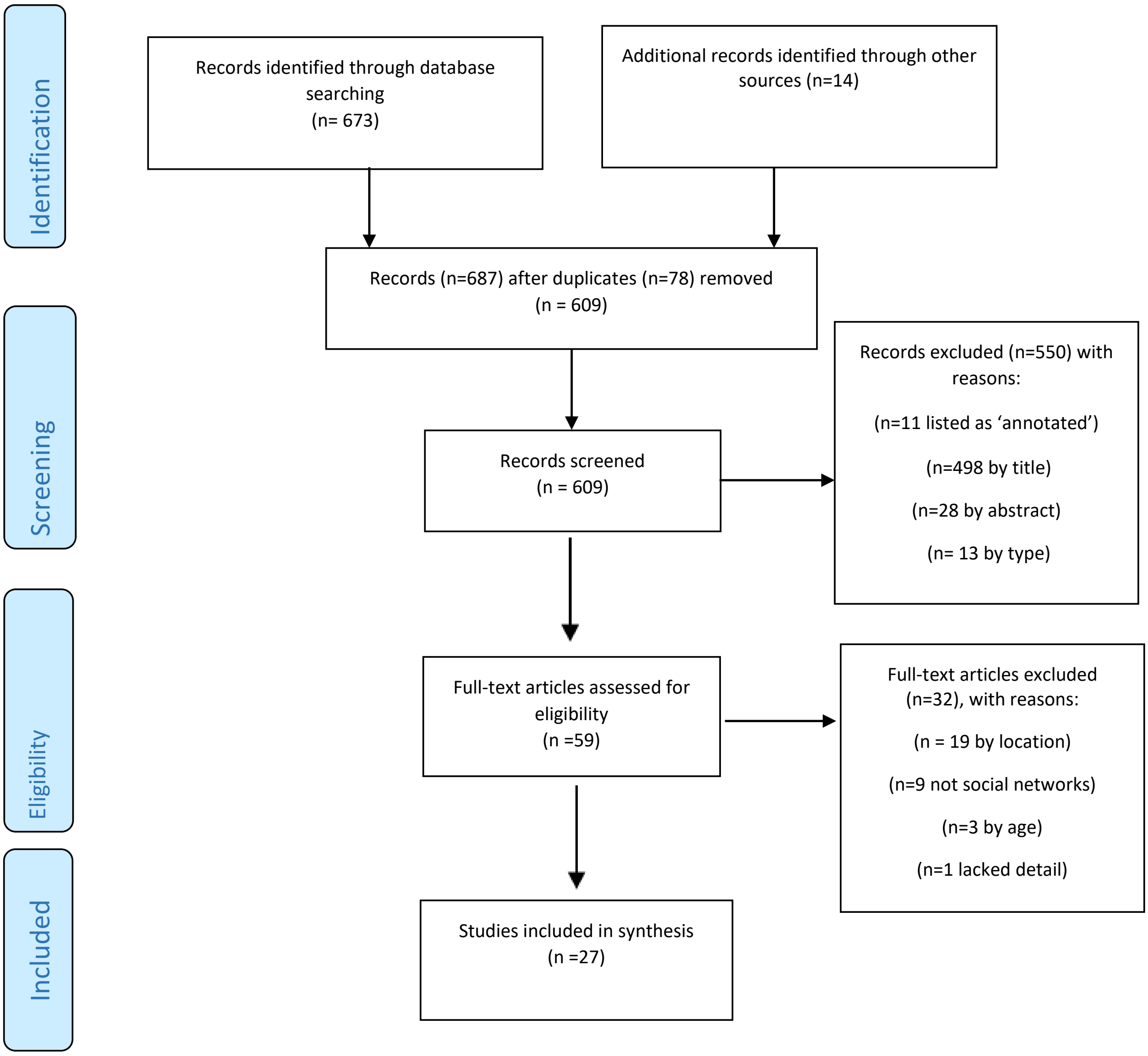
The asterisk symbol was used to account for possible suffix variation in keywords. Although several of these terms are considered disrespectful currently, they were included so as not to inadvertently exclude relevant studies published when these terms were considered appropriate or those which were conducted in the U.K., but had the terminology changed for publishing in international journals based outside the U.K..

Study Selection

In the first stage, 687 results were found of which 78 were duplicates. I screened the remaining 609 records and excluded 550 by title, abstract or type. In the second stage, my supervisor (second author) and I independently reviewed the remaining 59 articles against the inclusion and exclusion criteria with an inter-rater agreement of 56/59 (94.9%). Differences were discussed and agreed. Both authors then independently agreed the exclusion of 32 articles. The remaining 27 articles made up the systematic review and synthesis (see Figure 1).

Figure 1

Figure 1 PRISMA Flow Diagram Indicating Records Included and Excluded at Each Stage



Quality Assessment

The methodological quality of studies was assessed using Sirriyeh et al.’s (2012) Quality Assessment Tool for Studies with Diverse Designs (QATSDD). The QATSDD has good reliability and validity and includes a range of questions designed to judge the quality and rigour of research and therefore make judgements on whether it should be included (Fenton et al., 2015). The 27 included papers were rated against QATSDD quality criteria on a 4-point scale from “not at all” (0) to “complete” (3). Percentage scores were calculated using the actual score and the maximum total score of 42 for qualitative or quantitative studies, and 48 for mixed methods studies. Papers scoring over 75% were rated as being of “high” quality, those between 50% and 74.9% as of “good” quality, 25%–49.9% as “moderate”, and below 24.9% as “poor” (see Table 1). Seven papers (25.9%) were randomly selected and scored by the second author to determine the inter-rater reliability of the use of QATSDD for the 27 included papers. Overall inter-rater reliability for quality was 97.94%.

Table 1

Table 1 Characteristics of Included Articles

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Bhardwaj, A., Forrester-Jones, R. & Murphy, G. (2018)	Social networks of adults with an intellectual disability from South Asian and White communities in the United Kingdom: A comparison.	N = 47 consisting of 27 men (15 white, 12 South Asian) and 20 women (10 white, 10 South Asian)	Day services in Kent and London were approached. Samples were similarly matched in terms of age and gender.	Quantitative. Adaptive Behaviour Scale and Social Network Guide were used in interviews.	Social networks differed between white and South Asian participants. Social network size for both groups was 32. Impact of age on network size. South Asian participants more likely to have networks made up of mainly family.	University of Kent.	Good	More in-depth or a more ethnographic study needed.
Cooper, S.-A. (1998)	A population-based cross-sectional study of social networks and demography in order compared with younger adults with learning disabilities.	N = 207 consisting n = 134 aged 65+ n = 73 aged 20-64	n = 134 was a population-based study, n = 73 was a random sample.	Quantitative Demographic, Interview Measure of Social Relationships, Vineland Adaptive Behaviour Scale.	Most older people lived in residential care and had more restricted social networks than younger people and spent less time in enjoyable social interactions. Older people saw more people than the younger cohort, but these were limited to the residential home. Current services do not meet the needs of older people with intellectual disabilities.	Leicestershire Ethical Research Committee.	High	Cross-sectional design so younger and older group not matched.
Dagnan, D. & Ruddick, L. (1997)	The social networks of older people with learning disabilities living in staffed community-based homes.	N = 52 people aged 40+	Not clear. Participants live in small, staffed house in Solihull with support provided by one service. All had previously lived in an institutional setting.	Quantitative. Wessex Scale and Social Network Questionnaire (Krauss and Erickson, 1998).	Older people have less family and so less family contact. 92% (n = 48) of participants has at least one person in their social network. Mean number was 3.1 (SD = 2.1).	None discussed.	Poor	A range of people filled out the questionnaires. More men than women in the sample.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Donnelly, M.; McGilloway, S.; Mays, N.; Perry, S.& Lavery, C. (1997)	A three to six year follow up of former long stay residents of mental handicap hospitals in Northern Ireland.	N = 283 people discharged from institutional settings and a 40% sample followed up.	Quantitative data collected about all 283 people discharged. 40% followed up with additional measures were selected randomly in proportion to the type of community setting.	Quantitative measures of quality of life covering material, emotional and social wellbeing; development and activity; and service receipt.	Few opportunities for choice and disadvantage economically and socially continued. Poor social networks and no new or ordinary daytime activities took place in the new services. On average people were in contact with 2 family members and 2 friends. Normalisation and a mixed economy of care have limited success.	University of Kent.	Good	No baseline data. No comparison group. Possible bias towards those with higher levels of communication skills.
Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., Hallam, A., Knapp, M., Järbrink, K., Netten, A. & Linehan, C. (2000)	The quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities.	Quantitative data N = 40 (20 in residential supports and 20 in residential campuses.	Purposive sampling from a larger parent study (N = 414).	Cross-sectional design, range of quantitative measures, some using observation.	Small community-based homes provided better quality of life than larger new-built campuses, but at greater cost. Family contact was greater for those living in residential campuses, but social network size and composition was greater for those living in dispersed housing.	Not discussed but consent was gained from a range of sources.	Good	None identified.
Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Järbrink, K., Knapp, M., Netten, A. & Walsh, P. N. (2001)	Quality and costs of supported living residences and group homes in the United Kingdom.	Quantitative data on N = 270 people in 3 types of accommodation.	270 people from a target sample of 300 (10 samples of 30 adults supported by 10 agencies, randomly selected).	Cross-sectional design to establish characteristics of people and costs of services. Range of measures used.	People living in smaller homes had greater choice, did more community-based activities and had larger and more diverse social networks. They were also more likely to have their homes vandalised and were considered at greater risk of exploitation.	None given but consent procedures used and research staff from King's College London were involved.	Good	Organisations were not randomised or stratified. Few agencies involved. No random allocation re residential supports. Defined supported living as described by care providers.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Emerson, E. & McVilly, K. (2004)	Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England.	N = 1542	Random and non-random sampling by local managers.	Range of quantitative measures.	Low levels of friendship activity within supported accommodation, most people with intellectual disabilities were more likely to undertake activities with other people who had intellectual disabilities, the public sphere was a more likely location for friendship activities to take place.	Not discussed.	Good	Not possible to determine the response rate or representativeness of the sample.
Emerson, E. (2004)	Cluster housing for adults with intellectual disabilities.	N = 910 of which n =741 lived in dispersed housing and n = 169 lived in cluster housing.	Sampling strategies defined by locality managers across 10 geographical areas.	Cross-sectional using a range of quantitative measures.	Cluster housing does not provide the connected community that is often assumed. People living in cluster housing have less social and friendship activities than those in dispersed housing.	Not discussed.	Good	Sample size may not be representative. No within-study check was made on the reliability or validity of data collection. Analysis and reporting of results may be better based on measures of effect size and confidence limits rather than alpha levels.
Forrester-Jones, R., Jones, S., Heason, S. & Di'Terlizzi, M. (2004)	Supported employment: A route to social networks.	N = 18	First 20 people to use the employment agency service.	Social Network Guide, Adaptive Behaviour Scale, Life Experiences Checklist.	Average social network size increased over time from 36 to 42 members. Higher social network size was linked to higher quality of life satisfaction.	Tizard Centre, University of Kent.	Good	Carers' presence may have affected responses. Social networks size was already larger than average. Like for like comparisons are difficult.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Theories	Limitations identified by authors
Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M. & Wooff, D. (2006)	The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals.	N = 213	N = 272 participants from a previous study, n = 213 agreed to participate.	Social Network Guide.	Average network size 22. Accommodation type made a difference to the social networks of participants. Those in smaller services were more likely to experience close and companionable relationships than those in residential or nursing homes, but also more likely to experience aspects of relationships that were critical. Relationships also tended to be denser rather than dispersed.	Not stated but detailed consent information.	Good	Fewer than half of the participant answered all questions. Participants may overstate their network size. Participants had mild to moderate intellectual disabilities.
Grant, G. (1973, 1993)	Support networks and transitions over two Years among adults with a mental handicap.	N = 78 family carers over 2 years	From a wider study of N =100.	Quantitative measure in semi-structured interviews.	Mothers tend to be main carers, as they age, other network members or agencies may not step in to provide support. Relationships with people with intellectual are reciprocal. Earlier intervention and greater information could support mothers to see transferring the care role more positively. Changes in networks happen independently of changes to the needs of people with intellectual disabilities.	Not discussed.	Moderate	2 years is a short time period in which to consider change. People with intellectual disabilities not included.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Gregory, N., Robertson, J., Kessissoglou, S., Emerson, E., & Hatton, C. (2001)	Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports	N = 96 people with intellectual and developmental disabilities. 45 in village communities, 51 in residential support.	Parent project used consultation with interest groups identified as 'good practice services'. Participants chosen at random.	Cross-sectional mixed methods.	In village communities people are more satisfied with friendships and relationships than people living in residential, but all are happier with accommodation and day services than with friendships. All satisfaction with friendships is 'far from optimal' which may link to isolation, harassment and institutional constraints. More hours of support relate to more satisfaction with friendships. More people within a network relates to greater satisfaction with friendships. Structural and process factors affect friendship formation. Proximity to people without intellectual and developmental disabilities does not tackle the issues relating to making friends with people without intellectual and developmental disabilities. 'We' like people who are like 'us', 'so' people with intellectual and developmental disabilities express greater satisfaction if they have more people with intellectual and developmental disabilities in their networks. People are happier having regular hours and days for day activities.	No information.	Good	Quality of life may not be representative as organisations chosen were chosen for their better practice. Quality of life satisfaction measured once in brief interview, high number of statistical comparisons using two-tailed alpha level of $p < 0.05$ which leads to high level of type 2 error.
Hamilton, L. G., Mesa, S., Hayward, E., Price, R., & Bright, G. (2017)	'There's a lot of places I'd like to go and things I'd like to do': the daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom.	N = 26 people with IDD plus n = 13 support workers.	Purposive sampling.	Focus groups using qualitative methods. Critical realist approach to data analysis.	Links reduced eligibility with austerity and the fragmentation of social networks and reduced quality of life, including increased risk of isolation and exclusion.	York St John University Ethics Committee.	Good	Small sample from one Local Authority area, study did not capture the most excluded people, no statistically generalisable trends.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Head, A., Ellis-Caird, H., Rhodes, L. & Parkinson, K. (2018)	Transforming identities through Transforming Care: How people with learning disa bilities experience moving out of hospital.	N = 11 people with both intellectual and developmental disabilities and mental health conditions.	Participants were recruited through the local multi-disciplinary Transforming Care team. Participants were identified by members of the team and invited to approach the main researcher if they were interested in taking part. 11 additional people participated as Key Support Persons including parents, a social worker, a support worker, a nurse and a home manager.	Two different types of qualitative interview.	People reported that their relationships with other people, including friends, family and staff, played a significant role in how they experienced the move. Moving was also an opportunity for people to shift their ideas about who they were as a person and opened up a wider array of stories about their identity. A number of recommendations are discussed, relevant for staff working in this field to support positive transitions out of hospital.	NHS.	Good	No information.
Heyman, B., Swain, J., Gillman, M., Handyside, E. & Newman, W. (1997)	Alone in the crowd: How adults with learning difficulties cope with social networks problems.	N = 32 people with intellectual and developmental disabilities were interviewed, n = 6 case studies are used in this paper.	Through services and researchers' networks, people with intellectual and developmental disabilities who had some verbal communication ability.	Grounded theory using case studies and qualitative interviews.	People with intellectual and developmental disabilities accept fatalistic roles or non-conforming roles in relation to the stigmatising situations in which they find themselves. Many suggestions for change but lack of optimism for change. Self-advocacy as the way forwards.	No information.	Good	It is unsafe to generalise from small studies such as this, or to extrapolate findings from research with people with intellectual and developmental disabilities to other groups.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Hulbert-Williams, L., Hastings, R.P., Crowe, R. & Pemberton, J. (2011)	Self-Reported life events, social support and psychological problems in adults with intellectual disabilities	N = 38	Recruited from four counties across North Wales via social services departments and voluntary organisations.	A range of quantitative measures.	Social support does not impact psychological life events. Having people being critical of participants was associated with higher levels of psychological problems.	University of Wolver-hampton and Bangor University.	Good	Participants struggled with quantitative judgements, with judgements that involved time, carers assistance was required with significant events and with financial questions. Questions about sexual abuse were removed.
Jahoda, A., Cattermole, M. & Markova, I. (1990)	Moving out: An opportunity for friendship and broadening social horizons?	N = 25 people with intellectual and developmental disabilities, plus 12 mothers and 33 members of staff.	Via multi-disciplinary team and ATC managers. Eight hospital leavers, seven home leavers and 10 people who stayed living at home were chosen and interviewed twice, 8-9 months apart, before and after moving. Similar levels of ability.	Mixed methods empirical.	Four types of activities were identified, including inside and outside activities. Poor opportunities to make new friends in any of the three participant groups. Little contact with people who do not have intellectual and developmental disabilities. Additional activities tacked on to organised activities. Families important. In hospital little or no contact with family, which did not change when leaving hospital. Lack of daily occupation. Lack of money was the single most limiting factor in the development of social lives. Living more independently in the community does not mean integration with non-disabled people. Wish for sense of belonging. Lack of acceptance by non-disabled people. Type of residence influences the nature of social opportunities. Degree of satisfaction with social lives and social networks is central to sense of identity. Staff need to create opportunities for social activities. Friendship schemes could be set up. Benefits should be increased so people can socialize. Parents should encourage greater financial independence. Education of general public to foster integration and be more accepting of people with intellectual and developmental disabilities.	No information given.	Good	None listed.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Lippold, T.& Burns, J. (2009)	Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability.	N = 47: 30 with mild ID and 17 with physical impairments.	Recruitment from specialist day services in same geographical area, aged 18-60, not in full-time employment.	Quantitative comparison study, hypothesising that people with physical impairments have wider social circles and better Quality of Life.	Type of 'disability' matters. People with physical impairments have wider social circles while people with intellectual and developmental disabilities. People with intellectual and developmental disabilities do more activities and have more contact with family and have fewer friends. Higher numbers of friends do not equate to "better" relationships. For people with intellectual and developmental disabilities, more important than making new friends is support to maintain and foster current relationships.	None given.	Good	None given.
McConkey, R., McConaghie, J., Mezza, F. & Wilson, J. (2003)	Moving from long-stay hospitals: The views of Northern Irish patients and relatives.	N = 39 people with intellectual and developmental disabilities and n = 34 relatives.	All participants had been resettled from a long stay hospital in NI. Inclusion criteria was ability to give informed consent.	Mixed methods empirical study, but specific questionnaires used are not clear.	A failing of resettlement schemes is the inability to create social networks for the person with intellectual and developmental disabilities. Staff satisfaction with services outweighs other disadvantages of different settings. There is a need to recruit and retain high calibre staff.	Project steering group.	Moderate	Study was not able to collect data re: increases in adaptive behaviours and in contacts with the community and family.
Murphy, G.H., Chiu, P., Triantafyllopoulou, P., Barnoux, M., Blake, E., Cooke, J., Forrester-Jones, R.V.E., Gore, N.J. & Beecham, J.K. (2017)	Offenders with intellectual disabilities in prison: what happens when they leave?	N = 38 men.	Healthcare organisations and prisons identified 88 people due to be released from prison.	Mixed methods empirical.	Men were under-occupied and had limited networks (M = 29.1 rising to M = 45.2 for those in large secure units). Positive outcomes occurred where services were joined-up.	NHS and NOMS.	Good	Recruitment was difficult, there was no non-disabled control group, possibility of lost participants at later follow-up.
Perry, J.; Felce, D.; Allen, D.& Meek, A. (2011)	Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living.	19 people with intellectual disabilities who moved from institution to community living.	All participants who were moved minus one who died and one whose next of kin refused consent.	Quantitative quality of care and Lifestyle indicators assessed at four time periods before, during and after resettlement.	Quality of life remained the same or improved over time. Improvement in particular was found in greater family contact and in a reduction in staff-reported challenging behaviour.	Multi-centre Research Ethics Committee.	Good	Improvements within hospital before moving may be due to staff training and awareness. More time is needed to review staff training outcomes.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics?	Quality score	Limitations identified by authors
Power, A. & Bartlett, R. (2019)	Ageing with a learning disability: Care and support in the context of austerity.	N = 21 over 2 studies. 1st study n = 4. 2nd study n = 17.	1st study purposive, 2nd study via local advocacy service.	Qualitative. 1st study semi-structured interviews and photo-elicitation, 2nd study semi-structured interviews.	Retreating welfare state, absence of kin, variable neighbourhood support, limited opportunities and spaces for friendships to flourish.	University of Southampton.	Good	Sample is not diverse, so not necessarily generalisable. Austerity affected the shaping of the research.
Prosser, H. & Moss, S. (1996)	Informal care networks of older adults with an intellectual disability.	N = 32 carers of 32 people with intellectual disabilities.	Part of a wider study identifying older disabled people in a borough of Northwest England.	Qualitative, semi-structured interview schedule.	Parents are main carers for most tasks, with siblings taking less responsibility. Proximity to family does not equate to additional support.	No details.	Moderate	None given.
Robertson, J.; Emerson, E.; Gregory, N.; Hatton, C.; Kessissoglou, S.; Hallam, A. & Linehan, C. (2001)	Social networks of people with mental retardation in residential settings.	N = 500 people with intellectual disabilities across village communities, NHS campuses and community-based homes.	This study provides greater detail on social networks from previously reported from a larger project. Sampling was random within setting type.	Quantitative comparison study.	People with intellectual disabilities are excluded and marginalised. Social networks contain mainly other people with intellectual disabilities. Personal, structural and care environment structure all impact on social networks. Active support is linked to positive outcomes.	No details.	High	Sample of organisations was not random, small number of organisations used, where participant had severe intellectual disabilities, proxy responses may not be accurate.
Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M. & Sanderson, H., (2007)	Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities.	N = 93 over two years.	Purposive sampling of organisations. The first 25 people with intellectual disabilities to agree in each area, were included.	Quantitative study of the effectiveness of PCP after training.	The efficacy of person-centred practice (PCP) is affected by participant characteristics, contextual factors and elements of the PCP process.	None given.	High	Small sample sizes affected the ability to calculate bivariate and multivariate analyses.
Sango, P. & Forrester-Jones, R. (2018)	Spirituality and social networks of people with intellectual and developmental disability.	N = 36.	Purposive across two different services (one faith-based, one not).	Exploratory, mixed methods (surveys, semi-structured interviews and observation), empirical.	People in faith-based services had larger networks than those in non-faith-based services (M = 78 vs M = 44). Both groups had staff as largest component of their networks. Participants in faith-based services had more social acquaintances, more friends without IDD and more employers or colleagues in their networks.	NHS Ethics committee.	High	Relatively small sample, researcher bias, faith was restricted to Christian, not necessarily transferrable.

References	Title	Study Sample	Sample Approach	Design and methodology	Key findings	Ethics	Quality score	Limitations identified by authors
The Money, Friends and Making Ends Meet Research Group c/o Tilly. L. (2012)	Having friends - they help you when you are stuck from money, friends and making ends meet research group.	N = 11 to start and n = 7 by the end of the research.	All members of the group were invited to be participants.	Social model of disability, action research, grounded theory approach using qualitative individual and group interviews.	Links austerity and social networks. People with intellectual disabilities define 'friends' and what it is like to have no money. No work, no money, few friends and limited confidence means we feel we live very limited and unfulfilled lives.	None given.	High	Difficulty of some people to concentrate for long periods, conflicts of personality within the group.

Description of Studies

Sixteen of the studies reported on quantitative research, six on qualitative and five were mixed methods studies. All but two studies (Emerson, 2004; Emerson & McVilly, 2004) measured network size, but often in different ways. Other studies used social networks to evaluate interventions (Donnelly et al., 1997; Hamilton et al., 2017; Robertson et al., 2007); mental health (Hulbert-Williams et al., 2011); the needs and views of caregivers (Heyman et al., 1997; Prosser & Moss, 1996); or compared the lives of people who had intellectual disabilities with people who had physical disability (Lippold & Burns, 2009).

Data Analysis

Excel, Refworks and Mendeley were used to organise and store the search results and Nvivo was used initially to begin to theme the included literature. Theming the literature by hand was then undertaken. The review of the literature was undertaken using a thematic synthesis approach, as advocated by Thomas and Harden (2008) using Braun and Clarke's (2006) six-step analysis process. This process was also used to consider the means of understanding codes, themes and subthemes. Codes and themes were based on the research question "How do people with intellectual disabilities experience social networks?". The second author themed the literature independently and themes were agreed. The second author highlighted the need for greater clarity and the need for a diagram in order to better exemplify themes (provided later in this chapter with results of qualitative studies).

Results

A consideration of the factors which influenced social networks is now presented. Firstly, quantitative studies will be examined, including the quantitative aspects of the mixed methods studies. These findings relate to network size and characteristics, accommodation and location, and activities. These are followed by a thematic analysis of the qualitative studies, including the qualitative aspects of the mixed methods studies.

Quantitative Studies

Table 2

Nature of Social Networks Over Time

Quantitative Article	Relevant Policy for the Timeframe of the Study	Network Size	Network Characteristics
Bhardwaj, A., Forrester-Jones, R. & Murphy, G. (2018)	Community Care, The Care Act 2014.	Mean = 32.	N = 47 consisting of 27 men (15 white, 12 South Asian) and 20 women (10 white, 10 South Asian) in day service settings. South Asian participants' networks were more likely to contain members of different ethnic groups and be made up of mainly family. White participants had networks which included more service users and staff. Both groups had the largest number of networks members from extended family, then day services.
Cooper, S.-A. (1998)	Community Care: Care homes for older people.	Older people (aged 65 years +) living in care homes saw 27 people in the previous seven days. Younger people (aged 20-64 years) living in learning disability homes saw 16.5 people.	Older people tended to have social networks made up of more people with whom they lived. Day services for older people provided less opportunities for wider social network development than for younger people. Younger people had networks made up of more relatives and friends. Differences may be accounted for in lack of living relatives, and type of accommodation (care home vs learning disability home).

Quantitative Article	Relevant Policy for the Timeframe of the Study	Network Size	Network Characteristics
Dagnan, D. & Ruddick, L. (1997)	Community Care: Participants had moved from an institutional setting to small, staffed houses.	Mean = 3.1.	N = 52 people aged 40+ years. 8% of participants had no social network. 52% of participants listed family as part of their networks. 52% of participants listed co-residents, 42% listed friends with a learning disability, and 29% listed other people without a learning disability, 12% of whom were advocates. The most common type of support was personal and emotional.
Donnelly, M.; McGilloway, S.; Mays, N.; Perry, S.& Lavery, C. (1997)	Community Care: Less mixed economy of care in Northern Ireland than in the rest of the U.K. meant lack of accommodation choices.	On average people were in contact with two family members and two friends.	N = 283 people discharged from institutional settings and a 40% sample followed up after three and six years. Mixed economy of care was limited so most homes were large private residential homes. Visits from others were infrequent, most people had no friends outside their place of residence. Little choice or opportunity to maximise their potential socially or economically.
Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., Hallam, A., Knapp, M., Järbrink, K., Netten, A. & Linehan, C. (2000)	Community Care: community-based residential supports compared with residential campuses for people with severe and complex disabilities.	People living in dispersed housing had larger networks z = 3.30 than those in residential campuses (z not reported).	N = 40 (20 in residential supports and 20 in residential campuses. Family contact was greater for those living in residential campuses, but social network size and composition was greater for those living in dispersed housing. Participants in dispersed housing had people in their networks who were not staff, family or other people with intellectual disabilities. Participants in residential campuses reported no-one in their networks who were not staff, family or others with intellectual disabilities.

Quantitative Article	Relevant Policy for the Timeframe of the Study	Network Size	Network Characteristics
Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Järbrink, K., Knapp, M., Netten, A. & Walsh, P. N. (2001)	Community Care: supported living residences compared with small group homes, and large group homes.	Mean = 7.4 in supported living residences, 8.3 in small group homes, and 6.1 in large group homes.	N = 270 people in three types of accommodation. The networks of participants in supported living accommodation appeared to be larger only because they lived with larger numbers of people with intellectual disabilities. Participants in large group homes had the least number of staff in their networks. Participants in small group homes had the largest number of networks members who were not family, staff or other people with intellectual disabilities.
Emerson, E. & McVilly, K. (2004)	Community Care: Supported accommodation.	Friendship activities were measured. 65.3% of activities with friends were with network members with intellectual disabilities. 25.3% of friendship activities were undertaken with people who did not have intellectual disabilities.	The public sphere was a more likely location for friendship activities to take place than a person's home. Greater levels of adaptive behaviour were linked to greater numbers of friendship activities.
Emerson, E. (2004)	Community Care: Cluster Housing compared with dispersed housing.	Not measured.	People living in cluster housing have less social and friendship activities than those in dispersed housing.
Forrester-Jones, R., Jones, S., Heason, S. & Di'Terlizzi, M. (2004).	Supported Employment.	Average social network size increased over time from 36 to 42 members.	The most common type of support provided was providing company, invisible support, confiding and support with decision-making. All types of support rose from colleagues significantly after time in an employment setting. Networks were more diverse than is typical for this group.

Quantitative Article	Relevant Policy for the Timeframe of the Study	Network size	Network characteristics
Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M. & Wooff, D. (2006)	Community Care: resettlement from long-stay hospitals to small group homes, residential and nursing homes, supported accommodation, and hostels.	Mean = 22.	Accommodation type made a difference to the social networks of participants. Those in smaller services were more likely to experience close and companionable relationships than those in residential or nursing homes, but also more likely to experience aspects of relationships that were critical. Relationships also tended to be dense.
Grant, G. (1973, 1993)	Community Care.	At baseline: family: 6, friends and neighbours: 1.	N = 78 family carers over 2 years. Increased involvement by professionals was linked to policy development and accompanied a decrease in family and neighbour contacts, usually due to deaths, moves and loss of capacity to provide care. Mothers were most typically the main carer.
Hulbert-Williams, L., Hastings, R.P., Crowe, R. & Pemberton, J. (2011)	Community Care.	Median = 8.	38 participants. Participants reported 1.13 median members who criticised them and 2.3 median members with whom they were close. Social networks did not positively impact on ability to manage life events. Criticism was associated with higher levels of anxiety.
Lippold, T. & Burns, J. (2009)	Social Support.	Mean = 11.67 members.	N = 30. Family members made up 40.28%, friends (mainly with intellectual disabilities) made up 28% and staff 21.14%. Participants undertook community activities in groups with staff, which affected opportunities for integration.

Quantitative Article	Relevant Policy for the Timeframe of the Study	Network Size	Network Characteristics
Perry, J.; Felce, D.; Allen, D. & Meek, A. (2011)	Community Care.	Size not measured.	After moving, social contact in the previous month rose with neighbours, but no change found in contacts with friends.
Robertson, J.; Emerson, E.; Gregory, N.; Hatton, C.; Kessissoglou, S.; Hallam, A. & Linehan, C. (2001)	Community Care.	Mean size 2 people excluding staff.	N = 500. 83% of participants reported a staff member as part of their network, 72% a family member, 54% another person with intellectual disabilities and 30% had members which did not fit into these categories. Staff provided most practical, emotional, informational and close support. Friends with intellectual disabilities provided the most bi-directional reciprocity and were significantly more likely to have been known by the participant for more than five years. Networks are affected by the personal characteristics of the person with intellectual disabilities, the types of accommodation, staff ratios, institutional climate and whether 'active support' is used.
Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M. & Sanderson, H., (2007)	Person Centred Support (PCP).	Not measured.	Increased social network was associated with having a small network before PCP training was delivered and with living in an area of deprivation. Living closer to family did not link with having more contact with family.

Network Size and Characteristics. Table 2 indicates the nature of social networks over time as reported in the quantitative data. Network size in the 11 quantitative studies which measured this specifically, ranged from 0 (Dagnan & Ruddick, 1997) to a mean of 42 members (Forrester-Jones et al., 2004). Average network size reported in the quantitative studies was 12.059 members. Across the almost 30 years of this review, staff, family and other adults with intellectual disabilities most typically made up the majority of people's network membership, with other people without intellectual disabilities being in a minority. Those studies which measured networks in other ways, such as number of people seen in the previous seven days (Cooper, 1998), or number of activities undertaken with other people in the last four weeks (Emerson & McVilly, 2004) also found that networks were typically limited to these three groups. In Dagnan and Ruddick's 1997 study, where mean network size was 3.1 members, the authors suggested that low numbers of non-disabled people in networks could be as a result of participants only recently having moved from an institutional setting. In the most recent quantitative study, Bhardwaj et al. (2018) found the same three groups made up the bulk of adults' networks, with higher-than-average network size possibly linked to health, age and level of socially inclusive activities undertaken. Although social networks were defined differently in different studies, and contact was also measured differently, network size in all studies remained significantly lower and membership less diverse, than in non-disabled people's networks.

Accommodation and Location. A key positive influence on social network size and/or satisfaction with social network members was accommodation type and location, which were usually inter-linked. This was most often as a result of U.K. Community Care policies which resulted in the closure of many long-stay hospitals or other institutional settings. Studies found that larger settings, such as large residential homes, related to larger numbers of contacts with other adults with intellectual disabilities (Cooper, 1998), with few or no friends reported outside of the home (Donnelly et al., 1997). Cluster housing was reported to be related to having a smaller network than in accommodation which was more dispersed (Emerson, 2004). Smaller homes based in the community related to networks which were less dense (Dagnan & Ruddick, 1997; Emerson et al., 2000) and more likely to be considered close and companionable (Forrester-Jones et al., 2006). Grant (1973/1993) found that when adults with intellectual disabilities lived with parents, networks were typically small (six family and one friend or neighbour) with mothers providing most of the care and support required. The structure of networks in this study changed over two years as policies were introduced which led to professional workers becoming more involved in the lives of adults with intellectual disabilities and their parent carers. This tended to replace the one friend or neighbour with one professional worker, leaving network size unchanged. Perry et al. (2011) offered an alternative view of the influence of accommodation and location. In their study of adults moving from institutions into community settings, they found that staff training may have been an influencing factor in the higher number of activities undertaken by adults before they left the institutional setting. In that study, hospital staff knew that adults were going to be moving into community settings and that the institution’s day service would be closed; suggesting that while important, smaller community-based accommodation could be even further enhanced. Robertson et al. (2001) similarly found that while accommodation was a clear factor in network size and structure, personal characteristics, staff ratio, institutional climate and the use of ‘active support’ also affected the social networks of adults with intellectual disabilities.

Activities. Several papers reported numbers and types of activities undertaken by people with intellectual disabilities, measured in different ways, over different time periods and for different reasons. Dagnan and Ruddick’s 1997 paper for example lists the number of people in different groups who supported 52 participants to access activities but did not list how many activities were undertaken or when.

Emerson et al. (2000) found statistically significant differences between accommodation type and number of activities undertaken by their 40 participants. Those who lived in dispersed housing undertook a mean of 16.9 community activities in the four weeks preceding interviews. Those living on residential campuses undertook a mean of 6.7 community activities. Community activities included going to a pub, post office, place of worship or bank. The authors related differences in participation in constructive activities to whether or not active assistance was being provided by staff.

In another study, Emerson et al. (2001) found differences in numbers of ‘friendship activities’ undertaken between those living in Supported Living homes, small group homes and large group homes. These activities included having a friend to stay over, going out for a meal and having a day trip with friends. These were measured over four weeks. Those in Supported Living undertook a mean of 37. 2 activities in the preceding month, those in small group homes a mean of 33.3 and those in large group homes a mean of 21.8. These appeared to be regular activities, as the mean number of different types of activity undertaken was 10.4, 9.6 and 9.2 respectively for participants in these same groups.

In 2004, Emerson and McVilly used this same ‘friendship activities’ measure over the same timeframe with 1542 participants. They reported the median number of friendship activities (both within and outside of the home) undertaken with people with intellectual disabilities was two, while no participants undertook the same types of activities with non-disabled people.

Jahoda et al.’s (1990) article provided the most detail with regard to activities undertaken. They assessed the social networks and activities of 25 people with intellectual disabilities at different time points before and after they moved from their family homes or from long-stay hospitals into living in community settings. Activities which took place more than once every two weeks were measured quantitatively and categorised. Categories were ‘special’: which involved only other people with intellectual disabilities in specially organised activities; ‘ordinary’: which were classified as activities involving no potential to meet anyone other than staff or family; ‘semi-integrative’ which took place in a public space but with little opportunity for contact with non-disabled people; and ‘integrative’: which had the potential for interacting with and getting to know non-disabled people. These were then categorised further as taking place either alone or with others and as taking place either inside or outside participants’ accommodation. As the authors suggested might be reasonably expected, mean numbers of activities overall increased for those who moved from long-stay hospitals to community settings (from a mean of seven activities to a mean of eight) and from home to hostels (from a mean of 10 to a mean of 11). Both before and after moving, participants undertook more ‘ordinary’ activities than any other type of activity. Hospital leavers reported a mean of between one and six ordinary activities while home leavers reported a mean of between one and seven ordinary activities. Both before and after moving, both groups reported more activities being undertaken with other people with intellectual disabilities than any other group (a mean of between four and eight activities for hospital leavers and between five and 11 for home leavers). When in hospital, participants undertook a mean of two activities outside of the hospital, this rose to six after leaving hospital. A rise was also seen in those moving from home to hostels, from a mean of six to a mean of eight. The authors concluded that although moving to community settings could offer opportunities for more integrative activities, these needed to be actively fostered, created and embraced by staff, family and communities so friendships with non-disabled people could develop. Jahoda et al. did not report the days or times of day that activities took place.

Murphy et al. (2017) also measured activities; they used the same Social Network Guide used in this PhD research. They reported on the lives of 38 participants with intellectual disabilities who had recently left prison. They found a mean of four weekday activities, a mean of 0.55 activities in the evening during the week, a mean of one weekend daytime activity and a mean of 0.18 weekend evening activities. Mean of total activities per week was reported to be 6.16 activities. However, activities were only recorded if they involved leaving the house.

In 2011 Perry et al. reported the numbers of social activities undertaken by 19 participants with intellectual disabilities who demonstrated behaviours that challenged others to a ‘severe’ level. These participants moved from institutional to community settings. Activities were categorised as ‘social’ or ‘community’, but these categories were undefined in this article. Mean number of social activities per month did not change to a statistically significant level after participants moved (mean of social activities went from one to 0.78 and mean community activities from four to 4.58). The only statistically significant rise was in frequency of community activities per month, which rose from a mean of 11.8 to a mean of 15.5 when participants moved to community settings.

Over the timeframe of these studies, it was ordinary public spaces where friendship activities were found to be more likely to occur (Emerson & McVilly, 2004). Forrester-Jones et al.'s (2004) findings concurred; they concluded that being employed was a significant factor in increasing social network size and diversity. Day services, where these were available and accessed, were spaces where adults with intellectual disabilities could engage with others outside their home environment, but networks remained small overall (Bhardwaj et al., 2018; Cooper, 1998). Many studies highlighted that even though policies with their basis in normalisation principles, such as Community Care and person-centred planning, had had a beneficial impact on the lives and networks of adults with intellectual disabilities, the aim of full inclusion in terms of community presence and relationships that early authors had argued for had yet to be achieved (Cooper, 1998; Donnelly et al., 1997; Robertson et al., 2001; Robertson et al., 2007). Authors found that although activities had shifted location from institutional to community settings, these were still segregated from 'ordinary' activities enjoyed by non-disabled people. Activities often took place as a group of adults with one staff member all undertaking the same necessary household activity such as shopping or took place in day service settings. Both these types of activity, while important, provided adults with limited opportunities to create relationships or build networks as they were unlikely to either meet new people, or to meet a diverse range of people. Contacts with new neighbours did not necessarily lead to inclusion (Perry et al., 2011) and adults with intellectual disabilities remained criticised by others across settings and by different network members (Forrester-Jones et al., 2004, 2006; Hulbert-Williams et al., 2011). Where networks increased significantly and included higher numbers of non-disabled members, this was in a workplace setting and networks took time to develop as familiarity grew (Forrester- Jones et al., 2004).

Summary. An examination of the quantitative data has suggested that social network size and structure can be affected by policy. Policies based on normalisation from the 1990s led to adults with intellectual disabilities being moved from institutional to a range of community settings. This provided opportunities for social networks to be developed and maintained. Differences in social networks were found between accommodation type and location, and activity type. Networks remained smaller than that of the wider non-disabled population and were typically comprised of other people with intellectual disabilities, staff and family.

Qualitative Studies

Forrester-Jones et al. (2006) highlight the importance of enabling individuals with intellectual disabilities to report on their own social lives, rather than relying on staff accounts; individuals being the best judge of who is included in their social network. Gregory et al.'s (2001) study found participants valued relationships which were friendly, where people got on with one another and did ‘ordinary’ activities together, such as shopping, working, and conversing with neighbours. In that vein, supportive relationships, where they existed, were recognised and valued by people with intellectual disabilities (Bhardwaj et al., 2018). This could be seen in people with intellectual disabilities' definitions of friendships particularly. For example:

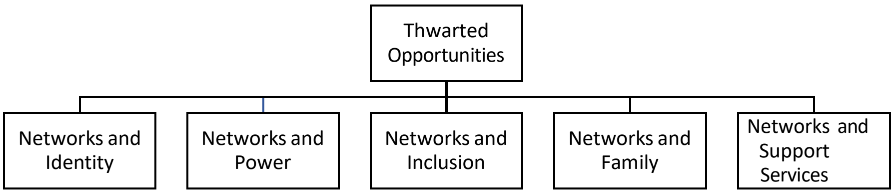
> We say that a friend is someone who is there for you when you are stuck, and someone who is gentle, kind and helpful. You can tell your friends things you do not want other people to know. It is also about having people to spend time with and do things together. (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly 2012, p. 130)

Using thematic analysis to consider the experiences of adults with intellectual disabilities from their own perspective, an aspiration for ordinariness was found throughout the qualitative literature, yet opportunities for the development of broader social networks were often thwarted (Hamilton et al., 2017; Jahoda et al., 1990). This was the main theme which emerged in the analysis of the qualitative data. The following subthemes were also identified: networks and identity; networks and power;

networks and inclusion; networks and family; and networks and support services (Figure 2). These are presented in turn below.

Figure 2

Diagram of the Theme and Subthemes Indicated by Qualitative Data



Networks and Identity. The ways in which people with intellectual disabilities made meaning of their experiences were directly affected by the ways in which they understood themselves in terms of their relationships with others (Head et al., 2018; Heyman et al., 1997). This could be confusing (Dagnan & Ruddick, 1997; Head et al., 2018) and work both positively and negatively for individuals. The dichotomy that adults with intellectual disabilities experienced was knowing that even while striving to be ordinary, they were being treated as other than ordinary, which could also negatively impact one's sense of self and one's relationships (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012).

Positive relationships and networks were found to be essential for the formation of a positive sense of identity (Gregory et al., 2001; Heyman et al., 1997; Jahoda et al., 1990). A negative social identity could equally be created through negative relationships and networks. Hulbert-Williams et al.'s (2011) study for example noted the relationship between some psychological problems and higher levels of criticism by others. The creation of positive social networks and identities included the need for support from others, which should be multi-dimensional in order to be effective. This included support to understand social norms which societies create around forming and maintaining relationships, and the ways in which identity can be affected by deviance from those norms (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). Support could be from a variety of sources which should include self-advocacy (Gregory et al., 2001; Heyman et al., 1997). Without support, the creation and maintenance of social networks and valued identities could be thwarted which could in turn lead to vicious cycles within relationships and networks. Where people with intellectual disabilities had devalued social identities they could deal with the frustration this caused through fatalistic acceptance of those spoiled identities, often experiencing depression, anxiety, hostility or anger (Hulbert-Williams et al., 2011). Robert for example explained how his lack of networks affected his sense of self "I have a bottle of vodka, big massive bottle of vodka on my own and drink it. I said "nobody wants me"" (Hamilton et al., 2017, p. 301).

Networks and Power. Thwarted opportunities also related to power, especially the powerlessness experienced by adults with intellectual disabilities.

When relationships with staff worked well, this could outweigh many other disadvantages which people experienced within their services, especially when moving out of institutional care (McConkey et al., 2003). A lack of control in relationships with staff was particularly apparent though when people spoke about their experiences of relationships in institutional settings. Abusive relationships with staff could have subsequent negative effects on sense of self (Head et al., 2018). As a participant in Gregory et al.'s study (2001, p. 287) explained "They're quite all right here, as long as you do what you're told".

People with intellectual disabilities also experienced little power over ending of relationships, especially when decisions about where they lived, with whom, and whether and when they moved were made at short notice, often without information or their input. Often the importance of maintaining relationships was thwarted by staff who were nevertheless ideally placed to support that maintenance (Jahoda et al., 1990; McConkey et al., 2003). When relationships, which often helped people to feel safe, were so frequently ended (especially relationships with staff), people were left feeling bereaved as they knew and were known by so few people (Hamilton et al., 2017; Head et al., 2018).

People with intellectual disabilities also reported finding a range of systems difficult or impossible to negotiate (Power & Bartlett, 2019). Many people did not have access to digital systems, and could not read or write, so needed support from people in their networks without intellectual disabilities in order to access and negotiate systems which were vital for well-being (such as welfare benefits, housing and finances). When this was lacking, people with intellectual disabilities could easily experience a slide into debt and crisis without the social networks and relationships which could slow or stop that slide into powerlessness (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012).

Policies introduced to promote adults with intellectual disabilities as employers of their own staff in principle appeared to afford the opportunity to move into more powerful roles. Yet people still experienced stigma and powerlessness even in these relationships (Hamilton et al., 2017), thereby thwarting possible opportunities for social network development.

Networks and Inclusion. People with intellectual disabilities who had moved from institutional life to living in communities were often “deeply disappointed” (Jahoda et al., 1990, p. 138) with their lack of integration into ‘ordinary’ community life and their lack of expected friendships with non-disabled people. Sadly, lower expectations were indicative of people's higher satisfaction with their move (Gregory et al., 2001; Head et al., 2018). Lack of community acceptance appeared to occur irrespective of a person with intellectual disabilities’ previous or current accommodation (Murphy et al., 2017).

Lack of meaningful daytime activity was also an issue (Murphy et al., 2017) and when staff attempted to involve people with intellectual disabilities in their communities through activities, these tended to be delivered to groups of people with intellectual disabilities rather than as part of ‘ordinary’ wider communities. The effects of the double stigma of having intellectual disabilities and having segregated activities affected individuals and their sense of self “Makes me feel that size, (the participant made a gesture towards the ground indicating how small he felt) as though I could just crawl into a hole and curl up" (Jahoda et al., 1990, p. 139).

This stigma was also seen in 'ordinary' activities and spaces. Adults with intellectual disabilities and the people who supported them were aware of often erroneous reasons for resistance from employers for example (Hamilton et al., 2017; Murphy et al., 2017). This was experienced even when people with intellectual disabilities performed above the standard of their non-disabled colleagues (Hamilton et al., 2017).

Much of the literature suggested the need for not only individualised approaches to the training of people with intellectual disabilities and social care staff, but also wider tackling of the social stigma attached to negative perceptions about people with intellectual disabilities. This stigma thwarted opportunities for social network development. Authors suggested tackling stigma could begin to dismantle barriers and negative stereotypes, which otherwise may have prevented non-disabled people from considering friendships with people with intellectual disabilities (Forrester-Jones et al., 2004; Head et al., 2018; Heyman et al., 1997; Jahoda et al., 1990; McConkey et al., 2003).

Networks and Family. Most studies highlighted that key relationships in the lives of many people with intellectual disabilities were those they had with family members. As with other relationships, family relationships (and their lack) could have an empowering or disempowering effect on people's understandings of themselves and their network development.

When people with intellectual disabilities received positive regard from people in their social networks, particularly family, (who were sometimes described as a "best friend" (Bhardwaj et al., 2018, p. 262)), it boosted their self-esteem and self-image. Being close to family both figuratively and literally could improve the way people with intellectual disabilities felt about themselves (Head et al., 2018; Heyman et al., 1997; Jahoda et al., 1990). Conversely, physical and emotional distance or abuse could have devastating effects (Grant, 1973/1993; Power & Bartlett, 2019).

While families could be a source of valuable and valuing support, Murphy et al. (2017) warned professionals not to make assumptions about family settings equating to positive relationships or as being solutions to a range of problems. When family were perceived as overprotective or abusive, people with intellectual disabilities experienced limitations in the rest of their relationships and networks (Bhardwaj et al., 2018; Grant, 1973/1993; Power & Bartlett, 2019). This could thwart opportunities to develop other, more supportive networks.

Just as authors suggested that policies based in normalisation, such as personalisation and Community Care, could be perceived as mere rhetoric when not backed by resources, families too were fearful of their family members falling through the gaps in any policy delivery (Grant, 1973/1993; Prosser & Moss, 1996). Families often therefore strived to protect people with intellectual disabilities from the “irresponsible” “drive towards increased independence and choice” when they felt this drive ran contrary to their family members’ needs (Hamilton et al., 2017, p. 295).

In situations where family were absent, the importance of being connected socially, including being connected to charitable services, became essential for well-being, relationships, social justice and rights (Hamilton et al., 2017; The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). These adults with intellectual disabilities were often reliant on a Social Worker or Care Manager to make decisions on their behalf. This made their struggle harder than for those who had family support (Hamilton et al., 2017; Power & Bartlett, 2019).

Both adults with intellectual disabilities and their parents could feel trapped in situations where their own expectations around coping were unrealistically high and support for improvement was desperately needed, but that support was neither trusted nor forthcoming. This could lead people with intellectual disabilities and their wider family members to crisis point (Prosser & Moss, 1996). Grant (1973/1993) argued that policies which promoted far earlier intervention by professionals, respected the reciprocal nature of care, and had a psychological understanding of the functioning of families and social networks could better enable the development of wider social network structures and community participation.

Networks and Support Services. Where L.A.s had reduced or removed the services they provided, often voluntary sector groups had been a vital source of support. Despite positive policy developments, when experiencing cuts to their services people with intellectual disabilities appeared thwarted in their lives and opportunities for relationships without significant additional support from others (Power & Bartlett, 2019; The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). Adults with intellectual disabilities needed support not only to access social activities and networks but also to access a range of support services (Sango & Forrester-Jones, 2018).

Negative impacts of cuts to services on existing networks were reported. Lack of money and irregular hours of support led to reports of boredom, isolation and harassment by strangers or neighbours (Power & Bartlett, 2019; The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). Hamilton et al. (2017) and The Money Friends and Making Ends Meet Research Group c/o Liz Tilly (2012) suggested that any positive outcomes of the personalisation agenda were greatly diminished by significant cuts to social care budgets. As Michael explained “they're trying to stretch people as far as they can without spending any money to give people support” (Hamilton et al., 2017, p. 294).

Proactive support and reciprocal social network relationships were required to prevent problems occurring in the first instance, with for example reading letters, paying essential bills, shopping, accessing food banks and budgeting on very limited or zero finances until benefits were available (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012).

As austerity policies continued, relationships and meaningful networks were perceived as being unimportant in the eyes of funders (Hamilton et al., 2017). It was therefore unsurprising that people with intellectual disabilities reported they could “sometimes” feel they were “in a battle” (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012, p. 131).

Discussion

While the need for human contact and relationships and more recently the importance of social networks has been acknowledged for non-disabled people, it is less often considered as an essential part of the lives of people with intellectual disabilities (Dunbar, 2015; Emerson & McVilly, 2004; Hall, 2005). There are several theoretical perspectives which can be used to illuminate this situation. Key amongst these are stigma (Goffman, 1990a, 1990b, 1991) and normalisation (Wolfensberger et al., 1972), which can be applied to the results of this literature review. In this way, it is possible to begin to consider not only the ways in which people with intellectual disabilities are perceived by societies more widely, but also the effects this could have on people's sense of identity, their social networks and their experiences of relationships.

Goffman considered stigma in terms of the ways in which the self can be presented in society and the social ‘norms’ that are created in relation to self, identity, institutions and societies. In his consideration of human relationships, broadly from the perspective of symbolic interaction, he showed that the power inherent within stigma and labelling can be dynamic (Goffman, 1990b, 1991). Goffman’s critique of a range of institutions as centres of social control of, and power over, many groups, including people with intellectual disabilities, highlighted how policies of institutionalisation actualised the desire for the measurement and medicalisation of socially constructed deviance. He considered the ways in which human interaction can be interpreted and understood in terms of stigmatisation, and how stigmatised people respond to social control. He explained that people are often aware of the stigmatised characteristic they embody and can feel shame. Goffman suggested that stigmatised individuals and groups are discredited, but that anyone discreditable (who has a stigmatising condition that is not immediately apparent to others) may choose to hide their characteristic, often out of fear. He argued just as actors in a drama must maintain an image of self which they feel will be accepted by their peers and society more widely, so people with stigmatising characteristics can feel they must hide their true ‘selves’ by managing their spoiled identities. Using this approach, various aspects of self, such as self-worth, are linked to the ability to understand and play valued social roles, in socially accepted ways (Goffman, 1990a, 1990b). Crucially, an understanding of self and identity is created in one's social interactions with others and is therefore significantly impacted by one's social networks, or their lack. Yet this literature review has shown that these opportunity structures (Forrester-Jones & Grant, 1997) do not appear to have developed into wider interpersonal relationships, which authors have argued could enhance the identities of people with intellectual disabilities (Sullivan et al., 2016; van Asselt-Goverts et al., 2013).

As individuals who may initially be only discreditable, the concept of stigmatisation is a key consideration when examining the lived experiences of people with intellectual disabilities and their relationships. One critique of Goffman’s work is the need to focus not only on what causes this situation, but also on how it can be overcome (Scior et al., 2020), in particular when positive social networks and relationships are formed between disabled and non-disabled people (Bogdan & Taylor, 1987). One such theory which is used to try to understand and develop positive relationships with self and others is normalisation.

Wolfensberger developed the theory of normalisation from its roots in the Danish Mental Retardation Act of 1959. Although this Act included the concept of normalisation, it had human rights at its fore, with equality as a central tenet. Wolfensberger et al. (1972) argued that these goals were ideals, yet while segregated services existed they were unlikely to be practicably achieved. They proposed that a focus on supporting people with intellectual disabilities in ‘ordinary’ day-to-day places, with ‘ordinary’ people was more likely to succeed in reducing stigma and the perceived social deviance of people with intellectual disabilities. Wolfensberger et al. suggested that this perceived social deviance identified people with intellectual disabilities in several specific ways: as sub-human organisms; as threatening; as menacing; as objects of pity; as holy innocents; and as eternal children (Wolfensberger et al., 1972). Until these perceptions of people with intellectual disabilities as dangerous, threatening or vulnerable individuals who need to be avoided and controlled were challenged and addressed, with a strong emphasis on advocacy, Wolfensberger et al. argued that they would persist unchecked. This could lead to perpetual institutionalised care and leaving people with intellectual disabilities to exist as one-dimensional, devalued citizens with devalued social roles. This in turn would continue to have negative effects on all aspects of the lives of people with intellectual disabilities, including their ability to make, develop and maintain their social networks. Wolfensberger et al. went on to argue that the cost of enacting this type of support was less than the cost of institutionalising people with intellectual disabilities. It could also lead to the benefits inherent in being part of an inclusive society which encourages social networks, relationships and support systems between people with and without intellectual disabilities.

Wolfensberger et al.'s ideas were developed further and became core to the ethos of *Valuing People: A New Strategy for Learning Disability for the 21st Century* White Paper which aimed to recognise the diverse roles people with intellectual disabilities could have and to provide opportunities for these to be developed in rights, independence, choice and inclusion (DoH, 2001). Critiques of this policy include flaws in implementation which resulted in unintended exclusion of some people with intellectual disabilities from a range of social and community opportunities (Simpson & Price, 2010). Critics of normalisation also suggest that its absence from sociological and ideological agendas render it inadequate. Challenges also include possible gender-bias (Williams & Nind, 1999) and that disability-specific spaces can be used to celebrate disabled identities and resist social discourse around what constitutes ordinary versus stigmatised locations. Chappell (1992) suggested normalisation reflects the views of powerful (non-disabled) professionals and their understanding of typical ways of behaving rather than the views of disempowered and impoverished people with intellectual disabilities. A lack of clarity of concept among policymakers and practitioners and lack of empirical evidence are therefore important concerns, though could be argued to be less important than understanding inclusion as a human rights issue (Culham & Nind, 2003).

Despite their flaws, using the concepts of normalisation and stigma highlights that social networks can either protect against or entrench the effects of stigma and segregation for adults with intellectual disabilities. Using these theories adds to our understanding of the possible reasons for a lack of focus on the social networks of adults with intellectual disabilities.

To consider this further, synthesising Goffman's theory of stigmatisation, and Wolfensberger's concept of normalisation to the thematic results of this review, it is possible to begin to consider not only the ways in which people with intellectual disabilities are perceived by societies more widely, but also the effects this can have on people's sense of identity, their social networks and their experience of relationships. When considering identity and forming ordinary relationships, this systematic review and synthesis suggests that one's identity can be understood from the perspective of symbolic interaction. Using this approach, various aspects of self, such as self-worth, are linked to the ability to understand and play valued social roles, in socially accepted ways (Goffman, 1990a, 1990b). Crucially the understanding of self is closely linked to identity which is created in one's social interactions with others. The desire for an ordinary identity can be at least partially explained by an awareness that one both is and is not perceived by others as ordinary (Wolfensberger et al., 1972). An ordinary identity requires a knowledge of the way in which societies function, and how to interact in ways which fit social norms, as well as a desire to do so. Wolfensberger et al. (1972) highlighted that this understanding requires people with intellectual disabilities to be immersed in, rather than isolated from, communities. Identity then is a joint, symbiotic activity, a verb as well as a noun.

Expectation is an important consideration for people with intellectual disabilities but is only part of the story in a stigmatising society where identity and relationships can be spoiled (Goffman, 1990a, 1990b; Heyman et al., 1997). Stigma can apply in all relationships and can be particularly complex and nuanced in families, who can often experience the effects of stigma from others. Family members of people with intellectual disabilities can also internalise the stigma they experience, blaming themselves for their family member's condition and situation (often known as affiliate stigma). As this review has shown, unrealistic expectations of and by families could lead to parents taking on the caring ‘burden’ and being unwilling to share that for many reasons (Grant 1973/1993; McConkey et al., 2003; Prosser & Moss, 1996). Often the opportunity for family members to create and maintain what Goffman (1991) referred to as ‘ordinary’ social identities as individuals rather than the ‘virtual’ stigmatised identities they inhabit, was not available. This was especially noted in this literature review and synthesis in settings where segregation and isolation were the norm, creating additional pressure for everyone involved. When this led to spoiled, discredited identities for family members without intellectual disabilities, and when relationships both internal and external to families were then affected, it becomes possible to perceive how ever-decreasing circles of negative relationships can develop. This too did not appear to change over time (Bhardwaj et al., 2018; Emerson, 2004; Jahoda et al., 1990; Power & Bartlett, 2019).

Limitations

There were a number of limitations to this review. Firstly, studies dating back as far as 1990 reflected the relationships and policies of the closure of large institutional hospitals of the time, which while relevant, have now been broadly superseded. Secondly, some papers did not give full details of any ethical procedures being followed. Some focused on cost rather than social networks specifically, and studies measured social relationships in different ways, some not including the views of people with intellectual disabilities directly. Different search terms or databases may have provided different results. Lastly, there were a number of theories which could have been used as a lens to illuminate the results of this study instead of stigma and normalisation, which may have suggested different interpretations of the experiences of people with intellectual disabilities.

Literature Review Update August 2023

As has been noted, this review and synthesis was undertaken in November 2019 and published in March 2021. The findings from this review influenced the direction and methodology of the subsequent research project. Updating this chapter prior to submission of this thesis may have caused a lack of continuity within it, hence a discussion of the literature published since November 2019 is presented here in order that consideration can be given to trends in research on the nature of the social networks of people with intellectual disabilities. It was also important to assess whether the results and synthesis presented above remain consistent with more recent research findings.

That research on the social networks of people with intellectual disabilities remains under-researched was suggested by the finding that when the same search terms were used in the same search engines with the start date of November 2021, only 20 articles were identified, of which none met the eligibility criteria. Given the pressures of the global Covid-19 pandemic during this time period and the lack of published literature on this topic generally, this is perhaps unsurprising. Related literature was therefore considered. Three relevant articles related to the use of the internet. The links between social networks, family support and wellbeing were reported in Wright and Wachs (2020) who found in their U.S.A. study that cyberbullying and online victimisation was related to young people with intellectual disabilities experiencing poorer health, greater suicide ideation and higher levels of self-harm. Parents were found to be instrumental in mediating these effects by providing much needed social support. In the U.K. Caton et al. (2022) found that during the pandemic the internet was found to be essential for the maintenance and at times development of social networks for people with intellectual disabilities. Online abuse was also experienced, as were threats to wellbeing regarding overuse and a feeling of intrusion into one’s privacy. Family was again found to be helpful in accessing and using the internet during this time. Bonilla-del-Rio et al.’s (2022) work related to use of social media by 10 people with Down’s Syndrome across seven countries (not including the U.K.) who used the internet to promote positive images of themselves. These actions were found to challenge stigma and build positive identities and self-image. Bonilla-del-Rio et al. suggested to further tackle stigma, political, sociocultural and educational interventions are needed to promote inclusive online processes.

Other research considered stigma and care ethics. Stigma remains a global issue requiring a range of effectively researched, locally appropriate anti-stigma responses in order to proactively promote positive attitudes towards those with intellectual disabilities (Scior et al., 2020). In 2022 Scior et al. published their Standing up for Myself programme review (STORM) which was used to enable people with intellectual disabilities to better tackle stigma on personal, peer and public levels. The opportunities for people with intellectual disabilities to become more empowered and support one another were highlighted.

In their recent work considering the views of sibling pairs with and without intellectual disabilities in Ireland, Boland and Guerin (2022) suggested there were a range of factors which influenced whether or not non-disabled siblings actively intended to promote the social networks of their sibling who had intellectual disabilities. Family dynamics were important, as were positive relationships with service providers. Siblings without intellectual disabilities did not appreciate feeling pressured by services to undertake support tasks around friendship activities, or the refusal of service providers to support the maintenance of friendships through activities for example. People with intellectual disabilities did not value services when they involved loss of familiar staff, loss of friendship networks, loss of residential services and lack of staff generally. In terms of location, living in an established neighbourhood where natural encounters and social roles were possible, walking through one’s neighbourhood regularly and thereby becoming ‘known’ locally were important. The effects of stigma could also be applied to Boland and Guerin’s work. Factors which they found detracted from social network building and maintenance included not only lack of staff time or supportive staff but lack of an ordinary life, instead “living in a bubble” or “having a divided life” (Boland & Guerin, 2022, p. 339). This resulted in people with intellectual disabilities being isolated from communities, activities and friends outside of family, with limited networks including mainly staff and others with intellectual disabilities.

In The Netherlands Nistelrooij and Niemeijer (2023) found that despite policies of inclusion, young people with intellectual disabilities who now lived in smaller, ‘ordinary’ neighbourhoods in community-based services, retained a sense of feeling displaced and unknown. Staff lacking an understanding of needs and of local knowledge and lack of inter-agency working contributed to the lack of social engagement and lack of friends that young people in this study experienced. The authors related these findings to Joan Tronto’s (2013) care ethics approach, where caring relationships are respected and celebrated as a key part of human existence and flourishing. They suggested that when needs are unmet, met in ways which work for only those providing care, or go unnoticed, society has morally failed. They suggested that Tronto’s notion of care ethics as a “life-sustaining web” could be used to identify physical gaps in care which may lead to the identification of broken relationships and opportunities to then address them in meaningful ways (Nistelrooij & Niemeijer, 2023, p. 655).

Finally, Dekker et al. (2022) studied the attitudes of 1797 Dutch people without intellectual disabilities towards those with intellectual disabilities. Participants thought of people with intellectual disabilities in less stigmatising ways during the Covid-19 pandemic, instead viewing them as friendly and in need of help. Although the authors suggested that empathy with ‘vulnerable groups’ may have increased during the Covid-19 pandemic, they suggested that ambivalent attitudes could themselves be stigmatising. They argued that raising of awareness of stereotypes, via advocacy and education, was required in order that positive encounters with people with intellectual disabilities could become more common. They argued that being better known may be linked to experiencing less discrimination.

In conclusion to this update, research since November 2021 has enhanced the completion of this review and synthesis, and the initial conclusions drawn appear to have validity when considered in relation to recent literature in related fields. Indeed, the importance of networks during the Covid-19 pandemic, which is highlighted in this new research, suggests strongly that the themes of identity, powerlessness, inclusion, family and support remain pertinent. The application of the concepts of stigma and normalisation to these themes remains key to understanding the social networks of people with intellectual disabilities. That no further research which focused specifically on the social networks of people with intellectual disabilities could be found suggests too that this topic remains under-researched.

Conclusion

This systematic literature review and thematic analysis has highlighted the lack of published research in the U.K. which considers the social networks of people with intellectual disabilities and includes the voices or experiences of people with intellectual disabilities, their families and/or carers. While globally the voices of people with intellectual disabilities are beginning to be reported more widely, until 2019 only 27 U.K.-based articles across the previous 29 years met the search criteria for this study and have been thematically reviewed and synthesised in this way.

Synthesising the results of the review with Goffman’s theory of stigmatisation and Wolfensberger et al.’s concept of normalisation, enabled a consideration of the ways in which people with intellectual disabilities are perceived by societies more widely, and the effects this can have on people’s sense of identity, their social networks and their experiences of relationships. People with intellectual disabilities need support in order to have access to meaningful, valued relationships and roles. Policies which affect people with intellectual disabilities can benefit their social networks but are bound by financial constraints which affect eligibility criteria.

The literature suggests that the dream of ordinariness for some people with intellectual disabilities is thwarted in several ways: in ordinary relationships and identities; through a lack of power; and through a stigmatised world. In addition, families can empower and disempower, and the importance of the voluntary sector in times of cuts to services must not be underestimated.

Suggestions for ways to enhance rather than thwart the dreams of an ordinary life are made. The need for appropriate policy which is adequately funded and takes full account of the desires of people with intellectual disabilities has been demonstrated. The need for funded support to make, develop and maintain relationships and social networks has been highlighted. The need for all the relationships of people with intellectual disabilities to be respected, valued and developed is important for the enhancement of positive identities and networks.

Without support, extreme marginalisation can further affect people's poor sense of self, which can be devastating (Goffman, 1990a, 1990b; Wolfensberger et al., 1972). Yet typical service approaches to integration, which are assumed to lead to wider friendships with non-disabled people, often do not deliver positive change, as Wolfensberger et al. (1972) warned. In addition to experiencing powerlessness in their relationships, stigma is also experienced by people with intellectual disabilities in their thwarted desire for ordinary patterns of behaviour such as being employed (Goffman, 1990a, 1990b; Hamilton et al., 2017; Parkin et al., 2020).

In a time of austerity policies leading to significant cuts to services, less statutory support is available for people with intellectual disabilities, and the voluntary sector is being relied upon to provide the most basic of support (NIHR, 2020). Yet support is needed to access the voluntary sector, making social networks even more essential; and the sector itself is experiencing cuts to the services it can provide. This study suggests this has affected the ability of voluntary sector organisations to act as part of meaningful networks which 'catch' those falling through the net of statutory support and has affected their ability to support advocacy (Power & Bartlett, 2019; The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012).

Stigmatised in so many ways, and unable to build positive social identities without support, people with intellectual disabilities can find themselves in desperate emotional and financial straits. There is a need to provide appropriately funded and assessed support. This support should focus not only meeting need, but also on developing and maintaining reciprocal, meaningful, respectful and valuing relationships and roles. The voices and experiences of people with intellectual disabilities, parent carers and staff can shed a brighter light on understandings and can illuminate the ways in which the day-to-day effects of policy are experienced. It is this holistic approach which is needed in order that policy can be informed, created, funded and implemented more effectively, benefitting not only people with intellectual disabilities, but communities and societies also, so that an ‘ordinary’ life can be grasped and embraced. Training for people with intellectual disabilities, families and staff should tackle not only people's own abilities in creating and maintaining social networks but also wider social stigma which so often thwarts dreams of ordinariness and creates negative environments where identities are spoiled, often despite the efforts of staff and families. Further U.K.-based research is needed in order to explore the ways in which the lives and social networks of people with intellectual disabilities can be affected by austerity.

Chapter Three: Methodology

This chapter will consider the methodological approaches taken in this study. It will provide a rationale for the ontological and epistemological positions chosen. It will provide detail on the research design and methods used for data collection and analysis. It will also consider some of the ethical issues which can arise when undertaking research.

The research question is:

> *What are the views and experiences of parents of adults with intellectual disabilities, providers and people with intellectual disabilities around care and social networks in times of austerity?*

The context of this inquiry is the effects of austerity on the lives and networks of people with intellectual disabilities, parents and service providers. The study needed to allow for a wide range of individuals to be included, and for a diversity of experiences to be collected in differing ways appropriate to the research question. Austerity measures were brought in as a response to the global economic crisis in 2008, hence 2008 was taken as the starting point for the timeframe of this study. Austerity for this study was defined as cuts to care, support, services and/or welfare (referred to in this thesis as ‘cuts to care’). This definition was used in order to encompass as broad a range of experiences as possible.

Methodological Considerations

Denzin and Lincoln (2000, p. 157) defined a research paradigm as “a basic set of beliefs that guide action” which deal with researchers’ worldviews. Powdermaker (1966) and Denzin and Lincoln (2013) suggested researchers’ choices of approach, methods and academic discipline will affect their ideas about what research ‘is’, what it is for and why and how it should/should not be carried out. Ontological and epistemological considerations are therefore discussed below and related to methodological aspects of this PhD research project.

Ontology

Ontology considers the nature of reality. It is “the study of being” (Crotty, 1998, p.10). In the social sciences, this relates to the nature of the social world, the nature of reality and the nature of human beings in the world (Denzin & Lincoln, 2005; Pope & Mays, 2020). Realist and relativist approaches to understanding reality are two theories at different ends of a continuum. Critical realism is considered to be a middle ground between these two positions. These three options for the ontological approach to this study are considered below. Related positions of positivism, constructivism and contextualism are also discussed.

Realism. Realist worldviews relate to ways of understanding reality which acknowledge there is more than one ‘scientific’ or ‘correct’ way of understanding reality but that there is a real world that exists independently of human theories and constructions. Schwandt (2015, as cited in Maxwell, 2022, p. 142) suggested realism can be seen in the ways in which we can easily behave as if the objects in the world (things, events, structures, meanings, society, disability, institutions and poverty for example) exist independently of us but are “just as real as the toes on our feet and the sun in the sky”.

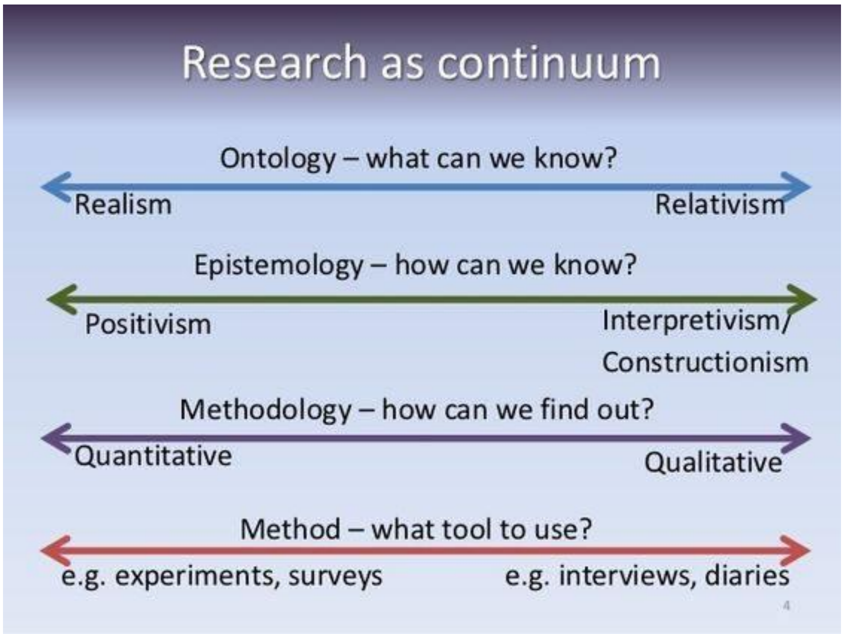
Realist views relate to positivism and (post)positivism. In positivism, a single external reality exists, and research of this external reality is considered to be value-free, with findings being context-free (Yin, 2016). In the 1970s, (post)positivism developed as a response to the perceived narrow worldview of positivism. (Post)positivists ascribe to the slightly broader view that reality can be measured while acknowledging that reality can never be fully understood. (Post)positivists argue that reality can though be approximated by the use of multiple tools designed to capture as much reality as possible. (Post)positivism is both an assessment of the nature of reality and an approach to knowledge. In positivist and (post)positivist research, focus remains on the verification of theories (Denzin & Lincoln, 2013).

Relativism. At the other end of the spectrum, relativist (also known as idealist) approaches consider that multiple realities can exist, research is value-laden and findings are context-dependent (Pope & Mays, 2020; Yin, 2016). Relativism consists of approaches which understand reality and human experience as one concept. Absolute truths do not exist. This effectively means that two different people do not simply experience the same phenomena differently, they instead create two entirely separate worlds. Every person has a different reality, and the purpose of research is to try to understand the multiple truths of these multiple subjective realities and worlds (Levers, 2013).

Relativism can be related to constructivist approaches. Constructivism holds that a social reality does exist but that it can be interpreted differently by different people at different times and in different contexts. This does not though create a host of separate worlds or realities but does argue that as humans we are influenced by our interactions with others and the social and cultural norms to which we ascribe. Language is considered to be important in creating rather than revealing these multiple truths (Braun & Clarke, 2021; Gergen, 2015). Reality then is constructed by and through our own social structures. The ways in which research can be seen as a continuum are illustrated in Figure 3.

Figure 3

Research as a Continuum (The Sociological Cinema, 2019)



Research as continuum

Ontology – what can we know?

Realism ↔ Relativism

Epistemology – how can we know?

Positivism ↔ Interpretivism/ Constructionism

Methodology – how can we find out?

Quantitative ↔ Qualitative

Method – what tool to use?

e.g. experiments, surveys ↔ e.g. interviews, diaries

Critical Realism. Pope and Mays (2020) suggested that elements of these and other ontological approaches could be compatible in the social sciences. They argued that it is plausible to consider that the social world exists independently of researchers, but that understanding this reality relies on the use of different tools in order to create a holistic account.

Critical realism can be considered as representing this ‘middle way’ of understanding reality. Although there is no one universally agreed definition of critical realism, it separates ontology (such as being, things, reality and the objects of investigation) from epistemology (knowledge, thoughts, systems, ideas, language). Bhaskar (2008, p. 37) argued it was an “epistemic fallacy” to suggest that “statements about being can always be transposed onto statements about our knowledge of being”. In relation to society, Bhaskar suggested society is like a magnetic field; it is unperceivable and cannot be empirically identified independent of its effects. He argued society then can “only be known, not shown, to exist” Bhaskar (1979, p. 57). Seiwart (2020, p. 220) summarises critical realism as embracing the view that “the existence of social realities then cannot be directly observed”.

Seiwert gave examples such as language, religion and capitalism to demonstrate this point. Archer (2016) suggested that critical realism offers an alternative to scientific forms of positivism and the desire to create laws. It also provides an alternative to reality understood purely as a social construction. Since originally described by Bhaskar in the 1970s, critical realism has been framed then as a way of working which recognises the strengths of understanding reality in both realist and relativist terms. It is a position that attempts to balance and reconcile both these approaches. Critical realism can therefore be related to contextualism.

Contextualism. This is a middle way between (post)positivism and constructivism. As an ontological approach, contextualism rejects notions of cause and effect as being identifiable. Instead, human beings can only be studied and understood in their own contexts. Multiple accounts of reality are possible and while all accounts are valid, some are more valuable, authentic or persuasive than others in different contexts (Braun & Clarke, 2021; Moruzzi, 2019). Contextual ontologies share models and views which are common to different parties and can be shared between these parties in local contexts (Bouquet et al., 2004).

As this study aims to understand reality as existing and relying on context, it takes a holistic approach to ontology. Critical realism was therefore considered to be the most appropriate ontological approach.

Epistemology

As has been shown, different ontological approaches can be related to positivist, critical realist and constructivist ways of understanding both reality and knowledge.

Research broadly aims to develop new knowledge or insights into specific topics of interest. Researchers then must make clear their research perspective regarding how they theorise knowledge (epistemology), how they frame knowledge (methodology: or the rules and procedures of research) and what processes they use to build their knowledge (methods) (Godwin et al., 2021).

Like ontology, epistemology is also affected by differing worldviews. Epistemology relates to the nature of knowledge, theories of knowledge and how we know what we know (Creswell & Plano Clark, 2013). Braun and Clarke (2021) suggest epistemology can also be understood as a spectrum of approaches from positivism and (post)positivism, through to constructionism.

Positivism. Positivism takes a narrow view regarding the production of knowledge. It focuses only on what can be measured and observed, and separates knowledge from the observer (Godwin et al., 2021). (Post)positivism still commits to objective measurement and observation but allows for the role of human perspective in knowledge production, in that only partially objective accounts of the world can be produced (Denzin & Lincoln, 2013).

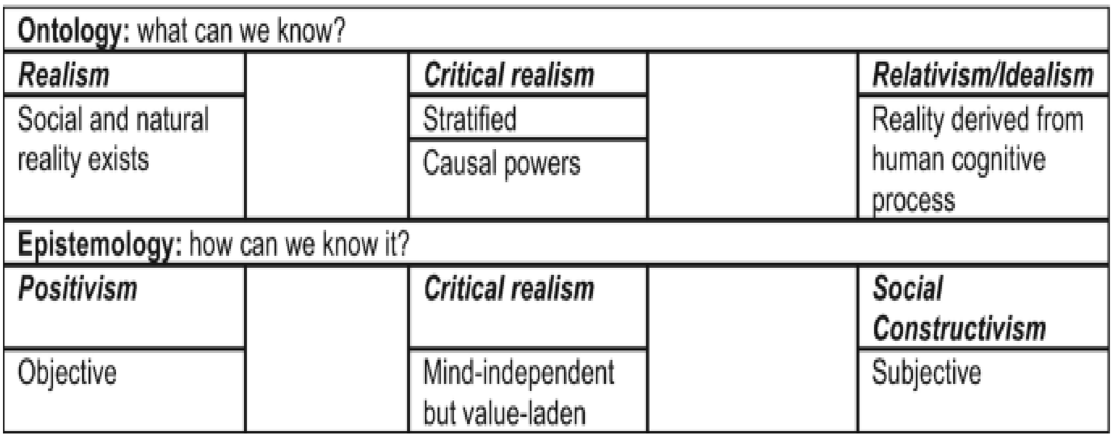
Constructionism. When applied as an epistemological approach, constructionism is used as an alternative to (post)positivism by researchers who consider that reality cannot be known; instead, it is social constructs which inform how and whether knowledge is or can be created (Willig, 2022).

Contextualism. Braun and Clarke (2021) proposed that contextualism occupies a middle ground between these epistemological positions. Kitzinger (1995, p. 161) suggested contextualism can be understood as “weak constructionism” in that a concern for provisional, contextual and liminal truth circumvents the anti-foundationalism of constructionism. Researchers who use a contextualist epistemology understand knowledge as created or co-produced between researcher and participants. Researcher objectivity in this context is not desirable or possible but should be discussed to enable the readers of research studies to make decisions about the researcher’s position in their research and their findings.

Critical realism. As can be seen in Figures 4 and 5, critical realism separates ontology from epistemology. Critical realism also allows for the examination of the possible causes and effects between knowledge and reality. Crucially critical realism is critical of traditional social science concerns regarding the often implicit and unspoken social theories that social scientists often use. It assumes nothing should be taken for granted and that our accounts of reality are fallible. It follows then that judgements we make are relative, but some are ‘better’ in that they can provide more plausible models of inquiry which include relatively objective reasons for our judgements.

Figure 4

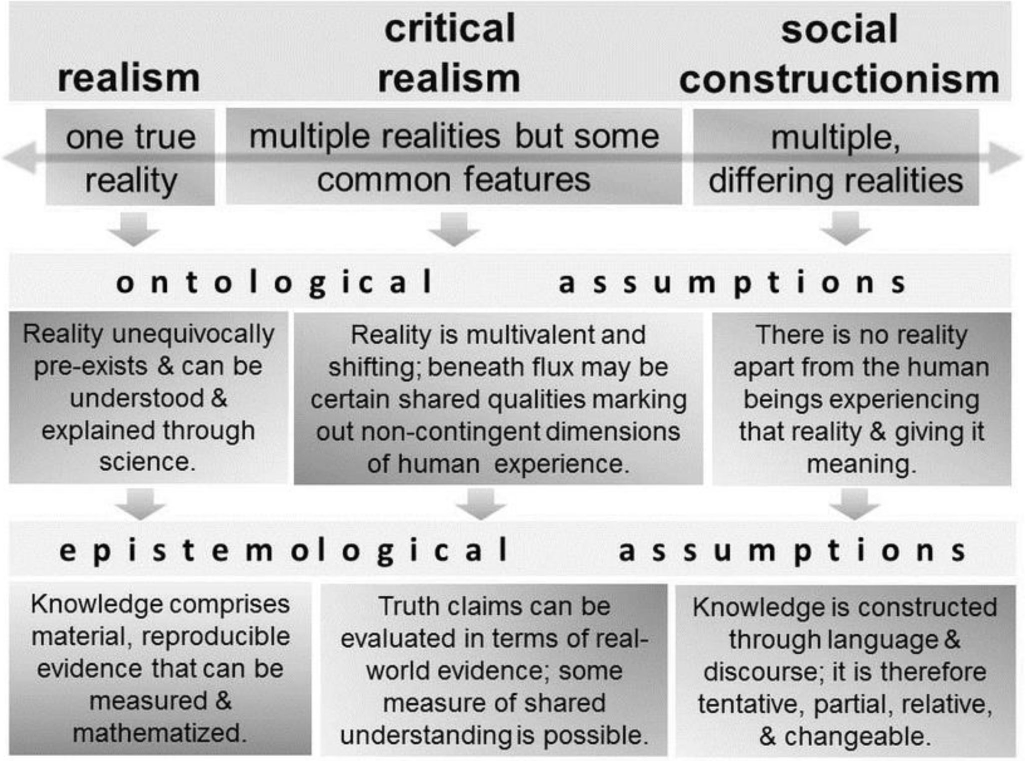
Critical Realism (Gilbert and Pratt-Adams, 2022)



Ontology: what can we know?				
Realism		***Critical realism***		***Relativism/Idealism***
Social and natural reality exists		Stratified Causal powers		Reality derived from human cognitive process
Epistemology: how can we know it?				
Positivism		***Critical realism***		***Social Constructivism***
Objective		Mind-independent but value-laden		Subjective

Figure 5

Some Key Assumptions of Realism, Critical Realism, and Social Constructionism (*Seamon & Harneet, 2016)*



realism	critical realism	social constructionism
one true reality	multiple realities but some common features	multiple, differing realities
ontological assumptions		
Reality unequivocally pre-exists & can be understood & explained through science.	Reality is multivalent and shifting; beneath flux may be certain shared qualities marking out non-contingent dimensions of human experience.	There is no reality apart from the human beings experiencing that reality & giving it meaning.
epistemological assumptions		
Knowledge comprises material, reproducible evidence that can be measured & mathematized.	Truth claims can be evaluated in terms of real-world evidence; some measure of shared understanding is possible.	Knowledge is constructed through language & discourse; it is therefore tentative, partial, relative, & changeable.

Knowledge produced then is contingent on time, history and culture but can over time, improve our knowledge of the ‘real world’ (Archer, 2016).

Braun and Clarke (2021) suggested that contextualism can broadly be mapped onto a critical realist ontology. They argued that just as a critical realism ontological perspective occupies a middle ground between realism and relativism, so contextualism also occupies a middle ground between epistemological positions of (post)positivism and constructionism. Critical realism allows for ontological inclusivity by allowing the exact nature of determinants and interactions to be empirically determined on a case-by-case basis, while including the insights which can be gained by the inclusion of other meta-theoretical positions.

Epistemologically, a key aspect of critical realism is the distinction between ‘transitive’ (the changing knowledge of things) and intransitive (relatively unchanging things that we try to know) objects of knowledge.

Bhaskar (1975) gave the example of transitive knowledge as a social activity producing knowledge as a social product which is not independent of its creators (as with armchairs or books). Intransitive knowledge is knowledge not produced by human beings, such as the gravity of mercury or the process of electrolysis.

Critical realism can go beyond experiential or interpretative creations of knowledge around the concept of disability to include the complex ways in which these interact with the mechanisms that may produce them. Bhaskar and Danermark (2006, p. 279) suggested that while other epistemological positions can be helpful, the use of critical realism can offer “something more” and less reductive in terms of mechanisms for understanding disability. In terms of choice of research topic, Bhaskar and Danermark (2006) in their study of the applicability of different ontological and epistemological approaches to understanding disability concluded that critical realism was the least restrictive and most epistemologically appropriate. They argued that disability is a necessarily laminated concept, which requires a theoretical approach which allows for these layers to be revealed, so that the phenomenon of disability can be researched in nuanced and fruitful ways (Bhaskar & Danermark, 2006, p. 278). These authors draw on Gustavsson's (2004) work in which he argued that the role of theory in disability research, such as tragedy, affirmative or social model definitions, is too restrictive. Both Priestley (1998) and Shakespeare (2013, 2017) made similar comparisons regarding the limitations of using social, individual and cultural models to understand disability. A critical realist approach allows for disability to be understood in terms of body, society, real lives and real worlds (Shakespeare, 2013; Williams, 1999). More specifically, Craig and Bigby (2015) called for greater use of critical realism in research with people with intellectual disabilities, also highlighting its strengths in regard to both the development of empirical knowledge bases and its recognition of the complexities of practice.

This PhD study aimed to create knowledge which was contextual and value-laden, it assumed that the 'world' is real but is understood by different people in different ways. The ontological position of critical realism and an epistemological approach of contextualism were therefore used as the most appropriate concepts for this study.

Deductive and Inductive Approaches

These ontological and epistemological choices left options in terms of the use of deductive and inductive approaches. Whether researchers use deductive or inductive approaches will be influenced by their ontological and epistemological stances. Critical realism values aspects of both deductive and inductive reasoning.

Deductive approaches. These are based in positivist understandings and so are hypothesis driven. They typically aim to test a theory, often using an intervention, gathering facts and objectively analysing data collected (Bryman, 2012). Cause and effect are key objectives in deductive approaches. Large-scale studies undertaken as randomised control trials using quantitative measures to gather 'unbiased' quantitative data are considered the 'gold standard' in this approach (Mabry, 2008). When used in qualitative research, deductive reasoning can be used to understand possible processes of perceived causation and theories may be used as analytical lenses for understanding data collection and analysis (Kennedy &Thornberg, 2018; Maxwell, 2018). However, deductive approaches are also critiqued within the social sciences. (Post)positivism and deductive reasoning are considered to be approaches which still assume that the is one objective 'truth' which can be measured objectively, that associated research is unbiased, that data interpretation is objective and that the beliefs and previous experiences of researchers will have no influence on the research process (Benton & Craib, 2011). Feminist and disability scholars for example have highlighted the ways in which these approaches traditionally exclude members of oppressed communities from meaningful places of power in the research process. These exclusions have led to significant gaps in research knowledge and have contributed to the perpetuated oppression of these communities (Johnson, 2009). Authors have argued there is now an obligation on researchers to challenge the exclusion of people with intellectual disabilities by researching in more flexible and creative ways (Ryan et al., 2023).

Inductive approaches. Conversely, inductive approaches are typically used by researchers who want to consider how people understand their worlds and the sense they make of these worlds. Theories, categories or conclusions will be derived from the data collected in order to make general statements or to create theories. This view focuses not on the cause-and-effect approach which deductive research aims to identify; the aim is not to test a theory. Instead, inductive approaches allow researchers to be surprised by the data they gather (Blumer, 1969) and to reveal new understandings about existing knowledge and conclusions (Reichertz, 2007). Inductive approaches have also been critiqued. Where deduction can be criticised for sticking too rigidly to theory, inductive reasoning can be critiqued for making false claims that no theory has influenced the research process (Kelle, 1995). Maxwell (2018) was clear that the undertaking of research is, by necessity, already theory-laden in terms of historical, ideological and socio-cultural contexts. Charmaz (2014) has suggested that inductive approaches to epistemology allow researchers to offer interpreted portrayals of the phenomenon being researched.

This research project is concerned with understanding and making conclusions regarding the effects of austerity on individuals and the experiences of people with intellectual disabilities, parents and service providers. Despite their respective flaws, critical realism in this study has drawn on inductive approaches to consider the research question: “What are the views and experiences of parents of adults with intellectual disabilities, providers and people with intellectual disabilities around care and social networks in times of austerity?”.

Research Design

Research designs can be located on a spectrum between broadly quantitative or qualitative, with mixed methods research design using elements of these approaches.

Quantitative Research Designs

Quantitative research designs allow data to be gathered for different purposes according to the ontological and epistemological approaches taken to research. Research designs in quantitative studies are typically either experimental or survey designs. In experimental designs a theory is tested, an intervention is used, and the effects of that intervention are measured. Data is gathered and analysed at different points across the stages of the intervention. In contrast to an experimental approach, a survey design is often used in order to gather quantitative data regarding the effects of a phenomenon. Survey designs allow for data to be gathered and analysed without the manipulation of variables, and all variables are collected simultaneously (Bryman & Cramer, 1997). Surveys can be conducted in a variety of ways including independently by participants without researchers being present, remotely, or face-to-face in structured or semi-structured interviews. In survey designs, data is analysed only after it has all been gathered. Benefits of using a quantitative research design include the opportunity to gain access to anonymised unambiguous data for large samples of people which is relatively economical and easy to collect (Bowling, 2014). Disadvantages can include frustrations when pre-coded responses do not sufficiently allow for nuanced and comprehensive responses, and there is a lack of participant responses. Quantitative interviews can be used as an approach to increase participant engagement and are particularly helpful when the issue being researched is complex. But they have been shown to decrease accurate responses when measuring stigmatised health issues such as mental health conditions for example. Bowling (2014) suggested this is linked to social desirability bias. The desire to present oneself positively can be understood in terms of the need to 'pass' as ordinary in order to adhere to social norms (Edgerton, 1993; Goffman, 1990a, 1990b). Godwin et al. (2021) questioned (post)positivist approaches and suggested that quantitative research, even in traditionally (post)positivist areas such as engineering, could effectively use a more 'person-centred' approach to its epistemological framings.

Qualitative Research Designs

Conversely qualitative research aims to uncover and consider the subjective lived experiences of research participants. It emerged as a way to challenge the dominance of traditional positivist quantitative research designs. It consists of a set of interpretative, material practices that make the world visible and involves researching things in their natural setting, interpreting phenomena in terms of meanings (Denzin & Lincoln, 2013, pp. 6,7). Qualitative research is empirical. It can offer a space for voices which are typically unheard, it can consider particular groups of people and consider the effects of policy on those groups (Denzin & Lincoln, 2013). Data can be analysed at different points depending on the study design.

Methods which will enable participants to share their experiences and understandings of different aspects of their lives are typically used. These might include ethnographic or participant observation techniques, unstructured or semi-structured interviews, or questionnaires about participants' feelings on a complex topic. Qualitative researchers recognise that culture can be communicated through stories (Bowling, 2014), so work to provide opportunities for these stories to be told.

Mixed Methods Research Designs

Mixed methods research designs aim to find a balance between these two research design types. Teddlie and Tashakkori (2013) suggested mixed methods research designs involve mixing of methodologies and methods. Teddlie and Tashakkori also suggested that methods should be used which best “fit” the research problem under consideration. Integrating both quantitative and qualitative methods and methodologies in the research process can also enable reflection on the relationship between these approaches (Åkerblad et al., 2021).

There are advantages and disadvantages in the use of mixed methods in research design. Advantages include possibilities for the collection and interpretation of a breadth of data, the use of multiple worldviews or paradigms, and practicality: as humans we tend to try to solve problems using both qualitative and quantitative data (Creswell & Plano Clark, 2018). Mixed methods can work particularly well when one data source is insufficient to answer the research question and both general (quantitative) and detailed (qualitative) understandings are desired (Creswell & Plano Clark, 2013, 2018). Mixed methods design has also been suggested as useful in tackling traditional, “paradigm wars” (Bryman, 2008, p. 23) and forging opportunities for more balanced research paths. Disadvantages of mixed methods research design include difficulties analysing and making sense of a wealth of data gathered in different ways using different methodological contexts. Creswell (2013) suggested that researchers undertaking mixed methods research should deal with the need for clarity in their definitions of mixed methods research, that designing mixed methods research can be confusing and that the value of mixing approaches should be clarified. Teddlie and Tashakkori (2013) considered that these and similar concerns can be addressed by the researcher being careful and transparent about their own position, research aims and assumptions.

A mixed methods design was chosen for this study. This supported the use of a range of qualitative and quantitative measures. Mason (2017) has highlighted some of the ways in which data and meanings can be layered and can intertwine. (Post)positivist approaches and data are therefore not privileged in this PhD study. Instead, the aim of this research design was to engage with both quantitative and qualitative data in meaningful ways in order to reveal some of the factors which may result from the effects of austerity. Willig (2022, p. 21) suggested a strength of what she refers to as, “methodological pluralism” is the enabling of researchers to use complementary approaches which can provide access to different understandings of realities. Both critical realist ontology and contextualist epistemology are used in this PhD study as approaches which value nuanced understandings of reality and knowledge-production. It is this research approach that this PhD study takes as its basis.

Method

Selection Criteria

The choice of participants in any study is important in order that research questions can be answered, and conclusions drawn from data analysis. This study aimed to gain insights into the views and experiences of care and social networks of people with intellectual disabilities and their parents in times of austerity. Population, random, cluster, stratified and systematic sampling were not possible given lack of population information available, as well as time and financial restraints. Participants were sought out who both did and did not report any effects of austerity across different areas of England and from a wide range of backgrounds. This approach was taken in order to attract and include a diverse range of participants and to capture as broad a range of mixed methods data as possible. This study planned to recruit people with intellectual disabilities, parents and later service providers in ways which would give the opportunity for diverse voices to be heard and for conclusions to be drawn from the data which could be considered in relation to people in these groups more widely. Capturing and valuing multiple voices and perspectives is in line with the ontological and epistemological approaches adopted in the PhD study.

Particular attention then was paid to the recruitment of participants as detailed below.

People with intellectual disabilities. The inclusion of a range of people defined as having intellectual disabilities was important in order to understand whether or not specific groups were experiencing effects of austerity in different ways. Individuals had a range of conditions, some self-defined as having intellectual disabilities, other participants were defined by others (parents or services) as having intellectual disabilities.

People with intellectual disabilities were recruited to this study via Social Services departments, local carer and service user organisations, and independent service providers. The sample was neither randomised nor unbiased. Without a U.K.-wide register of people with intellectual disabilities or parents it was difficult to gain access to participants and their data which could have enabled a more purposive, randomised sampling technique to be used. It was deemed inefficient in terms of both finances and time to send information directly to every home in England or to mount an expensive advertising campaign. Therefore, L.A.s and provider organisations which did have access to the required data were approached. Payment for taking part was not available, but recruitment techniques were aligned with those reported as appropriate by people with intellectual disabilities such as Kidney and McDonald (2014). Local and national charities and service providers were also contacted as they had access to the participant groups identified as important for the purpose of this study. Organisations and charities were asked to recruit as broad range of participants as possible across gender, sexual orientation, age, ethnicity and ability. Anonymised details regarding participants are provided in Chapter Six. Due to time restrictions and differing levels of engagement from gatekeeper organisations locally and nationally, I was not able to include equal numbers of participants across a range of geographical regions, ethnicities, marital status, gender or sexuality. I interviewed 56 of 150 participants: nine in the Northwest of England and 47 in the South of England.

One hundred and fifty participants was though a considerably larger number of participants than in previous studies which have begun to consider the impact of austerity on the lives of people with intellectual disabilities (such as Malli et al. in 2018 for example).

Parents. Similarly, 'parent' was used in as inclusive a way as possible. For this study a parent was defined as someone who was biologically a parent or had adopted their sons/daughters. Parents were also included whether their adult sons/daughters with intellectual disabilities lived with them or not.

Parents were recruited to this study in the same ways as people with intellectual disabilities. There is no register of parents of adults with intellectual disabilities across England, so access again had to be gained via a range of sources. During discussions at parent carer groups, parents regularly informed me they would like to take part in the study but did not have time as they were so exhausted from caring for their sons/daughters who had significant levels of need. Nevertheless, 10 parents did come forward. These included parents who were biological parents and those who had adopted their sons/daughters, across three different areas of England, and with different backgrounds. Anonymised details regarding participants and similarities and differences between them are described in more detail in Chapter Four.

Service Providers. 'Service providers' rather than 'managers' was used in order to include the experiences of a range of individuals who in some way worked with people with intellectual disabilities, whether paid or voluntarily, in as wide a range of roles as possible. The inclusion of the views of others such as parents and service providers is in line with Braun and Clarke's (2021) ideas about creating opportunities for the development of rich data with greater breadth and depth than can be garnered with the use of just one type of participant. Service providers were not actively recruited to this study. Instead, as the study began to progress and organisations supported people with intellectual disabilities to take part, nine service providers requested they be interviewed as part of the study. This was considered to be an opportunity to add further depth to understandings of the aims of this study. The nine service providers were based in two areas of England. Anonymised details regarding these participants are provided and similarities and differences within this group are described in more detail in Chapter Five.

Size and Scope of Organisations Approached. L.A.s, Health Authorities, organisations run by people with intellectual disabilities, key charities which support and advocate for people with intellectual disabilities and/or their parents and local support groups were contacted regarding this study. A learning disability conference for academics, parents, people with intellectual disabilities and practitioners was also used to advertise the study to interested parties.

Diversity of Experience. The information provided to organisations regarding this study stated that a broad range of participants was required. In order to try to attract a diverse sample of participants, the information provided specifically requested the inclusion both of participants who had experienced cuts and those who had not. Diversity in terms of age, gender, ethnicity, sexuality, marital status, location, experience of austerity and living situation was also requested. When approaching groups which included parents, active membership of parent support groups was not required.

In line with a mixed methods research design, different research methods were used in this PhD study with different participants.

Choice of Data Collection Tools

Self-administered quantitative questionnaires, participant observation, ethnographic approaches, focus groups, and a range of approaches to interviews were considered for this study.

Self-administered Quantitative Questionnaires. These aim to gather data from a specific sample of the population with the aim of generalising findings to a wider population. Data gathered can be coded numerically and can be used to determine a cause-effect relationship (Pyrczak & Oh, 2018). Self-administered questionnaires are typically administered through mail or internet surveys. These are undertaken without a researcher present. As respondents see the questions, aspects of visual representation are important (de Leeuw, 2008). Although mail, internet or self-administered surveys can be less costly and time-consuming for researchers, they can often elicit less thoughtful, less complete or lack of responses (de Leeuw, 2008; Gomm, 2008). Rates of completion for self-administered questionnaires are often low. Questionnaires administered in remote ways can also inadvertently create opportunities for misunderstanding of questions (Grix, 2010). These also rely on respondents having a level of ability to understand and complete questionnaires.

Participant Observation. Participant observation (Wolff, 2004) involves researchers observing a group of participants in their ordinary lives in a particular setting for a set amount of time. The aim is to better understand participants as actors, their interactions, scenes and events.

Ethnography. Ethnography (Willig, 2022) is a branch of anthropology which systematically studies individual cultures. It aims to explore culture and cultural phenomena from the point of view of people within that culture. Both participant observation and ethnography can be helpful in understanding the daily lives of participants in one setting, service or culture over a set timeframe. These do however require significant time to allow meaningful observations to be undertaken.

Focus Groups. Grix (2010) explained that focus groups, where participants share experiences in a group with a specific focus on key themes or topics, can be time-efficient ways for researchers to gather a range of views. However, focus groups are also open to the pressures of group dynamics. This may lead to participants' experiences being expressed or represented in ways they would not ordinarily have chosen and may prevent individual in-depth accounts being obtained (Foster-Turner, 2009).

Interviews. Interviews can be described as providing opportunities for gaining descriptions of participants' life worlds with the aim of interpreting the meaning of the phenomena described (Kvale & Brinkmann, 2009). Interviews do more than elicit views, they construct knowledge of a topic through the interactions between interviewers (Kvale, 1996). They can also offer opportunities for participants to share private thoughts and information, which could be important when asking people to share details of their lives and financial situations. Interviews can be understood as being on a spectrum between quantitative and qualitative.

Structured Quantitative Interviews. Structured quantitative interviews use a systematic approach where the same questions are asked in the same way and in the same order to a range of participants. They rely on predetermined instruments which use scales of measurement of attitudes or self-esteem for example (Creswell & Plano Clark, 2018). They also gather close-ended information regarding aspects of people's lives which can be counted (such as age, gender, accommodation status, income for example).

Un-structured or Semi-structured Qualitative Interviews. These have long been one of the most used data collection methods used to aid understanding of the unique experiences, relationships and perceptions of participants (Gilbert, 2008; McGrath et al., 2019).

Un-structured or semi-structured interviews can be used as ways to elicit narrative stories. As interviews also can rely on memory, which can be biased, interviews can also include key time points, photos and objects in order to aid recall. These are often popular with researchers who want to elicit the stories of people with intellectual disabilities, whose experiences are often unheard (Gray & Ridden, 1999; Mitchell et al., 2006). Practitioners who work one-to-one with people with intellectual disabilities can be naturally drawn to interviewing as an extension of their typical interactions. Interview skills however need to be learned and honed, which also takes time.

Semi-structured interviews have as their strengths the scope to allow for unplanned dialogue and for follow-up questions (Mason, 2017), allowing researchers to probe more deeply into pertinent ideas which may arise during the interview (Adeoye-Olatunde & Olenik, 2021).

Semi-structured interviews have though been critiqued as lacking structure thereby allowing researchers to drift into asking leading questions (Bryman, 2012). They do not tend towards consistency between interviews and rely on the skills of the researcher (Barriball & While, 1994; Flick et al., 2004).

Face-to-Face Interviews. Johnson et al. (2021) suggested that when conducting qualitative interviews, in-person interviews are often presented as the ‘gold standard’. Their research found that while remote interviews can be beneficial in some situations (when travel would be costly and time-consuming for example), these often are hard to manage, are likely to result in misunderstandings, and can create contexts which are challenging when asking sensitive questions. They concluded that remote interviews can yield data that lacks the richness of in-person interviews.

In this study quantitative and mixed methods questionnaires were used face-to-face with people with intellectual disabilities to answer the research questions regarding the effects of austerity on their lives, networks and care status. These methods were chosen in order to gather data which could be analysed statistically, and qualitative data provided alongside this gave context to participant responses. In addition, these methods were used to promote the use of quantitative and mixed methods measures with people with intellectual disabilities. Traditional approaches to researching the lives of people with intellectual disabilities can neglect the importance of amplifying their often-forgotten voices and life experiences (Atkinson et al., 1997; Stalker, 1998) and can exclude people with intellectual disabilities from defining their own lives, experiences and terminology (Barton, 2005; DeCormier Plosky et al., 2022; Oliver & Barnes, 2012). It was therefore important to gather this type of data from people with intellectual disabilities themselves.

Qualitative semi-structured interviews were used with parents and with service providers in order to gain qualitative data on their experiences of austerity on their lives and relationships and their perceptions of the effects of austerity on people with intellectual disabilities. For parents and service providers, qualitative data was used to gather their narrative stories and explanations, which could then be analysed thematically. This approach ‘fits’ within a mixed methods design.

Different Ways of Recording Data

Data gathered can be recorded in different ways when undertaking face to face questionnaires and interviews. Videorecording, audio-recording and writing down of participants' responses were considered.

Videorecording. This has become more popular as a tool for recording research interviews as the digital revolution has developed (Shopes, 2013). There are advantages and disadvantages to using videorecording. Advantages include the ability to observe and log quantitative and qualitative data in relation to human interactions, and that higher inter-rater reliability may be possible (Asan & Montague, 2014). Disadvantages include the labour-intensive nature of reviewing and coding video, additional ethical concerns regarding the discoverability and confidentiality of participants and greater data management issues in addition to higher cost and the need for training in both equipment use and coding (Asan & Montague, 2014; Shopes, 2013). Videorecording is most typically used not in recording research participant interviews but in observational studies. Even here the Hawthorne Effect (people change their behaviour when they know they are being observed) can influence research participants' behaviour. In their review of literature on the Hawthorne Effect, McCambridge et al. (2014) concluded that knowing one was being observed did change behaviour of participants, but that this effect could not be reliably measured as differences occurred between participants depending primarily on what participants were doing and the level of perceived social desirability involved. Cañigueral and Hamilton (2019) used video recording in interviews and similarly found links between feeling watched, feeling anxiety and reporting pro-social choices.

Audio-recording. When using qualitative questions to elicit qualitative data during semi-structured interviews with participants it is typical practice to use audio-recording (Lee, 2004). While audio-recording can influence participants' responses in research interviews, measures can be taken to reduce these which allow for more subtle recording than with video use. Using a small and unobtrusive recording device, building trust and taking care to ensure the interview venue is relaxed and social rather than formal can all aid in this process (Al-Yateem, 2012). Undertaking audio-recorded semi-structured interviews, transcribing these and analysing data can take significant amounts of time. Edwards and Holland (2020) however suggested that undertaking small-scale studies which prioritise the importance of individual accounts using recorded semi-structured interviews, can be seen as a way to challenge the assumption that research must be undertaken in as little time as possible. Nordstrom (2015) and Hermanns (2004) highlighted some of the ways in which unquestioned normalisation of audio-recording can be problematic. However, audio-recording of semi-structured interviews is often considered to be a helpful tool in the gathering and analysis of data, can aid research on sensitive topics, can be useful in giving voice to the narratives of those often excluded from research, is often seen by participants as an ordinary part of human life, and is usually viewed with suspicion only by those in high-ranking positions of power (Lee, 2004). Effective pre-planning regarding the effective and non-intrusive use of audio-recording in semi-structured interviews is essential (Al-Yateem, 2012). Parent and service provider interviews were therefore audio-recorded wherever possible and with agreement.

Writing Participant Responses. Rutakumwa et al. (2020, p. 566) explained that there will be times when not using an audio-recorder is the “best”, rather than “second best” approach. In their comparison of conducting interviews with and without voice recorders, Rutakumwa et al. (2020) were clear that data quality between methods was comparable. Typically, when using mixed methods questionnaires, data is not audio- or video-recorded as answers are multi-choice and leave little space for additional responses. Flynn et al. (2021) found writing down rather than audio-recording responses to be helpful specifically when interviewing people with intellectual disabilities. Reichertz (2004) suggested that taking inductive approaches can mean that gathering quantitative and qualitative data can enhance understandings of interview data. In line with the inductive approach taken in this study, qualitative comments were therefore collected during interviews with people with intellectual disabilities which used quantitative and mixed methods questionnaires. As with Flynn et al.’s study, people with intellectual disabilities in this PhD study also responded well to having their words written down. When this option is chosen, researchers being seen to write down answers can also add a feeling that one's responses are considered both important and valid (Sanjek, 2019). Responses to questions and other qualitative information and comments made by participants during the interviews were therefore written down word-for-word in order that participants' information and experiences could be recorded without interrupting the flow or spontaneity of their responses.

Data Analysis

The choice to use critical realist ontology and contextualist epistemology with inductive reasoning and a mixed methods research design created opportunities to consider analytic research methods for the quantitative and qualitative aspects of this mixed methods study.

Content analysis and inferential and descriptive statistical analysis are typically used to analyse quantitative data. Interpretative Phenomenological Analysis, Grounded Theory and Thematic Analysis were considered in terms of qualitative data. These are discussed below.

Content Analysis

This uses existing documents as its data source (Grønmo, 2020). Content analysis includes already existing information gained from patient health records or data collected from census records for example. When used in relation to quantitative research, it can be used as a research tool to count the number of key words used by participants in a study and can identify links between these key words.

Inferential or Descriptive Statistical Analysis

Typically, in quantitative data analysis statistical analysis is desired. Quantitative responses are coded into numerical values and variables are considered. Inferential statistical analysis assumes that a dataset is a sample of participants which is representative of an entire population. Descriptive statistical analysis summarises data and provides descriptions of particular characteristics within a dataset (Pyrczak & Oh, 2018). Descriptive statistical analysis is used in order to describe features of the data collected, including measures of central tendency and measures of dispersion and variance. Within descriptive statistical analysis, Exploratory Data Analysis (as described by Tukey in 1970) is usually undertaken as a first step in order to gain insights into the data collected. It focuses on analysing patterns in the dataset in order to assess whether there are potential relationships between variables. It can also aid in highlighting missing variables and outliers within the dataset. Univariate, bivariate and multivariate analysis can be used as part of this analysis in order that potential relationships can be further explored.

As data in this study cannot claim to be representative of all people with intellectual disabilities and uses new data, Exploratory Data Analysis and descriptive statistical analysis were used. The qualitative data gathered through the use of mixed methods questionnaires with participants with intellectual disabilities has already been the subject of separate thematic analysis (NIHR, 2020; Forrester-Jones et al., 2021). This PhD study therefore uses qualitative comments made by participants to add context to the quantitative data analysis. Details of papers published from research with thesis participants are listed in Appendix A.

In terms of qualitative data gathered with parents and service providers, analytic choices included Interpretative Phenomenological Analysis, Grounded Theory and Thematic Analysis.

Interpretative Phenomenological Analysis

This has idiographic analysis of very few participants as its goal (Smith et al., 2012). Interpretative Phenomenological Analysis can be defined as "a qualitative research approach committed to the examination of how people make sense of their major life experiences" in particular "what happens when the everyday flow of lived experience takes on particular significance for people" (Smith et al., 2012, p. 1). Husserl (1970) first suggested that using phenomenological approaches can bring new insights into the life-worlds of others, by creating and travelling along new pathways towards new understandings. As such Interpretative Phenomenological Analysis offers new opportunities to understand relationships in meaningful ways by valuing emotional touchpoints for example (Kuis & Goossensen, 2017). It has the "potential to penetrate deep to the human experience and trace the essence of a phenomenon and explicate it in its original form as experienced by the individuals" (Kafle, 2011, p. 183). Interpretative Phenomenological Analysis has though been critiqued for its requirement for a focus on language rather than meaning, for requiring participants to be able to articulate their experiences in sophisticated ways and for being limited to description without necessary wider engagement with historical or social context (Willig, 2022).

Grounded Theory

A different approach to analysis is the use of Grounded Theory. Rather than an idiographic approach, the use of Grounded Theory is considered to be a political act; as such it can be used to tackle issues of social injustice and to take explicit stances regarding the creation of agendas for change (Charmaz, 2006). It is typically linked to an interpretive constructionist approach. Using a precise coding method, it requires researchers to move back and forth in a constant iterative process between data collection and analysis, testing emerging theories and codes from current data and applying these to the next set of data gathered (Charmaz, 2014). Literature review is undertaken after data is gathered in order that existing theories do not create researcher biases. Grounded theory has a number of limitations. It has been argued that Grounded Theory subscribes to a positivist epistemology, that it offers limited opportunities for reflexivity and that it is too focused on social processes to pay full attention to the experiences of participants (Willig, 2022). There are suggestions also that undertaking a literature review after data analysis has taken place is unrealistic in terms of real-world research funding requirements (Bowling, 2014).

Thematic Analysis

This is becoming a common way to consider the social worlds of people using health and social care services (Braun & Clarke, 2006, 2021; Silverman, 2020). Thematic Analysis has many advantages including its flexibility, accessibility to new researchers, opportunities for "thick description", ability to allow social and psychological interpretations of data and opportunities for it to be used in policy development (Braun & Clarke, 2021, p. 95). It can “provide a rich and detailed, yet complex, account of the data” (Braun & Clarke, 2006, p. 78). Thematic Analysis allows for data and understandings to be interpreted and reinterpreted, building up a hermeneutic, layered and textured analysis of the possible realities and worlds of participants. Thematic Analysis has though been critiqued as having the potential for individual accounts and complexity to be lost when patterns are focused across datasets (Braun & Clarke, 2021). Thematic Analysis can also be criticised for possible lack of attention to language and the need for nuance of experience to be effectively captured (Braun & Clarke, 2021). As it is a hermeneutic process, different researchers may interpret participants’ experiences in different ways. Transparency regarding each aspect of the Thematic Analysis process is therefore recommended.

This PhD study was not focused on the specific experiences of a very small group of participants. It was not concerned with creating a theory, nor did it aim to make claims relating solely to the societal structures in which people with intellectual disabilities, parents and service providers may have found themselves. For this reason, Interpretative Phenomenological Analysis and Grounded Theory were not considered to be the most useful or appropriate research methods for understanding the daily lived experiences of parents and service providers in the context of a study which also included quantitative and mixed methods questionnaires with large numbers of people with intellectual disabilities. The study also aimed to include more participants than would be appropriate for Interpretative Phenomenological Analysis and was designed to interview participants concurrently. This did not allow time for one study to inform the next as is expected in Grounded Theory research. Thematic Analysis though has a flexible approach, can be used across ontological and epistemological positions and demands key skills required for many other qualitative analysis tools (Braun & Clarke, 2021). It seeks both to create patterns from the data and provide an analysis of those patterns as they relate to the research aims of a project (Guest et al., 2012). It was therefore the most appropriate option for me as an early career researcher. Thematic analysis aligns with the critical realist approach used in this study.

The Process of Thematic Analysis. In Thematic Analysis each semi-structured interview was treated as an individual account and a thematic analysis of the responses of each participant was undertaken and written before patterns across the dataset were considered. In order to avoid, “premature analytic closure” (Braun & Clarke, 2021, p. 263) codes were repeatedly reviewed and multi-faceted themes were developed reflexively in order to enhance the transparency of the analytical process of data interpretation. This occurred throughout the writing up of the analysis also, where the number of themes was reduced further in order to ensure clear theme functions and meaningful analysis were reported (as suggested by DeSantis & Ugarriza, 2000). Theories applied to discuss the data were used as tools for interpretation in order to avoid limiting the scope of the analysis. Similarity and nuance within themes were illustrated by the use of quotes from different participants. Consideration of the ways in which this analysis enhances and extends existing literature have been made in the relevant Results chapters (Chapters Four and Five) and in the Discussion chapter (Chapter Seven) in order that the study can be located within the wider social context (Connelly & Peltzer, 2016) of current understandings of participants’ experiences.

On a practical level, Braun and Clarke’s six step process to analysis was applied. First, the audio-recordings were listened to carefully and repeatedly. Then the audio-recordings were listened to alongside the verbatim transcripts. In this way it was possible to become familiarised with the data in both audio and written formats. For participants who were not audio-recorded, agreed written notes were repeatedly examined. In the second stage, initial codes were inductively generated based on phrases that were of importance to the participants. As is common in Thematic Analysis, in this initial coding stage there were no prior specific assumptions or theories which were considered, instead the data were analysed inductively. Initial codes were generated which included initial exploratory descriptive codes, linguistic codes and conceptual codes. These were then considered in relation to the study aims. In the third stage, the codes were collated into potential themes and data was gathered which related to each theme from across the dataset. In the fourth stage, themes were considered on two levels: firstly, the coded extracts and secondly, the entire dataset. Internal and external homogeneity were considered in order that themes had validity in terms of their similarity within a code; and the degree to which codes in different themes could be clearly established as different from one another. In the fifth stage, themes were defined and named. This involved ongoing analysis in order to refine the specifics of each theme, to consider the overall story the analysis told, and to generate clear definitions and names for each theme. In the sixth stage, results chapters were written as a scholarly report in order to finalise the analysis of the selected extracts. Braun and Clarke advised any extracts should be "vivid and compelling" (Braun & Clarke, 2021, p. 87). This stage provided a final opportunity for analysis, relating back to the research question and literature.

Ethical Considerations

Researching sensitive topics and collecting data from individuals about their lives and the lives of people close to them should be undertaken with care. Ethical considerations, which include ensuring voluntariness, consent and confidentiality, are crucial for ensuring research projects are carried out with respect for participants and the data they choose to share.

Many authors have highlighted the ways in which researching the lives of disabled people and in particular, the lives of people with intellectual disabilities, can present ethical issues (Stalker, 1998). This research project gained ethical approval from the Health Research Authority Social Care Research Ethics Committee (SCREC) on 4 May 2017: REC 17/IEC08/0009; IRAS ID 216910. That approval related to the inclusion of people with intellectual disabilities and parents in this study. Ethical approval to include service providers as participants was gained from the Tizard Centre Ethics Committee on 27.10.17. Easy-read versions of all information regarding the study including images and photos, were provided to possible participants and are included in the Appendices to this thesis

(Appendix A, Forms A1-A6). When access was gained to participants with intellectual disabilities who had consented to research with support from organisations, the project and consent processes were again explained, and consent gained for a second time in order to ensure that the project was understood and that possible participants had the opportunity to refuse to take part if they so wished. This also happened when participants requested a break and returned later in the day or the next day or in one case, the next week to complete interviews. Interviews took place at times and places chosen by participants. All gathered data was anonymised and kept securely (including password protection) on the Tizard Centre OneDrive. Ethical issues in this study arose when interviewing people with intellectual disabilities. Many participants shared their experiences of being raped as children and/or adults and one person explained they were being threatened with rape. Deeper consideration of these ethical issues is discussed in Chapter Six which reports the findings from Study Four, the quantitative analysis of the effects of care status on people with intellectual disabilities.

Quality and Rigour

Quality and rigour in quantitative research typically involve sets of criteria by which judgements can be made regarding the level of transparency of the data provided in terms of validity, reliability and generalisability. Quantitative measures can be considered valid or not in relation to both internal and external factors which may affect the meaningfulness of results. Internal validity relates to the repeated testing of measures in the populations for which they were designed. External validity relates to the generalisability of the research findings to wider populations (Bowling, 2014). Reliability relates to the replicability of the results of a study. This requires enough information to be provided to readers of studies that they can judge whether the scales within the measure could be used repeatedly and achieve the same or similar results (Creswell & Plano Clark, 2013, 2018). Generalisability is important in quantitative studies as it can be used to attempt to measure how well a study represents a population widely enough to be of use beyond the limitations of the study in question. This generalisability can be theoretical, inferred (by readers) or statistical (Gomm, 2008).

The quantitative and mixed methods measures used in this PhD are considered in terms of their quality and rigour in Chapter Six.

In contrast, the rigour and quality of qualitative research has been much discussed and often functions in different ways from criteria used in quantitative research. Qualitative research even within its own approaches uses different ontological and epistemological assumptions to consider the nature of what good quality research 'is' and how/whether it can be measured (Flick et al., 2004; Miles & Huberman, 1994; Sundler et al., 2019). Terry and Hayfield (2020) and Rogers and Ludhra (2013) argued that being methodical and transparent about the role of the researcher in each stage of the process, thereby making clear the reflexive nature of the researcher, is essential. Levitt et al. (2017) argued that the quality of methodological integrity in qualitative research can be evaluated when processes for both fidelity to subject matter and utility in achieving research goals are presented transparently. Braun and Clarke's (2021) suggestion that supervisors and PhD students discuss themes throughout the process in order to aid the reflexive nature of the research was therefore applied.

The principles of *sensitivity to context, commitment and rigour, transparency and coherence,* and *impact and importance* (Yardley, 2000, 2008) were also applied.

The first of these, Yardley suggested, starts at the beginning of the qualitative process and runs throughout it. This begins in terms of sensitivity to the choice of Thematic Analysis as a methodology, of engagement with the existing literature, and of accessing participants. This also relates to acknowledgement of the ways in which data collection and interviews are interactional, in particular in the ways in which power differentials are addressed in order that participants feel comfortable sharing often difficult experiences. In their review of the ways in which power relations can be better understood and addressed in qualitative research, Karnieli-Miller et al. (2009) suggested careful thought should go into every aspect of the research process. While no optimal relationship was found in their study, qualitative paradigms based in critical and constructivist approaches were felt to be more likely to be committed to rebalancing power relationships in different ways. This can include practical ways such as researchers demonstrating empathy and sharing meals with participants, mid-range ways such as acknowledging and promoting respect for participants by using their own words, providing thick description and committing to respectful conduct throughout each stage of the research, and more widely by focusing on marginalised understandings and experiences. Kvale (1996) was clear that despite these behaviours the power relationship still exists, it may simply be hidden. Transparent reflexivity throughout the research process then is essential if the issues surrounding power in research are to be addressed (Braun & Clarke, 2021; Knoblauch, 2004). Ensuring information was accessible, that participants set the times, dates and places of interviews, that consent was sought even when support staff had gained consent before I arrived, all help to add to the validity of my claim to be sensitive to the context of this study. *Sensitivity to context* also related to the analysis stage of this research, with close attention paid to the data and the emerging themes. It is hoped this thesis is compelling and demonstrates close attention to the context of the raw data and findings. Use of verbatim quotes from participants allows the reader to make decisions about the hermeneutic claims being made.

Yardley’s second criteria *commitment and rigour* relates closely to *sensitivity to context*. *Commitment* is a criterion used to consider the level of attention given to each participant during interview and the level of detail used in the closeness of attention to data collection and analysis. This requires a level of personal commitment on the part of the researcher and is considered in my reflexive comments in Chapters Four, Five and Six. *Rigour* relates to the level of engagement with the quality of the study overall, this includes the quality of sampling, of interview and of analysis. In addition, care was taken throughout this PhD study to ensure clarity regarding the balance between active listening and asking more probing questions, and movement from descriptive to interpretative analysis. Where possible, equal numbers of participants’ quotes being used to exemplify themes found in all of the participant experiences suggests rigour has been applied. For this reason, themes were only included in this PhD study if they were identified in the interviews from all parents or service providers.

Transparency and coherence can be demonstrated through the provision of information regarding each stage of the research process. This has been provided in relation to participants, the interview schedule, and stages of the process of analysis. Coherence relies on the researcher's ability to present an argument which is clear and coherent, where differences and nuance are presented openly. In terms of transparency and coherence, this study also contains clear links between the research undertaken and Thematic Analysis (rather than another type of qualitative research approach). Criteria used for assessing the rigour of the analysis stages in qualitative studies also include those suggested by Terry and Hayfield (2020) and Braun and Clarke (2006) covering the explicit and transparent analysis of data by the researcher at each of the six stages of analysis. This involves rigour in transcription, coding, analysis, the amount of time given to the project and the ways in which the final report is written. Braun and Clarke's 15-point checklist for ensuring quality and rigour in Thematic Analysis (Braun & Clarke, 2006, p. 96) was therefore applied to this PhD. The final piece of written research has hermeneutic approaches within each chapter, so that quality and rigour in the use of Thematic Analysis as an approach can be evidenced throughout.

Finally, Yardley suggested *impact and importance* as validity criteria can be judged not only by the quality of the research method but also by whether the research is deemed to be useful, interesting or important. Reporting of research in this PhD study therefore contains often informal language and is written in a tone which best reflects the meanings and intentions of the participants. In addition, examples of memos are provided in this study to demonstrate the thinking and the levels of engagement of the author with the original transcripts and developing texts (Appendix B Memo B1 & B2). Examples of developing codes throughout the analysis of this data are also provided within the appendices for this study (Appendix B Figures B1 & B2).

Potential Contribution

This study aims to contribute to current knowledge regarding view and experiences of parents of adults with intellectual disabilities, service providers and people with intellectual disabilities around care and social networks in times of austerity. Despite some valuable contributions to debates about the possible effects of austerity on the lives of people with intellectual disabilities and their parents, few researchers have considered this holistic approach to understanding effects of austerity on care and social networks. This approach is much-needed as the continuing cost-of-living crisis threatens to affect whether austerity measures will be lifted, remain or reduce care, support, services and welfare further (Ray-Chaudhuri et al., 2023).

It is hoped that by revealing the perceived effects of austerity on lives and social networks, positive social change may be initiated. From the start of this project, the research plan included the need to engage with not only academic audiences but also interested parties, parents, practitioners, charities and policymakers. Issues arising from this study, including good practice where it exists, will be aimed at both academic and a range of lay-audiences and presented in appropriate ways which can be easily understood in order to aid implementation of positive practice.

While this project is based in England, it aims to reveal possible common issues and experiences which may be helpful for other countries also experiencing the implementation of austerity measures. While some participant numbers in this study are deliberately small (10 parents and nine service providers) having 150 participants with intellectual disabilities sharing details of their lives from their own perspectives offers opportunities for practitioners, researchers, policy-makers and interested parties to consider whether similarities of experience may be shared in their area, or better still, may encourage others to investigate the effects of austerity in their own area using a range of voices to build a richer, deeper picture of individuals' current situations.

This research also hopes to fill another 'gap' in studies regarding people with intellectual disabilities. Often in research about people with intellectual disabilities, well-intentioned over-caution regarding the ability to consent and risk of harm has meant much research, particularly quantitative research about the lives of people with intellectual disabilities uses responses from families or workers (Feldman et al., 2014; Iacono, 2009). Rogers (2016) and Oliver and Barnes (2012) have highlighted that people with intellectual disabilities are often excluded from ordinary patterns of life, and that this can include opportunities to take part in research. Goodley and Van Hove (2005, p. 17) pointed out some of the ways that Disability Studies has often left people with intellectual disabilities being perceived as unproblematic and therefore existing only on the periphery of Disability Studies discourse. Asking people with intellectual disabilities themselves about their lives can recognise and promote the importance of people with intellectual disabilities being asked questions and answering questions about their own lives (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012).

The following chapter presents findings from the study which examined the experiences of parents in times of cuts to services, care, support and welfare regarding their own lives and social networks and the lives and social networks of their adult sons/daughters.

Chapter Four Results From Study Two: Thematic Analysis of Parents of Adults with Intellectual Disabilities' Experiences Around Care and Social Networks

This chapter will be used to consider the findings of Study Two. Study One reviewed and synthesised the available literature on the social networks of people with intellectual disabilities. That study highlighted the importance of social networks regarding identity, powerlessness, inclusion, family and support, and it related those findings to concepts of stigma and normalisation. This second study consists of analysis of semi-structured interviews with parents of adults with intellectual disabilities. The research had as its overall aim the exploration of views and experiences around care and social networks of people with intellectual disabilities, parents of adults with intellectual disabilities and service providers in times of austerity. This second study therefore had as its research question: “What are the views and experiences of parents of adults with intellectual disabilities around care and social networks and the care and social networks of their adult sons/daughters in times of austerity?”

Analysis suggests that parents could experience austerity as having negative effects on many aspects of their own and their sons/ daughters’ care, social networks, identities and relationships.

The background section will be used to highlight the lack of research in this area, and to make suggestions regarding the applicability of that research to this group of people and topic area. The methods used for data collection and analysis in this study are considered in depth in the Methodology chapter (Chapter Three) and are therefore summarised in this chapter. The results of the research will be presented, followed by a discussion regarding the analysis of the results. Conclusions are drawn and recommendations are suggested.

Background

Before the 2008 global financial crisis and the austerity policies associated with it in the U.K., the U.K. government’s *Valuing People* and *Valuing People Now* policies (DoH, 2001; DoH, 2009) had implemented changes for people with intellectual disabilities and their families in terms of services, care, support and welfare. These were intended to strategically move away from the large institutionalisation of services which Wolfensberger et al. (1972), Goffman (1991) and O’Brien and O’Brien (2000) had previously warned against. Yet these changes were often criticised for being a ‘postcode lottery’ of differing quality of and eligibility for, care and support, with claims of inconsistent, overly bureaucratic processes being unfairly applied between councils (Newton et al., 2006; Newton & Browne, 2008). The Fair Access to Care Services (FACS) (DoH, 2002) framework did little to resolve these inequalities.

Although legislation such as The Care Act (2014) aimed to reduce the unfairness perceived in previous approaches, and to promote wellbeing and prevent crisis, it was simultaneously used to reduce eligibility for services and to reduce social care costs, in line with austerity policies (Slasberg

& Beresford, 2017). The King's Fund (2023) for example reported that overall Government funding to Local Authorities (L.A.s) fell by 55% between 2010/11 and 2019/20.

More widely, cuts have occurred at the same time as demand for services and the cost of providing them has risen. NHS Digital also reported a rise in requests to L.A.s of 1.6% in 2017-18, these requests were for all types of adult social care support, equivalent to 5100 requests per day (NHS Digital, 2022). In 2019/20 £5.39 billion was spent on adults aged 18-64 with intellectual disabilities, with £0.71 billion spent on adults with intellectual disabilities aged 65 and over. NHS Digital (2022) also warned that rises in adult social care spending were being targeted towards tackling the Covid pandemic so should not be assumed to be associated with increased spending on meeting assessed adult social care needs. NHS funding from the Government, which rose by more than £1 billion during the pandemic, was also reported to have reduced the amount of money the Government has provided to L.A.s, requiring them instead to raise Council Tax and find other ways of funding adult social care (The King's Fund, 2023).

Against this background, families remain the longest and most consistent relationships people with intellectual disabilities have (Foundation for People with Learning Disabilities, n.d). Around half of people with intellectual disabilities live with their families, usually their parents, who are often their main caregivers. This has been found to be the least costly care option for L.A.s (NIHR, 2020; Forrester-Jones et al., 2021) as parents undertake the 'burdens' of the caring role (Bauer & Sousa-Poza, 2015; Egan & Dalton, 2019).

The Care Act placed a duty on L.A.s to undertake an assessment of parent carers' needs, regardless of the authority's view of the carer's need for support or the financial situation of the carer or person needing care. The Care Act focuses on the wellbeing of carers as being equal to that of people with intellectual disabilities.

Since the enactment of The Care Act, research on the effects of cuts to care, support, services and welfare on parents of people with intellectual disabilities both globally and in the U.K. has been sparse. Three studies which have specifically considered impacts of austerity in the U.K. suggested that austerity policies had detrimental effects on the lives of people with intellectual disabilities and their families. These included decreases in advocacy, eligibility for services, quality of life, wellbeing and having basic needs met (Forrester-Jones et al., 2021; Malli et al., 2018; Walmsley et al., 2017).

Research on the experiences of practitioners making assessment of needs under The Care Act is even more sparse. Symonds et al. (2018) investigated the experiences of a range of L.A. practitioners including Social Workers and unqualified support workers involved in decisions about eligibility under The Care Act. Although many practitioners identified strongly as advocates for social justice and as allies of their clients, they also highlighted the difficulties inherent in balancing making professional judgements under a bureaucratic system of budget cuts with promoting person-centred definitions of need. Assessors (both qualified and unqualified) reported that if a person with intellectual disabilities could ask for the help they needed, they probably did not have intellectual disabilities and were therefore deemed undeserving of and ineligible for support (Symonds et al., 2018, p.1908). Clients asking for more help than they were perceived to need angered assessors. Assessors felt knowing clients was important, yet this was typically not possible in the face of overwhelming requests for services. Unqualified assessors were found to be more likely to use their own judgement (including their judgements about a client's personality) and to restrict access to support than qualified Social Workers. In their 2020 work, Symonds et al. went on to argue that observational research of face-to-face assessments were required in order to better understand relationships and the extent to which person-centred practice is possible within an eligibility- and funding- centred process. Recent advertisements for Care Act assessors also suggested qualifications and experience were not required in this role (Indeed, 2023a, 2023b).

When considering the concept of care, the personal and political are inextricably linked in terms of power and control (Lloyd, 2010). People with intellectual disabilities and their families have often found themselves to be subjects of personal and political control. Both Goffman (1990a, 1990b,

1991) and Edgerton (1993) considered the nature of this power and control within social relationships. They highlighted the dilemmas which could arise for people with intellectual disabilities and their families when they tried to challenge their less powerful social roles by attempting to 'pass' as non-disabled people. In addition, the personal and political control aspects within the neoliberal agenda behind austerity policies and cuts to care can often push societies and citizens to feel that care is becoming a purely private matter (Nguyen et al., 2017). These social pressures may be linked to the new assessment systems under The Care Act being found to, "inadvertently" result in less parents seeking much-needed support for themselves and their sons/daughters (Forrester-Jones, 2021, p. 109).

Research on the Views of Parents of Various Ages

U.K.-based research which considers the views of parents of various ages has highlighted parents' negative perceptions of the people and systems which they felt should be supporting them. Social Workers were considered to be gatekeepers who had lost their focus on social justice and who perceived parents as problems (Kam, 2014), often perceived as viewing parents' requests for support as inappropriate or excessive (Wilkins, 2015). Some studies found that parents felt L.A.s were distancing themselves from parents. This included a lack of partnership working between parents and L.A.s, a tendency for L.A. workers to blame or ignore parent carers, and a pressure on L.A. workers to restrict budgets. These were considered to have significant detrimental effects on whole families (Gant, 2018; Wilkins, 2015) including increasing the 'burden' of care (Egan & Dalton, 2019). Feelings of powerlessness have also been described by parents (Power, 2008) and parents who thought professionals felt threatened described those professionals as trying to actively "seek to diminish parents" (Walmsley et al., 2017, p. 1372).

A Dutch study (Grootegoed et al., 2013) highlighted the ways in which parents often felt they had no right to complain or appeal against decisions to cut services as they felt they would be breaking a new moral code which had come about during austerity. In that study, researchers found that assessors did not see it as part of their role to intervene until families were at crisis point.

Some studies found that parent carers and families in the U.K. felt they must choose whether or not to 'fight' for appropriate care for their sons/daughters with intellectual disabilities (Ryan & Runswick-Cole, 2008; Walmsley et al., 2017). As relationships with professionals have soured (Mahon et al., 2019; Ryan & Runswick-Cole, 2008), and abuse of people with intellectual disabilities in commissioned services has continued (Bubb, 2014; Murphy, 2020a, 2020b), suspicion of L.A.s has been shown to be an ongoing concern for parents of all ages (McCarthy et al., 2021).

Research Specific to the Views of Parents of Adults with Intellectual Disabilities

As people with intellectual disabilities age, so more parent carers are likely to become 'older' parent carers. Parents of adults with intellectual disabilities have been broadly defined as being from 40 years old (Burke et al., 2018) to over 75 years old (Weeks et al., 2009). The lived experience of these parent carers of adults with intellectual disabilities specifically is an under-researched area (Brennan et al., 2020; Ryan & Runswick-Cole, 2008). In addition, while some research exists regarding the experiences of younger adoptive parents of children with Special Educational Needs (such as Good, (2016) and Perry and Henry, (2009)), there exists a gap in knowledge regarding the experiences of adoptive parents as their children age and negotiate their lives as adults. While research thus far has tended to try to avoid assumptions, often referring to 'family carers' as opposed to 'parents' for example, in a time of cuts there may be important differences in expectation and experience that current literature has missed.

In a recent literature review, only six U.K.-based studies were found which considered the experiences of parents of adults with intellectual disabilities. All of these highlighted a lack of information from L.A.s and services, and feelings of anxiety (Mahon et al., 2019). More widely, of the global and U.K.-based studies which have been undertaken, there has been a focus on mothers as opposed to fathers (Dunn et al., 2021) and a focus on future planning (such as Pryce et al. (2017), Brennan et al. (2020) and Lee and Burke (2020)). This has often included parents' fear regarding who would provide care when they die (Scior et al., 2020; Weeks et al., 2009).

Other research has suggested that for parents of adult sons/daughters, if assessments under The Care Act did take place, these were reported as often being undertaken by unqualified L.A. staff with no experience or understanding of intellectual disability (Forrester-Jones, 2021).

In this context, it may therefore be increasingly important to illuminate the lived reality of cuts to care specifically for parents of adults with intellectual disabilities.

Aim

The limited available research has shown that parents of adults with intellectual disabilities report difficulties getting the information they need, that assessments of need can be undertaken by unqualified staff and that parents fear for their sons and daughters after parents have died. What is not known is whether cuts to care, support, services and welfare have affected these and other issues for parents of adults with intellectual disabilities and if they have, in what ways. This research study aimed to focus on the question "What are the experiences of parents regarding their own care and social networks and the care and social networks of their adult sons/daughters in times of austerity?".

Method

In line with the qualitative nature of this study, semi-structured interviews were conducted with 10 parents between November 2017 and January 2019. This length of time was required for several reasons. Firstly, it took time to build trust with parents. Repeated visits to parental support groups which met only monthly were required in order to build this trust. Another justification is that many parents in different support groups explained they did not have time to meet with me as they were so busy. When parents did agree to be interviewed, they also stated they could only meet on set days and times, often giving dates which were several weeks in the future. They explained this was due to needing to meet at a time when they were not taking sons/daughters to day services, when sons/daughters would not be at home, and/or when they themselves would not be too tired. The justification for this method was considered in the Methodology chapter (Chapter Three) of this thesis. Eight interviews were undertaken with individuals and one interview was with a married couple interviewed jointly. Questions centred around participants' experiences of cuts to care. Interviews lasted from 46 minutes to 2 hours 17 minutes. Total interview time was 12 hours 6 minutes and the average length of the nine interviews was 1 hour 24 minutes. Interviews were arranged at a time and place of the interviewees' choosing. In order to protect anonymity, pseudonyms are used throughout, and location details are general.

Recruitment and Sampling

There are "no magic formulas" regarding sample size in Thematic Analysis (Braun et al., 2018, p.9), but often relatively small sample sizes of between nine and 17 participants can be used to better gain meanings across datasets and in-depth analyses (Braun & Clarke, 2020; Hennink & Kaiser, 2022). Vasileiou et al. (2018) raised their concerns regarding the perception that 'small' sample sizes could often be understood as 'insufficient'. They argued, however, that aiming to purposively recruit a small number of participants is intrinsic to the data adequacy of those qualitative studies which aim to consider commonalities across ideographic experiences. In order to recruit participants, national and local charities and groups were contacted via email, groups were visited and all relevant information regarding the study, including consent forms, information sheets and debrief information was provided and explained. Copies of these and indicative interview questions are provided in Appendix A Forms A1-A3 and Appendix C Form C2. These were agreed with the research team and with the ethics panel. However, as interviews progressed, I changed the initial question to be more open: "Tell me about what life is like for you in austerity". This was deemed to be a more appropriate opening question which was more likely to put parents at their ease and enable them to lead the interview in a direction which better reflected their experiences.

Inclusion Criteria were that participants had to be the parent (either adoptive or biological) of an adult with intellectual disabilities and had to have a continuing role in their adult son/daughter's care. The 10 parents had been informed of the call for participants via the range of agencies and networks they each used. Parents chose the time, place and length of interview. Three parents insisted on providing me with a homemade lunch. Parents were aged in their 50s through to their 70s. Sons and daughters were all adults aged in their 20s through to their 50s. They lived in diverse locations in four counties of England: from very rural areas through to the edge of cities. Two counties were in the South of England, one in the Southwest and one in the Northwest. Interviews were carried out in parents' homes except the married couple who requested to be interviewed in a charity building. A table of parent characteristics included in Table 3.

Table 3

Parent Characteristics

Participant pseudonym	Role	Son / daughter interviewed for this study?	Living with son/ daughter ?	Location	Rural/ Urban?	Age	Marital Status	Interview Type
Janet	Mother to a daughter.	No	Yes	South of England.	Rural.	70s	Widow.	Lone (with break for lunch) in her home.
Karen	Mother to adopted son and daughter.	Yes, both	No	South of England.	Rural.	50s	Separated.	Lone in her home.
Camille	Mother to a daughter.	No	Yes	South of England.	Outskirts of a city.	50s	Divorced.	Lone in her home.
Dana	Mother to two non-disabled sons and an adopted daughter.	No	No	South of England.	Outskirts of a small town.	70s	Widowed now living with partner.	Lone (with break for lunch) in her home.

Participant pseudonym	Role	Son / daughter interviewed for this study?	Living with son/ daughter ?	Location	Rural/ Urban?	Age	Marital Status	Interview Type
Fred and Frances (married couple interviewed together)	Mother and father to a son with intellectual disabilities who died in the last ten years, aged in his 20s; and a non-disabled daughter.	No	No	Northwest of England.	Outskirts of a small town.	70s	Married, living together.	Joint in a charity building.
Robert	Father to two adopted sons.	No	Lives with one son	South of England.	Very rural.	70s	Married, living together.	Lone in his own home.
Teresa	Mother of two sons and one daughter. One son had intellectual disabilities.	No	Yes	South of England.	Very rural.	70s	Widow.	Lone (with lunch) in her home.

Participants were made aware that if they disclosed any issues of serious concern, this would be discussed with my supervisors and possibly Social Services and the Police.

Measures

Parents were interviewed face to face in semi-structured interviews. These were audio-recorded. Questions centred on their experiences of cuts for themselves and their adult children with intellectual disabilities.

Analysis

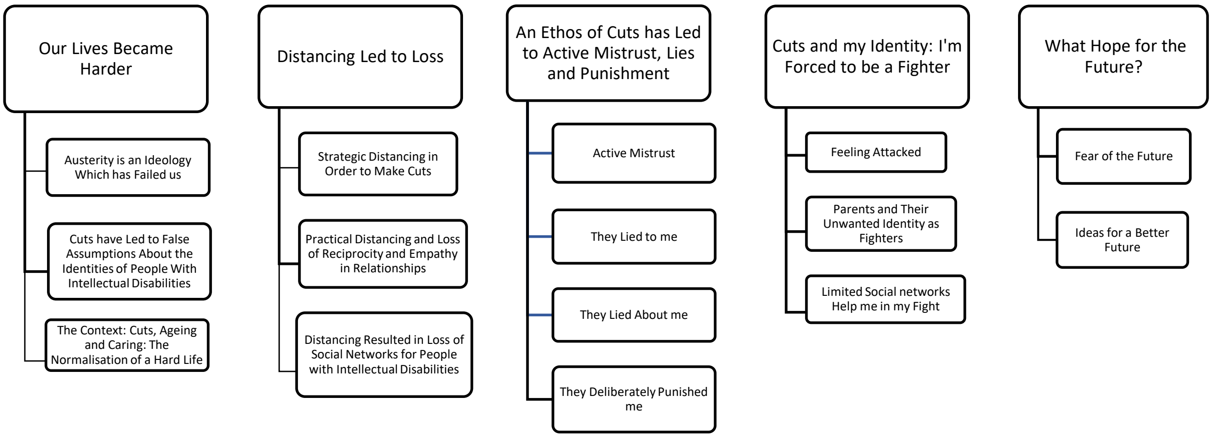
Braun and Clarke's (2006) six-step process was applied to the analysis of the data collected in this study. The justification for this method of analysis is discussed in the Methodology chapter (Chapter

Three). Interviews with parents were audio-recorded and transcribed. Memos were kept throughout the process which reflected on content, analysis and process of using Thematic Analysis. Themes created served to answer the research aim and to highlight the complex nature of parents' experiences in times of cuts.

Results

Figure 6

Themes and Subthemes from Parent Interviews



Themes created from thematic analysis of the participant interviews are presented below. Themes were: Our lives became harder; Distancing led to Loss; Cuts have led to Mistrust, Lies and Punishment; Cuts and my Identity: I'm Forced to be a Fighter; and What hope for the future? Themes were included in this analysis if they were present in 100% of the sample. This percentage was data-driven and deliberately high due to the large amount of data and themes which were created from the interviews. Other themes were present in some of the interviews but not all, such as two parents who reported that their sons had been abused in residential care and two parents who reported experiences of advocating for other parents. While these and a range of other experiences were important and deserve attention, this thesis did not focus solely on the experiences of parents. If it had, then space would have been available to draw out themes which were present in less than 100% of the sample. Braun and Clarke (2022) are clear that researchers should be able to step back from their research to present what can be demonstrated in enough of a sample of participants that claims can have robust coherence.

These themes and their subthemes are considered below. Figure 6 shows the themes and subthemes in diagram form.

Theme 1 Our Lives Became Harder

This theme explores parental perceptions of the context of care in which they found themselves. Parents described their daily lives as becoming significantly harder since an ideology of austerity had been adopted. The ways in which their sons'/daughters' identities had been spoiled by false assumptions were also highlighted. Parents described the ways that resultant cuts interacted negatively with their lives and caring responsibilities as they aged.

Subtheme 1: The Context: Austerity is an Ideology Which has Failed us. Many parents were clear that the political aspects of an ideology of austerity had failed them and their loved ones in several ways. They recalled their previous positivity about governments wanting to meet the needs of people with intellectual disabilities. As parents of adults with intellectual disabilities with long histories of caring for sons/daughters across many government approaches, all parents felt that the adoption of austerity as an ideology had meant that cuts to services, support and/or welfare benefits had become deeper over time. Having experienced the introduction and implementation of different legislation over the years, parents felt The Care Act's lack of requirements and duties were now being deliberately exploited by L.A.s in order to make cuts. Parents expressed feeling fear and powerlessness about this and about an apparent lack of meaningful overall strategy, policy and coordination between governments and L.A.s. Policy was considered to now be written from the fundamentally flawed perspective that adults with intellectual disabilities were able to continually improve their skills to the point that they would be able to live independently. They felt this "change of ethos" meant attitudes had "suddenly" (Dana, 541, 545) regressed from the positive ethos of *Valuing People* (DoH, 2001) to a focus on making cuts, which would inevitably have negative impacts. Janet commented "It's a nonsense. Austerity is a lie and people at the bottom like my daughter who knows nothing about it, she and I are paying the price" (Janet, 257-258). As Robert explained "people are being institutionalised even though they are walking around town …. an institution is not a place it's an attitude, and I just feel that's going to be one of the big damages of the cuts" (Robert, 143-146).

Parents found they were also 'suddenly' being charged for services which had previously been included in costs which L.A.s had paid to service providers. This included transport, day service provision and holidays. Some parents often empathised with organisations, feeling they were also in a difficult position, having their costs "screwed down" by L.A.s to the point that they could no longer deliver services (Dana, 368). Examples were given of charities now being driven by the need to make a profit as businesses, run by people whom parents felt had no experience of running businesses in this way. L.A. workers too were considered to have no expertise in financial matters or in understanding the nature of intellectual disabilities.

Other results of austerity as a failed ideology were felt to be reflected in the ways in which different government departments and/or L.A. departments were considered to have changed their focus away from meeting needs towards one of needing to 'shift' the financial burden of care away from their own department and onto another. This was felt to be one reason behind services changing from being registered as residential care homes to being registered as Supported Living services. Despite promises of more choice and control, parents felt this change was detrimental to their sons'/ daughters' wellbeing (Camille, Barbara, Janice, Fred, Frances, Dana).

As an attitude and ethos of cuts became normalised, holistic, individual reassessment of need and support was felt to have become a cost-cutting exercise where hours of support were routinely cut. Some parents found cuts were made after reassessment under The Care Act, every parent in this study also experienced cuts being made without any assessment, notice, consultation, or reference to previous assessments or agreements. This could happen quickly or over time. For example, Janice and Karen explained “although they agreed … that they maintain the [support] … the Council slashed [my son]’s total care package by over 30% without any explanation” (Janice, 713-716), “and also with my daughter’s care it’s sort of been skimmed away over the years and we did actually lose it last year without them even telling us” (Karen, 556-557).

All expressed anxiety about their health and wellbeing which they felt was considerably negatively impacted by the adoption of an ideology of austerity “no-one is actually counting the end product … which is premature death” (Barbara, 829-830).

This lack of valuing of parents was also reflected in the ways in which parents felt their adult sons/daughters were now treated. These are considered below.

Subtheme 2 The Context: Cuts have led to False Assumptions About the Identities of People with Intellectual Disabilities. There were three key ways in which parents felt their sons/daughters now had identities of people with no value in the eyes of L.A.s and Health services.

Some parents felt one spoiled identity reflected in assessment was that of being perceived as a permanent and inconvenient burden in need of permanent (costly) support. Parents felt unqualified assessors often had no understanding of intellectual disabilities. This then led parents to feel that these workers assumed that care could be regularly cut with no repercussions. Social Workers were considered to make cuts knowing that these cuts would cause negative outcomes. Parental assumptions of qualifications were based on whether assessors appeared to have any knowledge or understanding of the nature of intellectual disabilities and on whether assessors stated they were Social Workers. Both were felt to spoil identities. Fred (208-212) explained “Health didn’t want him because it cost them money, Social Services didn’t want him because it cost them money”.

This was also reflected in the deficit-model nature of the excessive paperwork parents described having to complete about their sons/daughters, which parents felt was “heart-breaking” (Teresa, 591-592).

The second way some parents felt identities had been spoiled was by their sons/daughters being treated as a temporary burden. In this instance, parents felt support was considered by L.A. workers to be a short-term stepping-stone to an identity of complete independence. Dana explained that after the introduction of The Care Act this affected every person living in the same residential service as her daughter. She explained “everybody had to be reassessed. And, without exception, they were assessed as needing less help than they had previously been getting. Which does seem rather strange, since none of them had changed” (Dana, 551-553).

The third way in which parents felt their sons/daughters now had spoiled identities in the eyes of L.A.s and Health services was described by parents whose sons/daughters were given a false identity of ability, or ‘normality’. They found this led to sons/daughters being reassessed under The Care Act as no longer in need of any support. Parents felt these sons/daughters often had services cut by workers who perceived abilities as divorced from, rather than reliant on, support:

> our son walked in and he was quite well-mannered and said, “Hello,” shook hands and then she had a few words with him and he walked out of the room and she said, “Well, he seems okay.” And, you know, it was a sort of comment, throwaway comment, that made us want to tear our hair out with everything that was happening in this house every day. So … it does make me think that a lot of it’s glossed over. (Robert, 369-374)

Parents also expressed their views that Social Workers were often in impossible situations when the consequences of cuts became apparent to them:

> And I suppose it’s a big conflict of interest for Social Workers because on the one hand, they’re supposedly trained to, erm, get people help and then, on the other hand, when they actually

> start work, they're trying to stop people getting help. So that doesn't really work does it? (Dana, 575-578)

This feeling that they and their adult children were devalued, and their lives were harder as a result of the attitude/ethos of cuts had become normalised for many parents.

Subtheme 3 The Context: Cuts, Ageing and Caring: The Normalisation of a Hard Life. The daily lived experience of being a parent of adult(s) with intellectual disabilities came with its own set of anxieties for 'exhausted' (Janice, Robert) parents in this study. As cuts deepened, the excessive daily struggle and stress they experienced got "harder" (Janet, 227) and this experience became normalised:

> things do go wrong, and nobody sees it … the carer becomes ill, the person with learning disabilities goes downhill, but the carers by that point are not really in a position to do anything much about it apart from just get on with day-to-day. That needs to be dealt with, you know? No-one should be expected to just get on with a caring role into their seventies and eighties. (Robert, 601-605)

Parents felt that as a result of services being cut "to an inch of its life" (Camille, 354) they now bore "the brunt of the caring role" (Robert, 394). Being "on-call 24/7" (Frances, 136) had negative effects on parents. Janice (998-999) explained "I was on the edge of a nervous breakdown, and I had shut down … just to keep going and I was in something I call 'survival mode'". This led some parents to feel that their and their sons'/daughters' lives were "slipping away" unnoticed (Janet, 234-235).

For all parents this became 'normal' life. This was brought home to Robert when he and his wife found and accessed charity support to appeal decisions which had cut or denied them welfare benefits. When asked by the worker why they had not answered questions in greater detail "We said, "That's normal life." He said, "No, it's normal life for you, it's not normal life for anyone else." …. it's that realisation that it is a very different life" (Robert, 583-586).

The loss of valuing relationships between parents and the organisations and workers they felt should be supporting them and their adult children had been negatively impacted by the adoption of an attitude/ethos of cuts. This was experienced as a series of losses.

Theme 2 Distancing Led to Loss

This theme analyses the ways in which the adoption of an ethos of cuts negatively impacted parents' relationships with L.A.s, Health services and organisations. Parents experienced an active distancing in their relationships with these agencies. This resulted in feelings of a loss of empathy and reciprocity for parents and loss of social networks for their sons/daughters.

Subtheme 1 Strategic Distancing in Order to Make Cuts. On a strategic level, parents felt that L.A.s, Health services and organisations had made decisions to proactively distance themselves from parents and people with intellectual disabilities in order that care could more easily be cut. This was perceived in different ways.

They suggested distance at a societal level was happening because "people aren't aware of what's happening to Social Services and how little care is out there, really. And … the direction it's going in I think" (Karen, 651-652). Whilst at governmental level distance was considered to be deliberately created because "we have a government who don't really care" (Janet, 240).

Parents felt the deliberate distancing of L.A.s from their responsibility for strategic decisions about cuts could be seen in the way in which they engaged external professionals to decide on which areas would be deliberately cut and by how much. The language of battle was used "hatchet people, and they're being brought in to cut and they're given however long they need to cut the amount of spending to whatever brief they've been given, and then they'll move on, so they're a moving target" (Barbara, 483-486).

Any L.A. consultation was now considered to be tokenistic at best. Robert, who had previously been a member of a religious order, explained "sometimes it's actually soul-destroying" (Robert, 316). At worst, parental experiences and expertise were felt to be unvalued or ignored “There’s all that which never gets documented and is seen as anecdotal somehow, rather than your lived experience” (Barbara, 815-816).

Distancing also happened on practical levels, with further significant negative effects on parents and their adult children.

Subtheme 2 Practical Distancing and Loss of Reciprocity and Empathy in Relationships. In practical terms, loss of reciprocity and empathy in relationships with professionals were considered to be key effects of strategic distancing. Parents felt strategic distancing was designed to ensure that parents and people with intellectual disabilities would find it almost impossible to build relationships which would enable access to support “the whole system is designed to make people disconnected from their work and the people that they’re supposed to serve” (Barbara, 569- 571). Organisational “gatekeepers” were considered to be in place to limit any traditional avenues parents and people with intellectual disabilities might have previously used to communicate their needs “unless it suits them” (Barbara, 315, 487). Parents felt central ‘hubs’ were designed to stop practical access to relationships with L.A. workers both directly and indirectly. Attempts to subvert these distancing systems usually failed:

> the net result was if you had a learning disability … you had no other way of communicating with the County Council … you had to go through the Hub, nobody else …. if you managed to find a number that sneaked you into County Hall … as soon as somebody realised it was Social Services, you were straight back to the Hub. (Fred, 682-689)

Robert, Dana and Karen (who had adopted their disabled children) felt particularly aggrieved that empathy and reciprocity were lost. They had not expected this because:

> we feel like we've in some ways done the State a favour by adopting them, in that their care needs would have been huge otherwise, and we've largely done that without any support when they were younger. So, you do sort of feel I suppose I've 'done my bit' in a way. (Karen, 422-425)

Robert, Dana, Teresa and Barbara also found Carer's Assessments were not offered, despite their L.A. knowing of the difficulties in their situations and this being a requirement under The Care Act.

A lack of reciprocity and empathy was also perceived in the replies which parents received when challenging processes, such as "Oh well, that's not my problem, that's the rules" (Teresa, 269) or just asking for support "when I complained about him not sleeping well the paediatrician we had at the time turned round and said 'well it's your own fault he's still alive, you shouldn't be such a good nurse'" (Frances, 757-760).

Daily experiences of this lack of empathy and reciprocity meant parents felt uncared-about:

> Nobody really bothers, cares much about family carers, they don't. Because they're unsung heroes and they're behind closed doors and they get on with it because they have to. And who goes to their funerals? Well, just relatives, isn't it really? (Barbara, 822-825)

Distancing also had negative impacts on the social networks of adult children with intellectual disabilities.

Subtheme 3 Distancing Resulted in Loss of Social Networks for People with Intellectual Disabilities. Parents were aware that as they aged and became less able to provide support and as cuts deepened, other people would need to fill the widening gaps in much-needed care relationships. The positive effects of a consistent supportive network of people who understood sons/daughters' needs and identities were highlighted by most parents. These networks meant sons/daughters could undertake small but meaningful 'ordinary' activities and "behave like a normal person going to the bar and ordering himself a drink" for example (Teresa, 505).

The adoption of an attitude/ethos of cuts and resultant distancing however meant that many parents felt their efforts to achieve a level of normality for their sons and daughters in terms of relationships were futile “the way that it’s organised it’s impossible to do that” (Dana, 494).

Direct and indirect cuts at strategic and practical levels were felt to be being made with no recognition of the importance of the role of activities for building and maintaining sons’/daughters’ social networks:

> We stopped doing drama…because it went up from £27.00 to £40.00 a term … so … do we pay for food for the dog, and for us, or does [my son] go and do two hours’ drama? So, we stopped doing that. (Teresa, 471-475)

Rather than the closeness and proactivity that parents desired, they felt that distance even in workers’ practical daily relationships with their sons/daughters had become the standard way of working “It’s like they’re there to do a care job, rather than to be a buddy and to be a friend” (Camille, 494-495).

Theme 3 An Ethos of Cuts has led to Active Mistrust, Lies and Punishment

The previous theme discussed the ways in which distance in relationships between agencies and parents had created a lack of empathy and reciprocity. This third theme specifically considers the ways in which parents felt they were now treated as a result.

Subtheme 1 Active Mistrust. Parents felt the increase in distance between themselves and Governments, L.A.s and workers meant they were now treated with fundamental mistrust “They trust providers, but they don’t trust family carers” (Barbara, 466). Parents in return therefore actively mistrusted these agencies. Parents described the ways even previously positive and relaxed relationships with Social Workers seen as friendly family advocates had changed since austerity policies had been introduced; “suddenly it became aggressive” (Dana, 575). Janet experienced this aggression when she requested support after a medical procedure meant she could not drive her daughter to day services for several weeks. She felt she was treated as if she was trying to shirk her duties as a parent. She therefore felt she no longer trusted nor wanted to contact Social Services "I'm now conscious of the fact that there is an edge to Social Services, you know, if I have to phone them up" (Janet, 135-136).

Parents felt this attitude of active mistrust enabled agencies to actively lie to and lie about parents, without apparent concern. Parents who had complained about services also described the ways in which they felt they and their sons/daughters had been actively punished for complaining. During interviews I was shown documentary evidence by Dana and Janice regarding their claims that they had been lied to and lied about. I have received further documentary evidence since then from Janice.

Subtheme 2 They Lied to me. Parents felt being lied to was deliberate act. Parents gave numerous examples of being lied to by workers in L.A.s, Health services and service provider organisations. Karen explained this began when she and her husband were adopting their two children. More recently Barbara and Dana were clear that Social Services staff had "blatantly" lied regarding assessments under The Care Act "in order to legally reduce, they had to tell lies actually" (Barbara, 520, 317-318).

When Dana complained about cuts to her daughter's services being purely cost-cutting tactics, she was told these cuts had been made in order to meet her daughter's needs. Yet when she gained access to her records, she found in an internal memo in which the L.A. had stated their decision was made purely for "cost avoidance" (Dana, 240). This led her to feel mistrust in her L.A..

Parents also gave examples where they felt that had been lied to by service providers about the minimal effects of cuts on the quality and type of services available. Feeling promises had been broken therefore also fuelled mistrust of providers "they assured me categorically that [my son] would have the same level of care and it would all be the same …. Then the sleep-in was withdrawn" (Janice, 505-512).

Subtheme 3 They Lied About me. Parents also felt lied about by L.A.s, Health services and workers, and gave examples of these experiences. The power imbalance in new relationships of mistrust was evident to parents when they found that records about themselves or their sons/daughters were either inaccurate or contained what they considered to be lies. Parents had discovered these inaccuracies or lies via meetings (Fred, Frances, Barbara, Janice), through new workers (Janice, Barbara), through friends and networks (Janice, Barbara), through Subject Access Requests (Dana) or via Ombudsman Reports (Janice). Parents felt they had to repeatedly challenge inaccuracies themselves. Parents reported they especially found themselves lied about in records if they had disagreed with agencies' decisions "the actual referral itself said I was rude and difficult and … I had turned down everything … it was a complete lie" (Dana, 242-251).

Parents felt new Social Workers were also wilfully ignoring evidence from parents, professionals and previous assessment records regarding sons'/daughters' needs. As such they were creating significant additional work and stress for parents "They have rewritten the history" (Janice, 819).

Parents felt Social Workers appeared to feel justified in writing what parents considered to be untruths as they 'owned' the documents, further highlighting the power differential parents now experienced in their relationships with these workers. Barbara related a conversation with a Social Worker "And she said, "Well, you realise this is not your document, it's ours?" [Pause]. I said, "But that still doesn't entitle you to put wrong information in it" (Barbara, 661-663).

A subset of parents who had complained about L.A.s, Health services and workers felt strongly that they had been actively targeted for punishment through cuts to services, support and welfare. These experiences are considered next.

Subtheme 4 They Deliberately Punished me. Power imbalances were most profoundly perceived by five parents (Janice, Barbara, Teresa, Fred and Frances) who related their experiences of feeling deliberately "targeted" for "onslaught" (Barbara, 476, 433) in a "mixture of austerity" and "personal vendetta" (Janice, 1114). They felt this was because they had complained about L.A.s and/or service provider organisations or felt they were judged to be so untrustworthy that punishment was considered to be acceptable. They felt they were seen as troublemakers and again the language of battle was used “there is a sort of recurrent theme here if I challenge anyone, they then decide that basically they will get their own back” (Janice, 525-526).

Barbara felt deliberate punishment included her L.A. holding meetings about her son’s care and deliberately excluding her, leading her to think “I might be on a hit list” (Barbara, 663). When Frances and Fred protested against cuts at a Council meeting they were punished by being “ejected” by “armed police” (Fred, 384). This was covered in the local press at the time (Moseley, 2011).

Sons and daughters were also considered to be deliberately targeted when parents complained about L.A.s, Social Workers and service providers. As a result of her complaints, Barbara (235) felt cuts to her son’s care package with “no step-down time” were deliberate. She explained that Social Workers knew this would mean he could no longer safely leave his home or have any medical checks. Previous arrangements for successful reviews which did not distress her son were also no longer used “I said, “But this is causing him distress,” “I don’t care” was the result” (Barbara, 351-352).

Janice felt that being targeted and punished for complaining was not limited to Social Workers. She felt she and her son had been targeted for punishment by Social Workers “I was secretly taken off the respite list for two years. I found out later from a new Social Worker” (Janice, 252-253) and by service providers:

> the [name of organisation] gave him notice so he lost all his friends in one hit, and erm Social Services said to him he has to move [back to live with me] because there were no other care providers, but there was a care provider. (Janice, 581-583)

Teresa felt she was targeted by one Social Worker who thought she was untrustworthy, being incorrectly judged as trying to falsely claim welfare support. She reflected “You sort of felt the attitude towards you was, what do you think you're doing asking for money? …. that's how I felt it was at the time. It made me feel very small" (Teresa, 611).

The ethos of cuts, feeling undervalued and being mistrusted led parents to feel they were forced to change their identities to ones of fighters.

Theme 4 Cuts and my Identity: I'm Forced to be a Fighter

This theme analyses the ways in which parental identities were negatively affected by the adoption of an ethos of cuts by L.A.s and Health services, the ways in which some parents felt attacked, and how they 'fought back' against these organisations. Parents described feeling they were being forced to inhabit the unwanted identity of a fighter. They also considered the ways in which their social networks provided support in their fights.

Subtheme 1 Feeling Attacked. Parents spoke about their powerlessness in terms of their fear of an inability to "survive another onslaught" (Barbara, 433) and the "precarious" (Janet, 230) nature of their "fragile" (Barbara, 795) positions. The perpetual conflict in their relationships with L.A.s, Health and other services wore down their resolve to fight back. Some parents felt this constant onslaught was part of a deliberate strategy "there's this feeling that the noose is getting tighter…that things are closing in" (Janet, 377-378). Barbara explained that feeling attacked could be exhausting:

> but it gets harder and harder, and you have to keep digging into that well of hope when someone keeps poking at you …. Poking, poking, poking, poking, poking. And the thing about this is, and what really hurts … is this is being done to the most vulnerable in the land. These are people who can't fight back. That's shameful [pause]. (Barbara, 558-563)

Parents also spoke in bleaker terms about identity and powerlessness, linking this to feeling unfairly blamed for governments' financial and strategic failings:

> Mind you, they're trying to kill off the baby boomers anyway, aren't they [laughs] 'cause we didn't put enough in. Nobody told us we weren't putting enough in, but we didn't put enough in

> and now we're costing more than we put in, yeah. Actually, what about the £132 billion that we've helped save the country in being carers? (Robert, 612-616)

Barbara directly blamed her husband's death on the ways in which Social Workers behaved, in particular regarding care reviews "he … had a stroke and he didn't recover … It was the manner in which it was conducted that was very threatening to the future, the portent" (Barbara, 807-811).

Subtheme 2 Parents and Their Unwanted Identity as Fighters. Many parents felt forced into having to adopt identities of fighters as their relationships became characterised by battles against L.A.s, L.A. workers, Health services, Social Workers and service providers. This was considered to be unnecessary and hurtful as parents felt these organisations and workers should have been working with them, not against them. Many parents explained this was contrary to their way of being (in particular Teresa and Robert). Camille summarised:

> I think the main thing is to say that every time you go for funding it is an absolute fight, and you have to be a Tiger Mummy if you know what I mean, and really fight for everything that you can get. And I think if you're not that natured, it's very hard and it's very stressful. (Camille, 21-24)

Some parents inhabited the role of fighter by actively trying to subvert the new norms and systems set by workers. Three parents reported they had always had to fight for services but that this had worsened under austerity. Whether fighting was new or increased, parents fought new systems in various ways. Some took on identities of people who fought and advocated not only on behalf of their adult child but also on behalf of others. After attempting reasonable responses that had previously worked well, but now failed, some husbands and wives had responded by inhabiting dualistic identities they found to be most productive for reversing or challenging decisions about cuts. This usually involved the father being overtly angry and shouting in order to achieve positive results against cuts or attempted cuts "it was a constant battle … we used to have the … Mr Nasty and Mrs Nice … we had to" (Fred, 204-205).

Inhabiting the identities of fighters though was considered stressful, with some L.A. workers perceived to be unaware of the stress they caused in funding battles, even when overtly angry fathers ‘fighting back’ caused detrimental funding decisions to be reversed (Camille, Frances).

Subtheme 3 My Limited Social Networks Can Help me in my Fight. Robert summed up many parents’ feelings regarding their social networks in times of cuts, describing his networks as “very little” and being able to spend time outside of the family home as a “luxury” (Robert, 529, 447). Parents described having reduced capacity and time to maintain their social networks as cuts deepened. They described the ways in which the increased caring workload they felt cuts had affected their abilities to maintain their social networks, “I have no life. I go nowhere, see no one, apart from [name of friend] who I see very occasionally. I have no life. It’s not worth living.… I’ve got no energy left” (Janice, 1185-1188).

Some parents explained they did not feel the importance of having a social network was understood or appreciated by some L.A. workers, and when this was raised “they looked quite surprised ... it hadn’t actually dawned on them” (Dana, 108-110).

Several parents went further by suggesting that the cutting of support groups, networks and advocacy services which could provide parents with support in their fights, was a deliberate act by L.A.s in order to reduce parents’ abilities to fight back against cuts, thereby decreasing parents’ power even further. Cuts to these groups and services were felt to lead to further loss of social networks in terms of expertise and support (Barbara, Dana). Although social networks were typically very limited in times of cuts, they were felt to be important for providing “a little bit of ammunition” and support for fighting back against failing systems (Camille, 313). Parents who had access to networks explained this ‘ammunition’ included information, shared experiences, offers of advocacy and feeling supported and understood. Each parent gave examples of social network members offering support. These included other parents, friends, specialist disability legal services, staff in

Health services or approachable welfare staff and charity support groups. Parents felt this fight and the need for networks was important in the present and would remain important for the future.

Theme 5 What Hope for the future?

Parents explained their experiences of cuts in relation to their fears for their adult children's futures and had ideas for ways in which the future could become more hopeful.

Subtheme 1 Fear of the Future. Parents felt that in times of cuts, society at large did not care about their lives, and would not care about their deaths or the lives and deaths of their children. Services were considered to be on a downward trajectory in times of cuts, "better services are a mark of a civilised society, not this free for all of, you know, the free market and nature red in blood and claw" (Janet, 404-406).

This future where sons and daughters were left to fight alone in an uncaring world was a significant source of "fear" and "terror" when they considered what would happen to their sons and daughters when they as parents had died and could no longer mitigate the effects of cuts (Barbara, 729).

One response to this increased feeling of powerlessness for the future was described by parents who expressed feeling that in times of cuts they had no choice left to them except the murder of their sons and daughters and their own suicide. Camille spoke about this in general terms, while Barbara recalled distressing conversations with other parents in her social network. Teresa explained she had considered this course of action when she was left without any income and felt powerless to challenge the L.A. worker whom she felt had caused this. The impact of having social networks for her was lifesaving:

> And had I not had a daughter who was working, with a really lovely husband, [my disabled son] and I wouldn't have survived that six months. We very nearly came to going over [place name] Cliffs in the car. (Teresa, 614-616)

Subtheme 2 Ideas for a Better Future. Parents were pragmatic or fatalistic in their acceptance of the reality of cuts to services and money needing to be saved. Parents highlighted that previously positive changes were:

> absolutely, totally down to the groups who are actually struggling with that kind of oppression and have made great headways in making sure that people understand what it's like. And so, they will still have to continue that battle and fight [pause, gets upset]. (Barbara, 640-643)

Strategic and practical suggestions were made regarding opportunities for positive change. Parents felt a mutually beneficial and meaningful future was only possible if they and their sons and daughters were included at all levels of decision-making as equal partners and experts "and that we have good rational conversations about what that will mean in terms of their financial support" (Barbara, 620-621).

In terms of policy, the creation, development and maintenance of social networks were considered to be crucial. Involving powerful people with local knowledge (to whom L.A.s would feel obliged to listen) was considered to be an important way of being heard. Local support organisers or "lynchpin" people were suggested (Dana, 412). These would not be L.A. workers as they were perceived as having no local knowledge or expertise and no understanding of people with intellectual disabilities. Dana (433-434) explained "unless you have a team which knows the people they're dealing with, it's never going to be any better".

Practical solutions included L.A.s holding a database of carers, particularly carers of adults with intellectual disabilities, many of whom were felt to be unknown to Social Services. Parents were keen to be able to access and update this database themselves. It was felt this and annual checks on these parents could lighten the new excessive administrative burden on parents and give them the power and opportunity to correct inaccurate information. Parents also suggested services such as residential homes and Supported Living accommodation should be situated with easy access to activities their sons/daughters could enjoy and afford. The accessibility of services was considered vital for the social networks, relationships and wellbeing of sons/daughters with intellectual disabilities. Although parents' networks and support groups were at times considered less than perfect (Dana, Robert), their importance in the continuing fight for a safer society for the future was highlighted:

> we need to be allies with everyone that's in the business of providing care, and we should all be looking to the people we serve as the centre of all we do and the motivation for what we do … [to make sure] …That what we're producing is a society that we're not afraid to live in, you know [pause]. (Barbara, 737-742)

Summary of Themes

Analysis of parent interviews suggests that it was not cuts per se which had damaged the lives and identities of parents and their sons/daughters. Instead, it was the active adoption of an attitude or ethos of cuts by L.A.s, Health services and service providers which had caused parents to feel that the organisations and workers with whom they dealt no longer trusted them, understood them or cared about them or their sons/daughters. Parents considered that by adopting an ethos of cuts these organisations had at times unwittingly, but often actively, chosen to take actions which would negatively impact parents and their sons/daughters. The language of fighting and battle was used by parents throughout their interviews when considering their relationships with governments, L.A.s, Health services and service provider organisations. Analysis suggests parents made sense of the powerlessness they now felt in a range of ways, which included suggestions for improved futures where power was shared.

Discussion

This study had as its research question: "What are the experiences of parents of adults with intellectual disabilities regarding their own care and social networks and the care and social networks of their adult sons/daughters in times of austerity?". This study therefore analysed the lived experiences of adoptive and biological parents of adults with intellectual disabilities in light of the implementation of an ethos of cuts by governments, L.A.s, Health services and organisations. For parents, ‘governments’ related to successive or particular political parties who were or had been in power. The people leading and running entire political systems were felt to do so with a lack care and understanding. This approach was felt to then filter down through all systems and departments of both national and local government. Findings indicate that parents found their lives became harder under austerity policies, which were perceived to have led to losses in their relationships with L.A.s and workers and the loss of social networks for their sons/daughters. When they did have relationships, parents perceived these as being characterised by mutual mistrust. Parents described feeling powerless, being lied to and lied about by L.A.s. Parents also described their identities as being changed as a result of austerity, feeling they had to adopt identities of fighters in order to fight back against perceived attacks by L.A.s. Social networks were described as being diminished under austerity but as nevertheless helpful in these fights. Parents also discussed their hopes and fears for the future. Areas in which this study enhances the current literature are now discussed. These centre on policy and legislation, identities, adoptive parents, adversarial relationships and the future.

Policies and Legislation

Parents and academic authors have previously suggested that the *Valuing People* and *Valuing People Now* (DoH, 2001; DoH, 2009) policies had been helpful in progressing the need for support for people with intellectual disabilities and their parents (Gant & Bates, 2019; Shakespeare, 2013). This study goes further by suggesting that in times of cuts, parents felt it was not policies per se that could help or hinder their attempts to access support for themselves and their sons/daughters, but policy interpretation and implementation. Rather than feeling, “cautiously optimistic” about The Care Act (Gant & Bates, 2019, p. 432), parents in this PhD study actively criticised both The Act itself and its implementation. For parents comparing previous policies to The Care Act, previous policies had felt further reaching. The closure of institutions and move to living in homes in communities had been an important shift in policy. It may be that parents had expected The Care Act to provide further support for further moves towards more ‘ordinary’ lifestyles. They may also have expected the Act to be the tool they felt they needed in order to fight the effects of austerity they had experienced and to get further support for themselves and their sons/daughters. In this PhD study, parental perceptions of The Care Act were similar to those expressed in Hamilton et al.’s (2017, p. 295) study where parents did not trust policies which were felt to have gaps in their delivery and therefore be “irresponsible”. Parents in this PhD study identified gaps in The Care Act too: it held no weight as it contained no duty to provide services and did not provide effective external recourse for parents who felt it had not been appropriately applied.

This PhD study also suggests that parents felt the interpretation of what they considered to be a weak Act was also flawed. In their study, Fernandez et al. (2020) suggested budgetary pressures on L.A.s negatively affected the carers’ rights which The Care Act was designed to enhance, while Walmsley et al. (2017) had previously found that parents felt they were treated as though they had no expertise in their sons’/daughters’ care. Symonds et al.’s (2018) work found that both qualified and unqualified Care Act assessors regularly made false assumptions about the abilities of people with intellectual disabilities and then regularly excluded them from support. This PhD study develops these ideas further, highlighting the ways in which in times of cuts The Care Act appeared to parents to be actively ignored or misinterpreted by L.A.s in order to make cuts. Parents felt failed by the ways in which reassessments under The Care Act were undertaken. These assessments related both to parents and their sons/daughters. In addition, this current study suggests that some parents felt they were experiencing a deliberate strategy of unrealistic assessments brought about by the adoption of an ethos of cuts. Instead of “inadvertently” (Forrester-Jones, 2021, p.109) resulting in less parents seeking support, this current study suggests that parents strongly felt that in times of cuts not only assessment systems, but also the many other systems they now had to negotiate were barriers deliberately designed to stop them getting support of any kind.

This finding is aligned to those of Wolfensberger et al. (1972), Goffman (1991) and O'Brien and O'Brien (2000). This study suggests that despite the promises of The Care Act, the adoption of an ethos of cuts meant some parents were experiencing a regression back to institutional attitudes and policies, so no longer felt they or their sons/daughters were valued people. More widely than in previous studies, analysis in this PhD study therefore suggests that austerity was perceived as a failed ideology which negatively affected both policy and practice.

This specific focus on the lived experience of austerity as a failed ideology is not well-documented elsewhere, nor is the lived experience of parents of adults with intellectual disabilities explaining the ways in which they felt they and their sons/daughters had been failed at governmental, local and personal levels.

Identities

Analysis of the parental experiences in this study regarding reassessment can also be linked to perceived identities. In terms of identities, in the 1960s Goffman (1990a, 1990b) explored the concept of “passing” which he defined as "the management of undisclosed discrediting information about self" (1990b, p. 58). He explained in relation to identities and social interactions, it is not an attribute in itself (intellectual disabilities for example) which is creditable or discreditable. Neither is it the attribute itself which causes others to behave towards individuals in ways which are positive or discriminatory. Instead, Goffman suggested it is the social meanings which are ascribed to different attributes which then influence the ways in which individuals think about themselves and others, and subsequently how they behave towards themselves and others. Goffman suggested stigma therefore was relational; created in interactions between people and meanings.

Edgerton too considered the importance of “passing” or wearing a “cloak of competence” for people with intellectual disabilities and their families in his 1960s research and as he revisited these participants over time (Edgerton, 1993). Edgerton's cloak can be spread more widely to encompass views and experiences of parents' feelings and dilemmas in times of cuts. There were negative effects on identities when parents and their sons and daughters were reassessed as ‘passing’; as people who were competent and could therefore cope when support was cut. Identities of parents could be affected when they felt they were consistently not ‘seen’ as people in need of support, and repeatedly felt uncared about and mistrusted when they asked for that support.

Adoptive Parents and a Sense of Unfairness

Although some studies have considered the needs of families who adopt children with ‘special needs’ (such as Good (2016) and Perry and Henry (2009)) there is little current research on the daily lived experiences of parent carers who have adopted their now adult sons/daughters with intellectual disabilities and are living in times of cuts. This study included three parents of adopted sons/daughters. Analysis in this study has suggested that adoptive parents may feel they have been treated particularly unfairly if they perceive themselves as having saved the State many thousands of pounds but were getting little or no support in return. The lived experience of reciprocity or its lack between adoptive parents of children who are now adults with intellectual disabilities and the State is also worthy of greater study in order to better understand the experiences of this group.

Adversarial Relationships

This study has suggested that in times of cuts, parents in this study experienced a significant shift in the nature of relationships with workers from one of trust to an adversarial relationship characterised by mutual mistrust. Previously Kam (2014) found that Social Workers were considered by parents to be gatekeepers who had lost their focus on social justice and Wilkins (2015) found that Social Workers saw parents’ requests as excessive. Analysis in this PhD study suggests that parents of adults with intellectual disabilities too have found this to be the case. In addition, in times of cuts, governments, L.A.s and Health services at a strategic level were also considered to have no feelings of reciprocity or empathy for the lived experiences of parents or people with intellectual disabilities. This study found that instead, an ethos of cuts had meant at all levels parents of adults with intellectual disabilities felt either ignored or actively targeted for cuts. Walmsley et al. (2017)

reported that restricted budgets negatively impacted families and led to workers ‘actively diminishing’ parents. This study goes further by suggesting that the active adoption of an ethos of cuts had fostered an environment where many parents felt they had been actively lied to and lied about by workers. Several parents in this PhD study felt they experienced this when they complained or were felt they had been judged to be untrustworthy. This PhD study suggests that in times of cuts, active diminishment had for some parents become active punishment.

This study also extends the literature on parents feeling the need to fight (Ryan & Runswick-Cole, 2008). Analysis suggests that for parents of adults with intellectual disabilities in times of cuts, social networks although diminished, were important as providers of ammunition and in interpretations of the nature of systems and workers as opponents. L.A.s and Health services on a strategic level, and workers on a practical level, were felt to be adversaries, who were seen as either incompetent and unaware of the consequences of their actions, or highly aware that their actions ‘hurt’ parents and people with intellectual disabilities, and yet continued with those actions. Analysis of parental responses in this study also adds to the literature on these relationships by considering the way parents at times may battle their opponents by using gendered identities to fight for services in times of cuts.

The Future

This study has also explored the ways in which parents felt failed in their expectations of governments, L.A.s and Health services. As in other studies (such as Pryce et al. (2017) and Weeks et al. (2009)), parents in this PhD study reflected on their future planning and their fears regarding who would provide care for their sons/daughters as parents aged and died. This PhD study analysed the ways in which parents framed their futures in relation to feeling they and their sons/daughters were uncared about by governments, L.A.s, Health services and wider society. The adoption of an ethos of cuts meant that parents of adults with intellectual disabilities feared the future. They felt the organisations and structures which they had previously expected would support their sons and daughters after they themselves had died, were being constantly and deliberately dismantled.

Analysis of parents' responses also highlighted a wide range of possibilities regarding the ways in which the fundamentally flawed ideology of austerity and ethos of cuts could be addressed at social, governmental, local and practical levels, whilst still providing parents and people with intellectual disabilities with appropriate and cost-effective support. These add to the suggestions already reported in the small amount of published literature regarding the daily lived experience of this group, such as the importance of listening to parents as experts and working in partnership for better outcomes (Forrester-Jones, 2021). The desire to be heard may be a response to the powerlessness parents appeared to feel in times of cuts. Use of important social network members could therefore be a way for parents to vicariously get their voices heard via allies perceived by L.A.s as more powerful than parents.

This study has highlighted the ways in which parents of adults with intellectual disabilities could experience cuts to care. Analysis of these experiences has suggested that the perception of an active adoption of an ethos of cuts could have negative impacts on many areas of parents' care and social networks, and the care and social networks of their sons/daughters. Perceptions of deliberate and active distancing in social and personal relationships by L.A.s, organisations and workers in order that cuts could more easily be made, could leave parents feeling their only option was to fight back against their more powerful adversaries. Social networks were being diminished as a result of cuts but could at times be the only weapons parents felt they had in their defensive armouries.

Limitations

As with the majority of studies, the design of the current study is subject to limitations. In terms of sampling, parents in this study, as with many studies, could choose whether or not to take part. They were all dissatisfied with their experiences, some but not all had relevant professional backgrounds and were experienced as advocates for others. All were able to make time to be interviewed. This may have skewed the study towards parents who were articulate, used to fighting for services and who had a grasp of strategic and practice issues. These participants may also have been more likely to want to take part as they were dissatisfied with services for themselves and their sons/daughters. This dissatisfaction had for some parents existed for almost the lifetimes of their sons/daughters. For others this was more recent and had been experienced only since a crisis had arisen and they had found additional support was needed. In meetings where participants were invited to take part in the study, several parents reported they did not have time. Future studies would need to address ways in which this barrier to research inclusion could be overcome.

A different study which included parents who felt they had had a different range of experiences may have produced different results, as may studies which included parents without professional backgrounds, and those which included parents from a wider range of ethnic and socio-economic backgrounds. This study was a small qualitative study, and the aim was to attempt to grasp the meanings that participants gave to their experiences. Future studies which provide further insights into the experiences of parents of adults with intellectual disabilities, including adoptive parents of adults with intellectual disabilities, across different geographical and L.A. areas would be beneficial.

As has been highlighted, this study includes two fathers. One was a biological father, the other an adoptive father. Future qualitative studies which include fathers of adult sons/daughters with intellectual disabilities are needed in order to enhance understandings of their (rarely reported) experiences.

Reflexive Considerations

Braun and Clarke (2021) suggest reflexive considerations should include personal and professional positioning, a consideration of values and reflection on the process of undertaking and writing the research. These are briefly examined below.

Memos and reflections on my work with parents suggest that my personal and professional positioning were important in how I interpreted and then presented my interpretations of their stories.

I realised during the analysis stages that I had begun to give additional weight to the parts of parents' stories I found to be the most 'heart-breaking', believing these to be the most important to parents. These were often the parts of their stories where they, or both of us, cried. I reflected that I had expected parents to be angry. I had not expected to feel such a connection to parents or to feel their frustration, desperation and grief around their situations. This of course influenced my coding in a new, far more emotionally engaged direction than I had expected. It took time to become used to this as something to be embraced, rather than pushing it away, as if creating distance from the emotions of the data was a more 'valid' approach, which would hold more weight with readers of my work. Recognising the intimate nature of the research relationship has been a key part of reflexive research for some time (see Horsburgh (2003) and Pillow (2003) for example). This engagement with participants and their data enabled me to recognise that emotional and intellectual reactions to participants can themselves be sources of knowledge (Mauthner & Doucet, 2003).

Professional positioning influenced my choices too. As previously having managed residential care homes for people with intellectual disabilities, I had often interpreted parents' anxieties about their adult sons/daughters as overprotective. Many parents had been told their adult children would always remain as children, and those parents often treated their adult children as toddlers. Being in the role of manager meant my sole focus was not parents but the adults with intellectual disabilities, for whose care I was legally responsible. There was a gulf between the ways in which parents and I saw their adult children.

As a researcher, I realised I could listen to and engage with parents in different ways. The parent(s) in the interview was/were my sole focus. I had no responsibilities towards their adult children, so could engage with parents without the ‘legally responsible manager’ lens. I could listen and hear their stories and experiences and give priority to parents and their experiences. My responsibility was to them only. In this role, I interpreted no parent as overprotective. Instead, I found parents wanted a ‘normal’ life for their sons/daughters. This gave me a type of relationship with parents and a depth of appreciation for their circumstances which I had not previously experienced.

Soon after I started the interview stage, I was invited by a parent carer forum manager to speak to parents and invite them to take part in the research. Despite not having a child with intellectual disabilities (or any children at all), I was warmly welcomed into this group. I interviewed one parent, and this snowballed over time to include some other members of the group. I am still attending, listening to their experiences and providing information where I can. I take this to be a sign of continued trust which adds another dimension to my relationship with these parents, long after the interviews for the research project had stopped. I am still invited and welcomed into this part of their lives.

Implications for Research, Policy, Practice and Families

By working in partnership to better understand parents as experts, and people with intellectual disabilities as people in need of support, policymakers could enhance current and future relationships whilst creating financial savings. Recognition of the damage some parents felt had been done by the adoption of an ethos of cuts could also aid the rebuilding of partnership working for mutual benefit. Joint understanding of the importance of partnership, working for long-term, effective, timely support in order to prevent crises in parental health, and in the support needs of people with intellectual disabilities could be beneficial. For practitioners, a focus on meaningfully assessing and meeting the needs of whole families, by working in partnership with parents as experts in their sons’/daughters’ care could aid the creation of mutually beneficial solutions. Building bridges to partnership over the current battlegrounds of practice may help to gain back lost trust and lead to better working relationships between all parties.

For families, becoming part of a supportive network was seen by parents to be key to survival when experiencing cuts to services and trying to fight these cuts. Although typically small, their potential to create spaces for support was considered to be important.

Conclusion

This study has suggested that parents of people with intellectual disabilities could experience cuts to services, care and support in ways which caused them to feel harmed. Parents in this study felt that they and their sons/daughters had their identities spoiled by the adoption of an ethos of cuts. Previously positive relationships with governments, L.A.s, Health services and Social Workers had become spoiled by active distancing, resulting in a lack of empathy, lack of reciprocity and mistrust. Relationships which had previously been considered to be negative were reported as worsening as austerity policies were enacted. These relationships were now experienced as battlegrounds in which parents felt they must fight against attacks, which included cuts to basic support and personal attacks against them and their adult children. Social networks were felt to have been crucial in providing parents with ammunition for these constant battles. These networks and a desire for partnership working were reported as being important for a sense of hope for a safer future.

The importance of parental perspectives on the experiences of austerity on their own lives and social networks, and the lives and social networks of their sons/daughters, included their perspectives regarding funders and service providers. Service providers' experiences of austerity and their relationships with funders are also worthy of consideration. It is therefore to this group that the next chapter turns.

Chapter Five Results From Study Three: Thematic Analysis of Service Provider Experiences of Care, Relationships and Social Networks in Times of Austerity

This study aimed to explore the experiences of 'service providers' (including a Chief Executive Officer, a Treasurer, managers and a government worker) in relation to their experiences of care and relationships, and the care and social networks of the adults with intellectual disabilities whom they supported in times of austerity. This consisted of analysis of semi-structured interviews with providers of services.

The background section will be used to highlight the lack of research in this area. Very few studies were found which considered the experiences of care, relationships and social networks on the lives of people who provided services in time of austerity, or their views on the care and social networks of people with intellectual disabilities. This section will also make suggestions regarding the applicability of related research to this group and topic area. The methods used for data collection and analysis will then be considered. The results of thematic analysis of the data will be presented, followed by a discussion regarding the analysis of the results. Results highlighted the differences in the ways in which care can be understood, and the effects of feelings of loss and of powerlessness. Conclusions and recommendations regarding policy, practice and families are suggested.

Background

Social networks can contain a range of people including professionals and service providers, who may be in contact regularly or occasionally. Social networks can often rely on the provision of care via a range of staff and services in order to function well (Murphy et al., 2017). People with intellectual disabilities themselves often include staff in their social networks, and these staff can be fundamental to the successful development and maintenance of those networks (The Money, Friends, and Making Ends Meet Research Group c/o Liz Tilly, 2012).

Financial cuts to services and welfare systems as a result of the Global Financial Crisis in 2008 have negatively impacted on many aspects of the lives of disabled people, including people with intellectual disabilities (UN Committee on the Rights of Persons with Disabilities, 2016). Some small research projects have begun to consider the effects of continuing reductions on some of the services and opportunities provided to people with intellectual disabilities. McConkey et al.'s (2018) research suggested for example that one effect of austerity measures in Ireland was that people with intellectual disabilities were having to live with their ageing parents for longer, as funding for new residential home placements was reduced. Malli et al. (2018) in their review of 11 studies found that the wellbeing of people with intellectual disabilities, and that of their parents, could be negatively impacted by austerity, as did Forrester-Jones et al. (2021). Bates et al. (2017) found that paid work opportunities for people with intellectual disabilities could become more precarious as cuts were made to welfare. Other research has considered the impact of relationships between staff within services; staff and their employers; and less frequently the relationships of staff with people with intellectual disabilities (Beadle-Brown et al., 2015; Mansell, 1996). Much less research relates to relationships between leaders, managers and specialist providers of services ('service providers') and the funders of their services in the U.K. or globally. In Canada, Courtney and Hickey (2016) found workers responded to cuts to their wages, as a result of austerity, by forming coalitions linked to unions. In Greece, healthcare workers battled austerity by trying harder to continue to provide high-quality services for individual patients (Kerasidou et al., 2016). Current available U.K.-based research which can be related to service providers' experiences of care in times of austerity is considered below.

Care as a Moral Activity

The adoption of austerity measures, where care and welfare budgets are seen as expenditure to be cut for the greater good, is one of many ways of understanding how societies should function. However, cutting or withdrawing care and hoping or assuming that this will force people to fend for themselves does not mean that they will be able to (Power, 2008). 'Care ethics' approaches are different way of considering societal functioning, recognising the fundamental value of human relationships and emotions for ethical and moral decision-making. This can be at global, national, local and personal levels. Kittay (1999) described a model of caring relationships which promoted the need to understand care as ethical action in the pursuit of social justice, understanding and meeting the needs of others in ways which were meaningful to each person in any care relationship. Herring (2013, p. 57) also highlighted the importance of caring relationships within service provision, suggesting “emotions are central to good care”.

‘Care ethics’ challenges the individualistic, mechanistic and distant approaches often taken towards political, social and financial decisions. Instead, it requires consideration of the ways in which societies could be overhauled in order to achieve caring relations at all levels and in all social and political spheres (Gilligan, 1993; Held, 2006; Noddings, 2013; Tronto, 2013), actively including people with intellectual disabilities and those in their social networks (Rogers, 2016).

There are practical barriers to working in these ways, however. Having a desire to help others in need may not necessarily mean that this desire will translate into excellent care (Wolfensberger et al., 1972). In addition, employers’ understandings of care which do not recognise the importance of care as a meaningful moral activity, can negatively affect staff members’ abilities to engage in reciprocal relationships with people with intellectual disabilities (Green & Lawson, 2011). Lack of focus on care as a relationship-based, moral activity can also negatively affect people with intellectual disabilities. When care moves from being a moral activity to being commodified, inequalities, suffering and vulnerability can be obscured (Bates et al., 2017; Bowden, 1999; Clapton, 2008; Lolich, 2017). In times of cuts therefore, exploring the nature of care and relationships between employers, staff and people with intellectual disabilities is essential.

Organisational-level Care Relationships

Research is available which considers organisational-level leadership and management relationship styles and cultures in a range of settings. These are typically in business but also occasionally in health and social care settings, where some research considers relationship styles and cultures in organisations which support people with intellectual disabilities. In their review of 14 papers, Iacono et al. (2014) for example suggested cultures within hospitals can work against the safety of people with intellectual disabilities and can be linked to institutional discrimination. In Bigby et al.'s (2009) and Beadle-Brown et al.'s (2015) research, organisational culture was found to affect the quality of life of people with intellectual disabilities. Differences between the value-base of managers and the value-base of the organisation for whom they worked were found to be a key indicator of underperforming homes, whereas leaders whose values aligned with the value-bases of the organisation were found to relate to person-centred, enabling approaches. In 2022 Humphreys et al. found that effective collaboration between managers and staff, and an understanding of one another's roles, were important but rarely researched topics within intellectual disability services.

Meaningful, mutually reliant professional relationships have been found to be fundamental to positive identity in health and social care (Holmesland et al., 2010). Managers' and leaders' relationships with staff are perceived as crucial for effectively supporting people with intellectual disabilities in person-centred ways (Deveau & McGill, 2016).

Having a sense of power in one's role is reported as important in literature regarding organisational-level relationships. Ryan et al. (2021) found managers experienced less stress than frontline workers suggesting this could be because managers had more power. A lack of positive working relationships can negatively affect the ability of leaders, managers and staff to maintain and use power to enhance their own wellbeing and the wellbeing of people with intellectual disabilities whom they support. Workers appreciate feeling they are valued and that their relationships with their employers are in some way reciprocal (Beadle-Brown et al., 2014; Beadle-Brown et al., 2015). Gray and Muramatsu (2013) found that workers who felt they had some form of control over their working environment were more likely to be able to demonstrate self-advocacy. Managers taking the time to ensure staff were empowered to understand the value-bases behind policy has been found to be essential in ensuring person-centred policies are enacted in practice (Northway Davies et al., 2007). Gridley et al. (2014) suggested that an ongoing and stable cross-organisation approach was required in order that the quality of person-centred practice would not be jeopardised as financial constraints put pressure on service delivery. Higher levels of work overload and burn-out have been associated with reported intentions to leave a role, often linked to a perceived lack or loss of expected reciprocity between workers and people with intellectual disabilities (Rose et al., 2010; Thomas & Rose, 2010).

Powerlessness has been highlighted when considering relationships and ways of working which were empathic to the needs of people with intellectual disabilities in therapy settings (Webb-Peploe & Fredman, 2015; Clare et al., 2017), and in relation to communication in health settings (Ziviani et al., 2004). Feelings of powerlessness could also lead to the depersonalisation of care and support (Thomas & Rose, 2010). It is therefore of concern that managers have reported their largest challenge in providing person-centred care to be funding and budget cuts, which can result in a lack of funding for activities, transport or even food. Budget cuts can also negatively impact on managers' abilities to lead organisations and to undertake or offer staff training (Bradshaw et al., 2018). This literature suggests that managers and staff who see care as a moral activity can feel powerless in some of their relationships and roles.

Frontline Staff and Care Relationships

Research which considers the experiences of frontline workers in their relationships with people with intellectual disabilities has tended to cover specific issues or areas of work. In end-of-life care for example, a lack of understanding by organisations about the depth of staff relationships with people with intellectual disabilities can worsen staff feelings of loss when people with intellectual disabilities die or move away from a service (Hussain et al., 2019; McEvoy et al., 2010). Other research has aimed to measure and improve the quality of life of people with intellectual disabilities (Donnelly et al., 1997; Gregory et al., 2001; Perry et al., 2011). Research related to the evaluation of interventions designed to enhance staff relationships with people with intellectual disabilities has begun to consider staff members' perceptions of those relationships (Johnson et al., 2017). This has often been in the context of trying to understand interactions when people with intellectual disabilities have significant needs or exhibit behaviours that challenge staff and services (Emerson & McVilly, 2004; Friedman, 2021; Ryan et al., 2021; Stevens et al., 2021). Gridley et al. (2014) argued that long-term trusting relationships between staff and the people they supported enhanced the ability of staff to meet the needs of people with severe and complex conditions and behaviours.

These long-term relationships could help to turn the rhetoric of personalisation policy into meaningful practice. However, the most committed workers in intellectual disability services have been found to be those who were most likely to experience stress and burn-out (Stevens et al., 2021). In both Stevens et al.'s (2021) review of the literature on the stress levels of staff working in intellectual disability services and Simons et al.'s (2021) review of literature regarding relationships experienced by these workers, relationships which had a level of reciprocity between staff and people with intellectual disabilities were found to be less stressful than those which were characterised by staff's fear of violence and feelings of inequality in their wider organisational relationships. These vital relationships between staff and people using intellectual disability services may be under further threat in times of cuts.

The little research which exists regarding relationships between service providers and funders of services however has suggested that both commissioners and senior managers of services have previously been considered to be uninterested in improving the quality of life of people with intellectual disabilities (Mansell, 1996). Service providers have previously reported that in times of financial restraint, the interdependency which they felt should be "at the heart of social relationships" between all people and organisations involved in the support of disabled people could be lacking (Harris & Roulstone, 2011, p.111).

Aim

As the concept of societal interdependence and the relational nature of care becomes more apparent (Power & Bartlett, 2019; Rogers, 2016) the ways in which different people and organisations interact in care relationships in times of austerity is worthy of greater scrutiny. The experiences of service providers as they try to negotiate these care relationships, run their services and support the lives and social networks of people with intellectual disabilities in times of cuts is therefore of interest. As has been shown, there appears to be little research which considers the perspectives of service managers, C.E.O.s and specialist workers ('service providers') in intellectual disability services and their relationships with funders and with people with intellectual disabilities in times of cuts. This current study therefore aims to add to this small body of literature by investigating the experiences of service providers when cuts are made to the care of people with intellectual disabilities whom they support. This study had as its research question: "What are the views and experiences of service providers regarding their relationships with funders and with people with intellectual disabilities regarding care and social networks in times of austerity?".

Method

Holstein et al. (2013) suggested that semi-structured interviews provide opportunities for qualitative data to be gathered in ways which can be meaningful to both participants and researchers. In keeping with a qualitative approach, semi-structured interviews were chosen as an appropriate method to best gather data regarding the experiences of providers (discussed in Chapter Three: Methodology).

Inclusion criteria were that participants had to be working or volunteering in an organisation which supported adults with intellectual disabilities and have a role which was not frontline (working wholly directly with people with intellectual disabilities). Nine participants were interviewed in seven semi-structured interviews between September 2017 and February 2019. Interviews took place with participants individually or with participants in pairs, depending on their wishes. Five interviews were with individuals (GA, NWP, SR1, SR2, SA) and two interviews were each with a pair of participants (ST1&2 and SV1&2). All participant interviews were audio-recorded except for SV1 and SV2. As per their wishes, notes only were taken and later agreed with those participants. Questions centred around participants' experiences of cuts to care, support, services and welfare for people with intellectual disabilities. Participants were not asked about their length of experience or their level of qualifications. Interviews lasted from 20 minutes to 1 hour 39 minutes and were arranged at a time and place of the interviewees' choosing. Total interview time was 9 hours 54 minutes and the average length of the seven interviews was 1 hour 36 minutes. Information forms, consent forms and de-brief forms were provided (as per the forms for parents). Indicative interview questions are provided at Appendix C Form C1. These were agreed with the research team and the ethics panel to be deliberately broad as it was service providers who had come forward to express their experiences.

Recruitment and Sampling

National and local charities and groups were contacted by email, and groups of disabled people, families and organisations were visited, in a call to recruit people with intellectual disabilities to take part in a wider project regarding austerity and its effects on people within this group, and their families. During this process, nine service providers also asked to be interviewed in order that their views also be understood. I did not set out to interview service providers. However, as they were keen to share their understandings of the effects of austerity in themselves, their organisations and the lives of people with intellectual disabilities whom they supported, it was felt that their views would have value and add another dimension to the research study. All bar one service provider expressed the view that they felt the research would gain an inaccurate view of the effects of austerity if it relied only on the views of people with intellectual disabilities. Eight service providers were gatekeepers who had provided access to people with intellectual disabilities for this PhD study. These service providers felt they wanted to share their views that if people with intellectual disabilities were stating that services were the same under austerity, and that austerity had had no effect on them, this was not because austerity was having no effect. Instead, service providers stated they were working harder to fundraise and were making cuts elsewhere in order to try to protect frontline services. They also felt that if people with intellectual disabilities were sharing their displeasure that services were declining in any way, then this was because service providers had cut everything else they could cut and had been forced to now cut these frontline services. The one service provider who did not act as a gatekeeper was keen to take part to share his experiences of trying to raise awareness in a government welfare department of the needs of people with intellectual disabilities in times of austerity.

Cambridge and Forrester-Jones (2003) have highlighted that information sheets which include a photo of the researcher are good practice; I therefore used my photo in the information sheets I produced. Before each interview, informed consent was gained from each participant. Participants were informed that they could withdraw consent at any time up until their data had been anonymised, that there was no obligation to take part and that taking part or not would not affect their charity/organisation. Participants were made aware that if they disclosed any issues of serious concern, this would be discussed with my supervisors and possibly Social Services and the Police.

Table 4

Service Provider Characteristics

Participant pseudonym	Role	Location	Organisation Type	Interview Type
NWP	Manager.	Northwest England. Small, deprived town.	Charity signposting and information service.	Lone.
ST1	Treasurer.	South England. Large, deprived town.	Charity providing services to people with intellectual disabilities.	With ST2.
ST2	Job Club Manager.	South England. Large, deprived town.	Charity providing services to people with intellectual disabilities.	With ST1.
SV1	Residential Home Manager.	South England. Rural location near a small, deprived town.	Charity providing services to people with intellectual disabilities.	With SV2.

Participant pseudonym	Role	Location	Organisation Type	Interview Type
SV2	Residential Home Deputy Manager.	South England. Rural location near a small, deprived town	Charity providing services to people with intellectual disabilities.	With SV1.
SR1	Supported Living Service Manager.	South England. Rural Location.	Charity providing services to people with intellectual disabilities.	Lone.
SR2	Chief Executive Officer.	South England. Rural Location.	Charity providing services to people with intellectual disabilities.	Lone.
GA	Government agency worker.	South England.	Government agency.	Lone.
SA	Theatre Company Manager.	South England. Affluent city.	Theatre company charity.	Lone.

The burden was minimised by offering breaks and ensuring interviews were timed to suit participants. Participant characteristics are included in Table 4.

Measures

Service providers were interviewed face to face in semi-structured interviews. These were audio-recorded where possible and written notes taken for those who requested that approach. Questions centred on their experiences of cuts for themselves and the adults with intellectual disabilities whom they supported.

Analysis

Thematic Analysis was chosen as the most appropriate method of analysis for this study, in order that the ways in which service providers experienced their relationships within their own lived social worlds could be illuminated. Thematic Analysis offers the opportunity to understand experiences as interpreted through participants' own biographies and stories, through a process of self-reflection (van Manen, 1996).

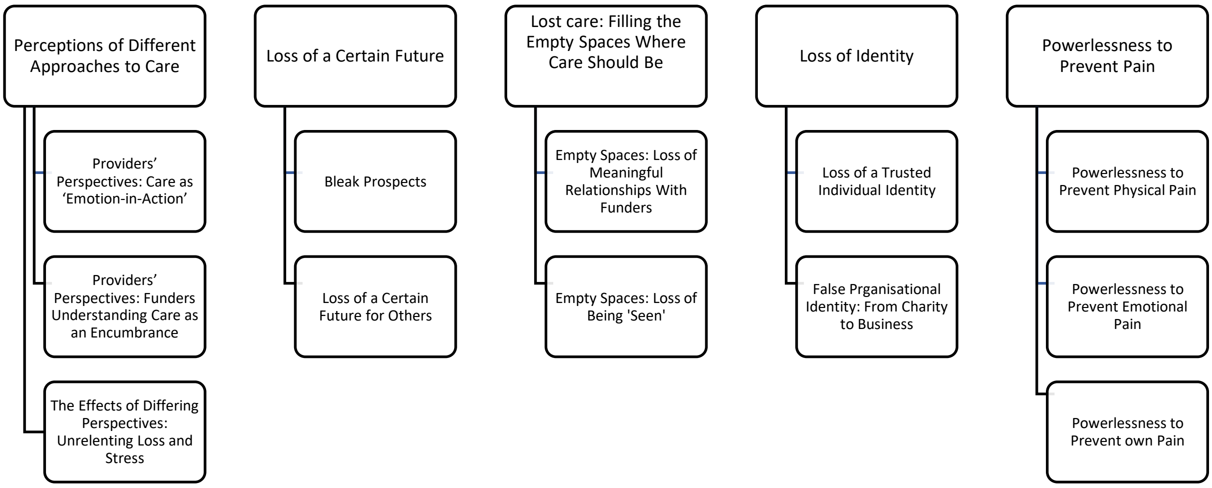
As in Study Two (Chapter Four), Braun and Clarke's six-step process was applied to the analysis of the data collected in this study. Themes were created which served to answer the research aim and to highlight the complex nature of providers' relationship experiences in times of cuts. This process is discussed in the Methodology chapter (Chapter Three) and in Study Two (Chapter Four). The same processes were used for the analysis of service providers' experiences in this third study.

Results

Interlinking themes which emerged from the participant interviews are presented below. Themes were included only if they were present in 100 % of the sample. Figure 7 shows the themes and subthemes. Themes were Perceptions of different approaches to care; Loss of a certain future; Lost care: filling the spaces where care needs are not commissioned; Loss of identity; and Powerlessness to prevent pain. Subthemes are presented within these main themes.

Figure 7

Service Providers Themes and Subthemes



Theme 1 Perceptions of Different Approaches to Care

This theme suggested a fundamental shift in the ways in which service providers felt they, and the people with intellectual disabilities whom they supported, were perceived by others in times of austerity. This was particularly prevalent in their accounts of their perceptions of deteriorating relationships with funders. Analysis of their experiences suggested two differing approaches to understanding care which had come about as austerity measures progressed. The understandings of service providers and those of funders were considered by service providers to be in diametric opposition to one another, and the cause of significant stress, distress and loss. These perceptions are considered below.

Subtheme 1 Providers' Perspectives: Care as 'Emotion-in-Action'. Service providers felt they understood care as emotion-in-action, as a 'way of being' linked to their identities which involved emotions of compassion and concern leading to *action.* For them, care was a virtue, a moral responsibility which had personal value (SR1). Providers in this study gave many examples of the ways in which this compassionate, virtuous and moral understanding of care was demonstrated as emotion-in-action "very sort of person centred even in the, you know, face of challenging financial times" (GA, 118-119). Service providers often measured the effects of the caring actions they took in the improving interpersonal skills and abilities of people with intellectual disabilities, which in turn gave pleasure to providers (NWP, SR2, ST1&2). Small but significant acts of care by service providers and their staff included creating voluntary or occasionally paid employment opportunities for people with intellectual disabilities when these were lost due to cuts (SR2, ST1&2). Service providers described trying to continue to address everyday needs, such as trying to maintain regular social networks, budgeting "appointments, shopping, washing, household tasks, keeping up their tenancy, all of these things you know that everyone else takes for granted that they need support with" (SR1, 607), when support for these activities was cut. These acts had importance to those undertaking them, as well as to those whom they supported. Emotion-in-action activities which tried to meet the emotional and relational aspects of people's social network needs were also described "At Christmas several older people here have no family so staff go to … charity shops and buy four gifts for four … older people who have no families" (SV1&2, 26-27).

Their perceptions about funders are described below.

Subtheme 2 Providers' Perspectives: Funders Understanding Care as an Encumbrance. Funders were perceived by service providers as seeming to have slipped from any shared understanding of care as emotion-in-action into experiencing care as an emotionless financial encumbrance:

> eligibility criteria under the Care Act specified outcomes perhaps are being more and more scrutinised in terms of how they're interpreted, and more imaginative interpretations are … [used to] … justify why someone may not be eligible for, say, a supported employment service. (GA, 18-21)

All the providers in this study suggested that their own experiences of providing care with emotion were of no relevance or value to funders "care should be person centred, now they are trying to say it can't be person centred" (SR1, 376-377). The nature of assessment was felt to have changed under austerity policies. Reassessment under The Care Act was seen as a cost-cutting tool as opposed to a tool for actively assessing and meeting need "it's all about the money in the budgets" (GA, 45). Reassessment measures used by L.A.s to decide whether or not a person with intellectual disabilities kept, lost, changed or maintained their support were felt to measure nothing of value to either service providers or people with intellectual disabilities. Instead of holistic support, which included the importance of regular contact with social networks members for example, reassessment under The Care Act was felt to be limited to assessment of predefined support 'tasks', which were described as predefined by L.A.s and being measured only "in minutes" (SR1, 173). Providers felt these quantitative measures were created only in order that support could be cut. Providers felt these 'tasks' were instead being pushed onto others, for example family or staff members. This included undertaking online banking on behalf of, rather than with, people with intellectual disabilities, as this was less time-consuming and therefore less expensive for L.A.s than paying staff to accompany people to the bank (SR1, NWP, GA, SR2). Delivery of time-limited personal care was at times agreed, but not support with mental health, physical health, prompts to maintain personal care and hygiene, tenancy issues, relationship and social network issues, abuse issues or hate crime (SR1, NWP, GA, SR2). In terms of experiences of social networks in times of cuts, ST1 explained "the one-to-one support work that we do is for social interaction, it must be the most vulnerable aspect" (ST1, 206-207). These seemingly emotionless reassessment measures were considered to be undoing decades of progress in policy and practice:

> there is a real risk that if we sort of accept what's happening now as the norm, that we will just go backwards and people with learning disabilities will not be full members of our society, they will be second-class citizens that are forgotten and not cared about. And I think that would be just a terrible retrograde step. (SR2, 414)

The differences in perspective were summarised by ST1 "it's a very labour-intensive activity I would say and the reward would seem very minimal from a funder's point of view but from an individual's point of view it would make a world's difference" (ST1, 450-452).

This, "world's difference" then formed part of the emotional activity of care which service providers felt added meaning to their own lives and the lives of people with intellectual disabilities. Service providers' feelings that funders lacked engagement with this perspective of care meant unrelenting loss and stress could be experienced by service providers.

Subtheme 3 The Effects of Differing Perspectives: Unrelenting Loss and Stress. The constant pressure that service providers described feeling, while trying to meet people's needs in innovative ways in situations of extreme stress, was experienced as taking a toll on providers in many ways. Austerity was experienced painfully by providers who described the perpetual feeling of "a thousand cuts happening in small slices" (SR2, 225). The sense of constant and accelerating loss and stress was substantial:

> I call here the magic porridge pot of misery because that's how it feels. It's a constant [pause], no matter how hard you work and how difficult things are, and how hard you try, it never ever ends and actually, it keeps coming faster and faster and faster. (NWP, 1000-1004)

The knock-on effect of a focus on budgets meant that cuts were interpreted by service providers as "a constant battle to keep the costs under control" (ST1, 165-166).

Cuts were felt to have led to significantly more administrative work for providers in their daily battles with L.A.s for funding, particularly in relation to paperwork repeatedly required by L.A.s for new data management systems "it's absolutely mind-numbing", and service providers chasing L.A.s for thousands of pounds of unpaid invoices "it's an absolute nightmare" (SR1, 790, 381-382). The future of even financially secure services was described as needing to be constantly fought for "very strongly" (SA, 581). Providers explained the constant pressure on their wellbeing, which meant even news of a successful fight against a cut felt like "a stay of execution, rather than a final decision" (SR2, 129).

This stay of execution meant that the future was not considered to be at all secure by service providers, which added to their sense of loss. It is this theme which is considered next.

Theme 2 Loss of a Certain Future

Another of the losses which this study highlighted was the way in which service providers equated cuts with a bleak future, replacing their previous assumptions of a fairly secure future for people with intellectual disabilities. They described the ways in which a future, where people with intellectual disabilities would be cared about by a society and by social systems that felt any form of responsibility towards them, was being lost.

Subtheme 1 Bleak Prospects for People with Intellectual Disabilities. Service providers felt their plans for the future had gone from relatively secure to “uncertain” during austerity, in addition to their broader “general uncertainty about of course the whole population, certainly throughout the government as to how it’s going to pan out” (ST1, 510-512). The expectation of a caring society which would protect people with intellectual disabilities from future abandonment was felt to be slipping away by service providers “all of a sudden, they’ve not got that support, but are expected to look after themselves …. I’m just waiting for something really bad to happen” (NWP, 57-60). Providers felt that cuts placed the responsibility for care of people with intellectual disabilities onto people with intellectual disabilities themselves, with minimal or no support “you often cannot put the onus on an individual unless you have put appropriate support mechanisms in place to enable that, and that sometimes escapes [government] staff” (GA, 185-187). Providers described experiencing the benefits system as unfair to those who could do small amounts of paid work, “we know it takes weeks and weeks and weeks and weeks … everybody’s like ‘don’t rock the boat’ basically, because if you rock the boat you might not get back in it, and then what the hell would we do?” (SA, 480-482). Funders’ approaches towards their responsibilities to care now and in the future were identified by service providers as “bleak” (ST1, 217), “there’s just not the will … a ‘culture of indifference’ … that’s what I feel” (GA, 844-851). The future for people with intellectual disabilities without care was described as “Armageddon” (ST1, 525).

Some providers felt this future without care would inevitably include the avoidable deaths of people with intellectual disabilities:

> natural wastage, that’s how the government sees it. It’s cheaper …. I don’t think anybody cares … I think if I walk through town tomorrow and there was 15 people dead in the street, I don’t actually think it would change anything (NWP, 924-921).

Subtheme 2 Loss of a Certain Future for Others. Service providers also considered that colleagues and families were at risk of losing any sense of certainty they may have had about the future. SR2 explained for example:

> Parents are, you know, reaching their seventies and even their eighties and are still the primary carer for that individual. And we've done nothing about it as a society … the parents are exhausted, literally exhausted…. Local Authorities, politicians, just aren't facing up to it. SR2 (436-445)

GA explained that workers in a government agency who thought that cuts in 2012 had increased the number of people they supported who had complex needs "ain't seen nothing yet still" (GA, 373) as he predicted growing numbers of people with much more complex needs would need support.

Providers then felt increasingly exhausted trying to fill the gaps between care needs and funded care provision.

Theme 3 Lost Care: Filling the Empty Spaces Where Care Should Be

Service providers described losing meaningful relationships with funders and feeling they were no longer 'seen' by others These subthemes are considered below.

Subtheme 1 Empty Spaces: Loss of Meaningful Relationships with Funders. Providers spoke about their experiences in relation to their perceived lack of concern by others regarding the effects of cuts to care. Their sense of feeling a social contract had been broken led to different responses from providers, as they tried to make sense of their feelings and place in a new and seemingly uncaring world "nobody seems to worry or be interested particularly" (ST1, 307). The burden of care was described as a "real heavy responsibility" (SR1, 216) which was getting heavier for service providers, as they tried to fill the gaps in care which cuts had created, which they felt must be provided by someone, and in the absence of anyone else that someone would have to be them.

Most providers expressed their perceptions of deterioration in relationships with funders in combative terms. On an organisational level, service providers felt “fighting” (SR1, NWP, SA, SR2) and “battling” (ST1, NWP, SR1) on behalf of those who could not fight for themselves, in a variety of ways, had become a regular occurrence. In response, friendship, advice, advocacy and hate crime groups were started by several providers with little or no funding (SR1, SR2, NWP).

Providers described being frustrated with agencies and L.A.s whose actions had originally been considered to be due to possible “incompetence”, “at the moment … we lurch from crisis to crisis with the Local Authority because it’s all over the place” (SR2, 42, 457-460). Over time however these were understood as the actions of people as “wrapped up rhetoric that it’s all going to be okay …. I think that’s just disingenuous” (SR2, 463-465).

Subtheme 2 Empty Spaces: Loss of Being ‘Seen’. Providers often felt they were the only people ‘facing’ realities of the effects of cuts and ‘seeing’ people with intellectual disabilities “people don’t see it, they see what they want to see” (NWP, 259).

Politicians were considered to not understand or care about the effects of their cuts (SR, 85-90) and in relation to societies, NWP explained:

> it’s very easy for people who don’t work in this environment to turn the other way and not actually see it and not hear, but I can’t, and we can’t here in this building ‘cause we just, we live it every day. (NWP, 190-192)

Funders were perceived by service providers as being “backward-looking” SR1 (121-122) and as missing “the sort of psychology of looking externally” (GA, 243).

This psychology was linked to service provider’s interpretations of L.A.s ‘shifting’ budgetary responsibility between their own departments, and from their own departments onto government agencies. Service providers felt this had resulted in people with intellectual disabilities also being ‘shifted’, sometimes against their will, from residential care to Supported Living accommodation.

SR2 (144-146) explained this change could be at strategic rather than individual needs levels “this particular Local Authority made a decision three years ago that they wouldn’t fund people in residential care with learning disabilities” because, in her view, “the costs are almost identical but who pays for it is very different” (SR2, 157). As a result, providers reported numerous examples of emergency services experiencing significantly higher callouts to people with intellectual disabilities who had had their care services cut but still needed support. SR1 explained her frustration with this shifting of responsibility and the gaps in care it created:

> because people are phoning [999] because they are lonely, people are phoning because they are scared, people are phoning because they have cut their finger that would usually be dealt with by a support worker, who’d put a plaster on it. So, all of these things, you know, are putting pressures on the NHS which actually, it’s the same money is probably being spent but just in a different department ... That’s quite a frustration that they can’t see the bigger picture. (SR1 356-362)

It was considered by service providers to be a “tragic irony” (GA, 658) that governments and L.A.s appeared to be unaware of the ways in which they worked against their own national policies designed to improve the wellbeing of people with intellectual disabilities. SR2 highlighted the effects of this:

> There’s an irony that the government have just launched a loneliness strategy aimed at older people which again, is the right thing, but on the one hand they’re spending money on this loneliness strategy and the other, they’re cutting the lifelines of people to stop them from being lonely. (SR2, 367-370)

In the midst of this situation, cuts led providers to feel they had lost their sense of identity.

Theme 4 Loss of Identity

This theme encompassed the loss of a loved and cherished identity and the unhappiness which service providers experienced with the new false identity, into which they felt they had been forced on both individual and organisational levels.

Subtheme 1 Loss of a Trusted Individual Identity. Providers described experiencing a change from having an identity of a trustworthy individual to one where they were not trusted by funders and must justify every penny claimed. Feeling they were no longer believed by funders was experienced as frustrating and was linked to providers feeling that their identities and the identities of people with intellectual disabilities were being fundamentally misunderstood:

> I do feel that people with learning disabilities are being treated now as second-class citizens and it's being wrapped up in this idea that actually, it's providers that are somehow mollycoddling people and hanging onto support hours. As a charity … we're not in it to make lots of money, we're in it to help people be more independent. (SR2, 78-83)

This perceived change in relationship meant many smaller providers felt they had been cut out of negotiations and contract opportunities. ST1 explained for example that "the council … can screw that supplier down to the price they want to pay" ST1 (270-271).

Providers felt their concerns were now ignored unless they made formal complaints against L.A.s (SR2). Even then, they perceived that L.A.s did not appear to show an understanding of the needs of people with intellectual disabilities, the function of charities, the ways in which services were priced, or how to effectively plan a budget (NWP, SR2, ST1, GA).

Service providers described this as happening while L.A.s were providing less support to charities while expecting greater levels of service "the specification we got for the new service to replace us was substantially reduced financially" (GA, 36). The combination of their feelings that their trustworthy identity could be removed so easily, and that their expected new identity was the antithesis of their own values, also had negative impacts on organisational identities.

Subtheme 2 False Organisational Identity: From Charity to Business. The perceived differences in the ways in which they were treated under austerity meant that providers felt they now must behave in ways completely opposed to their own values. This challenged their perceptions of their identities and roles “it’s not just a do-gooders coming together with a common purpose it’s now much more of a business” ST1 (344-346).

Pressure from L.A.s led providers to feel the need to change their funding models, requiring skills and time they felt they did not have and could not afford to purchase, such as campaigning, fundraising and associated business administration (ST1, SR2). Service providers felt they had now to view people with intellectual disabilities as commodities over which they must compete. One provider explained how this change in identity from human charity worker to ‘business animal’ felt:

> because there are so many of us at this trough isn’t there, trying to get money, it’s that we are amongst the first of these pigs to get to the trough rather than somewhere back in the queue. I don’t have that experience; I’m just a volunteer and the world has changed hasn’t it? (ST1, 339-342)

The only provider who did not experience a change in his identity was SA who was already running his charity as a business, which he explained was commonplace in arts-based services. He explained that unlike funding for care services, accessing Arts Councils’ funding had for many years required a formal business approach.

The additional pain which providers experienced as they watched people, whom they cared about, lose care was compounded by the feeling of being powerless to prevent that pain.

Theme 5 Powerlessness to Prevent Pain

Providers realised they felt they were almost powerless to defend people with intellectual disabilities against physical and emotional pain. They also described feeling powerless to prevent their own pain.

Subtheme 1 Powerlessness to Prevent Physical Pain. High levels of distress were experienced by providers who shared their stories of people with intellectual disabilities, and the avoidable harm to which they had been exposed by perceived unfair cuts to or removal of all care support:

> these people you might think are quite able, they can make a cup of tea … but quite often they cannot read, they can't write, and they can't do the other basic things that you need to do to lead a life with dignity and respect and that's where the issue comes in. [Long pause]. (SR1, 562-565)

This powerlessness was demonstrated in their tears and in their attitudes, as they described people with intellectual disabilities whom they knew well becoming significantly more vulnerable to attack and harm, being homeless, and/or physically and sexually abused (NWP, SR1, SV1). Providers also felt they had been powerless to stop the escalation of inequalities they saw in the range of avoidable health conditions people now experienced. These included examples of self-neglect, diabetes, severe dental pain, toenails growing into feet, poor diet and weight gain (ST2, SV1&2, NWP, SR1). SR2 for example described a situation with one man with intellectual disabilities who had his one hour a week of support cut. SR2 set up a friendship group for him and others who had lost all care and support. This was done with no funding. Through this group SR2 then found that this man had an untreated urine infection:

> 'cause he didn't know how to contact his doctor. You know, it's as basic as that. You know, so…we set up an appointment for him, he was able to go to the appointment on his own, it got sorted. It turns out he'd had it for a year and, you know, who cared? Makes me so cross [tearful]. 'Cause it could have been sorted. If he'd had, you know, just somebody come and see him once a week, it could have been sorted. (SR2, 338-342)

Subtheme 2 Powerlessness to Prevent Emotional Pain. Providers also described their awareness of the emotional pain they felt both their staff and people with intellectual disabilities had experienced as a result of cuts:

> I … massively worry about the staff … it's not just about dealing with like the incident there and then …. It's dealing with the aftermath as well and the emotional impact that it has on the staff that are dealing with it. (NWP, 63-79)

Service providers' feelings of powerlessness to prevent the harm they had uncovered was also evident when explaining the rise in numbers of people with intellectual disabilities becoming suicidal or having increased episodes of very significant self-harm "One resident had personality disorder and hung herself 13 times; staff had no training and she cut open her veins" SV1&2 (62-63).

The loneliness and loss of opportunities to undertake activities as people with intellectual disabilities had no-one to care about them, nowhere to go and nothing to do, was reported by providers who, as funding was cut and despite their best efforts, felt seeing network members regularly and undertaking meaningful daytime activity was becoming a pipedream:

> it also helps people in routine like I said they have got a purpose to do something every day, they have to get up, dressed, washed, get out the house to come to whatever it is that they find in that day, so yeah. That would be lovely wouldn't it to have something like that? (ST2, 695-698)

Subtheme 3 Powerlessness to Prevent own Pain. Providers also highlighted the dichotomies they experienced in caring about other people and protecting oneself from becoming overwhelmed. They were aware that having positive relationships with people they knew well may have heightened the pain they experienced, describing experiencing caring in times of austerity as a form of "suffering" (ST1, 332-334). Providers had coping strategies for dealing with their guilt, anger and fear of becoming desensitised, as cuts became unrelenting:

> Dreadful stuff. I'm not desensitised though, 'cause I did worry about that for a while, I thought what if I get desensitised to people's suffering, I hear that much about it? But I don't 'cause I'm still very sad and I still, you know, I have to check myself to stop myself becoming emotional. All the time. (NWP, 830-833)

Meanwhile other providers explained how they tried to distance themselves emotionally from the people they supported, in order to avoid the emotional overload of suffering as much as those individuals were:

> the people that you're battling it out for, they're going to be the ones … that … suffer ... and you just feel very, like a weight is on you trying … to get the best care they can possibly get, and to do that, you need people to not have an agenda just for cuts. (SR1, 213-219)

Summary of Themes

This thematic analysis has highlighted the importance of relationships, and some of the difficulties which this group of service providers identified within those relationships, when cuts to services were made. When people with intellectual disabilities experienced loss of care, service providers could also feel a deep sense of loss. Moreover, when service providers spoke about their experiences of cuts to care, their experiences raised questions about the nature of loss, relationships and powerlessness more widely. In their relations with funders in particular, they felt they experienced 'care' in fundamentally different ways.

Discussion

This study analysed the experiences of service providers in light of cuts to care for people with intellectual disabilities. Findings centred around five key themes. These were: the ways in which service providers felt they and funders had different approaches to care; the loss of a certain future for service providers and others; the empty spaces where care previously existed but now did not; the ways in which they felt they had lost their identities; and their powerlessness to prevent pain. Areas in which this study enhances the current literature are discussed below. These centre on different understandings of care, feeling powerless in relationships, feeling pressure to fill the gaps which cuts have created and the ways in which policies impact service providers.

Different Understandings of "Care"

The findings of this study strongly link with care ethics approaches whereby care is perceived as a moral activity which recognises interconnectedness and relationships as a basis for decision-making. Care ethics suggests that approaches which do not use relationships in this way are doomed to perpetuate injustice at all social levels (Gilligan, 1993; Held, 2006; Kittay, 1999; Noddings, 2013; Rogers, 2016; Tronto, 2013). Findings from this PhD study extend this concept further by highlighting the challenges that some service providers can face when they perceive care as emotion-in-action in the context of cuts to services, including challenges to their identities.

It also provides greater depth and context to Power's (2008) research regarding the ways in which parents felt services worked to protect their own interests. Power found this went beyond lack of funding and included service providers' negative attitudes. In this PhD study, service providers had similar feelings, but these were experienced regarding the attitudes of funders. Providers felt it was funders' attitudes towards service providers that were the cause of their difficulties. Rather than wanting to work against parents, service providers expressed concern for parents and the situations in which they were felt to have been placed by governments, L.A.s and welfare agencies. Analysis suggests that funders were considered to understand care not as a moral activity but as an encumbrance, hence funders' (rather than service providers') ability to make cuts. This suggests a chain of differences in perceptions of the ways in which experiences of cuts to care can be understood by families and service providers.

Feeling Powerless in Relationships

In this study powerlessness was also found to be linked to deteriorating relationships. Previous studies suggested that mutually respectful relationships are crucial for positive professional identities (Holmesland et al., 2010) and to person-centred practice with people with intellectual disabilities (Mansell, 1996). Previous studies have also found that organisations and employers considering and respecting the emotions of their workers often related to positive outcomes for staff (Hussain et al., 2019; McEvoy et al., 2010). This PhD study however gives detail and context to the negative outcomes that providers themselves could experience when funders were felt not to have respected their emotions or expertise. Previous research has also provided information regarding the ways in which lack of reciprocity with people with intellectual disabilities can link to feelings of burn-out and stress (Rose et al., 2010; Thomas & Rose, 2010). Those findings are echoed here in this PhD study, suggesting that feelings of a lack of reciprocity with funders was a cause of significant stress and feelings of burn-out for service providers. This study suggests that strong emotional connections with people with intellectual disabilities in times of cuts can be both beneficial and detrimental to providers. Benefits were described as knowing people well and having relationships in which service providers felt they were making positive differences in the lives of the individuals with whom they worked. Drawbacks related to feeling pain when cuts were made to the care of those individuals, which led to feelings of powerlessness.

However, rather than powerlessness leading to de-personalisation of services (as in Thomas and Rose (2010) for example), powerlessness in this PhD study was linked to fighting strongly for each individual person with intellectual disabilities to have some form of service which providers felt met at least some of their individual needs. This included providing a range of support, advocacy, friendship, employment opportunities and services with the service providers meeting the unfunded costs. These findings also echo Gray and Muramatsu's (2013) work, which reported that fighting against funders was felt to be a form of self-advocacy. This PhD study expands Gray and Muramatsu's work however, by suggesting that fights can go beyond the battles they describe: to stop accommodation moves, day service closure, loss of employment opportunities and loss of a range of services. Examples from this PhD study include the ways in which service providers could perceive they were also fighting more existential battles. They felt they were fighting a losing battle against the breaking of their expectations of social contracts on several fronts. This included fighting against funders' expectations of them to change their ways of working from a charity to a business model; fighting for their identities as 'good' and caring people; and fighting for their understandings of what they thought shared understandings of 'care' were meant to be. The person-centred identities of providers were challenged as they experienced powerlessness to prevent pain for themselves and others. This powerlessness meant service providers could often feel almost as badly treated by funders as they perceived their staff and people who had intellectual disabilities being treated.

Rather than a lack of reciprocal feelings (Green & Lawson, 2011), this study has found that the negative impacts of cuts on people with intellectual disabilities could be felt vicariously as pain by service providers. Service providers also experienced concern for their staff and their professional social networks more widely, also feeling their perceived pain. Rather than person-centredness being reduced, in times of cuts these service providers appeared to feel the need to focus on having and maintaining meaningful person-centred relationships with others, despite the pain this appeared to cause them when cuts were made.

Funders however may also have felt powerless in the face of cuts and may also have been feeling significant emotional pain when they had to make cuts to care. They may have felt powerless in the face of their own perceived onslaught of attacks from governments, parents, the Press and from people needing and/or using services. As demand for services increased, and pressure to make financial savings increased, a feeling of powerlessness may have pervaded a range of relationships funders had, including those with service providers.

Feeling Pressure to Fill the Gaps Which Cuts Have Created

People with intellectual disabilities have often included staff as important members of their social networks (The Money, Friends and Making Ends Meet Research Group c/o Tilly, 2012). Findings from this study suggest that providers can undertake the role of social network member with a strong sense of moral and emotional commitment. Previous studies have highlighted the ways in which families can feel pressured to fill gaps in care (Power, 2008). Study Two (Chapter Four) extended that research. This third study has built on and complimented Study Two, by illuminating the ways in which service providers too could feel pressured into filling the gaps in services which they felt cuts had created. The ways in which service providers filled these gaps included providing lost services they felt individuals needed and carrying the cost themselves by providing the same or similar services for free. Gaps were also filled by service providers and their staff spending their own money to ensure people with intellectual disabilities had meaningful experiences with staff and one another.

It may be that funders were unaware of the gaps they were felt to be creating, or they may have been aware and be making strategic decisions about making savings on services where parents and service providers were felt to be able to fill those gaps. This may have left funders freer to spend their dwindling resources on organisations they felt were providing the most efficient services to the most people, or to people who had the highest needs.

The Ways in Which Policies Impact Service Providers

This study posits that service providers can be affected by austerity policies, not only in terms of finances but also in their identities and their senses of loss and powerlessness. Lolich (2017), Clapton (2008) and Bowden (1999) have highlighted the ways in which the commodification of care can mean that inequalities, suffering and vulnerability can be overlooked. This study has shown that for some providers, when care is commodified and then cut, this remains the case. Findings also provide further illumination on the concept of hidden suffering, showing that in times of cuts, service providers can 'see' and 'feel' the pain of inequalities very strongly for people with intellectual disabilities, staff, families and themselves.

Findings also affirm the importance of Gridley et al. (2014)'s work regarding the significance of meaningful long-term relationships with people with intellectual disabilities for effective policy and practice as financial pressures rise. For staff within organisations Gridley et al. (2014) found that a lack of ongoing and stable cross-organisational approaches negatively impacted person-centred practice. In this PhD study, in the face of cuts, a lack of cross-organisational approaches by funders was perceived by service providers as short-sighted, neither displaying nor supporting a person-centred approach. Examples given add to previous understandings of the ways in which wider lack of cross-organisational relationships can also affect practice.

However, in opposition to the work of Northway Davies et al. (2007) and Bigby et al. (2009), the service providers in this study did not suggest that employee training should focus on value-bases behind policy in order to positively affect practice. It appeared to providers that it was not they or their staff who needed training. Instead, providers felt it was they who understood and delivered value-based practice, while it was funders who either knowingly or otherwise, misunderstood and misapplied policy and legislation.

It may be however that funders were trying to find ways of ensuring that people with intellectual disabilities were still able to maintain some level of care in the face of increasing pressure on funders to save large sums of money. Funders may have been perversely incentivised to shift budgetary responsibility from themselves to a range of different government departments by individualised cost-reduction targets. It may be that some people with intellectual disabilities had been moved from one service to another because their needs had reduced, or that they had previously been in receipt of more care than they needed. In these cases, a move from residential care to Supported Living, shifting from staffed to automated systems and using minute-by-minute assessments of need while knowing emergency services staff could deal with health emergencies, could make sense to funders caught between trying to meet the needs of people with intellectual disabilities whilst also having to justify and save public money.

However, this study supplements the literature (such as Bradshaw et al., 2018) which highlights the difficulties managers can face when cuts are made. This PhD study suggests that providers felt it was politicians, funders and benefit systems workers who needed to fundamentally shift their value-base, and who should meaningfully engage with the emotional impact of cuts on providers of services.

Limitations

This study provides analysis of in-depth accounts of nine service providers in differing roles across a range of charities and one government department. By taking full account of the reasons providers gave for their levels of stress and experiences of loss, and the environment of austerity policies within which they worked, this study provides possible interpretations of experiences of service providers and suggests reasons as to why these experiences may have occurred. While it does not claim to be representative of all organisations providing services to all people with intellectual disabilities in the U.K., the analysis presented may provide opportunities for subsequent considerations in other research projects.

There are a number of limitations to this study. Providers proactively volunteered to take part in the study. Eight of the nine providers were gatekeepers in this research project: providing access to people with intellectual disabilities. Eight service providers feared that when interviewed, people with intellectual disabilities they supported would not reflect service providers' perceptions of their difficulties of funding and providing services in times of cuts. They may have been motivated by fear of being perceived as lacking any care or concern about people with intellectual disabilities, which may have influenced their responses regarding the levels to which they were going to meet perceived needs in ways which appeared caring. Their focus on feeling powerlessness may have been linked to not wanting to be blamed for perceived reductions in service quality. They may also not want to have been perceived as 'rich' organisations in times of austerity, which could have linked in their minds to being seen by funders as an easy target for further cuts. These possibilities suggest a need for further research which takes account of a different range of providers across different types of service and business approaches who may have different experiences. The views of funders, L.A. workers and commissioners of services would also add greater breadth of experience to this study.

Reflexive considerations

Reflecting on the nature of relationships was an unexpected theme in this study.

Including service providers was not part of the original PhD proposal. If I had simply followed the original plan, this research study would have lost the perspective of service providers who often described themselves as doing their best to support people with intellectual disabilities and their families. However, this sample of service providers was biased and included service providers who were gatekeepers to participants with intellectual disabilities. People with intellectual disabilities and parents in this study expressed dissatisfaction with service providers. To them, service providers were often seen as making cuts in similar ways to governments and L.A.s. By including the views of service providers, greater depth was added to understanding the positioning of service providers, who often appeared to feel almost as powerless as people with intellectual disabilities and parents. They could be understood to be positioned on the same side of the 'fight' against cuts as people with intellectual disabilities and parents.

As a person who had previously managed services and worked in services for people with intellectual disabilities for several years, I felt empathy with service providers who described not being able to provide services when funders did not fund the full costs of the service provided. I assumed they were trying to do a very difficult job in increasingly difficult financial circumstances. I had therefore expected service providers to speak about the difficulties of providing services in terms of staffing, finances and activities. These had been the difficulties I had encountered and felt I knew well.

I had not expected service providers (both male and female) to be in tears telling me about their experiences and the effects of cuts they had seen on the individuals they supported. I was surprised that they had similar relationships with individuals as I had had. I had not expected people at their level (a government worker, a Treasurer, a Chief Executive Officer) to be so emotionally engaged with every aspect of the lives of individual people they supported. As has been stated, they may have been presenting this persona as a way of appearing caring and powerless in order to defend themselves from attack from people with intellectual disabilities, parents and L.A.s. I also had expected them to fight back against cuts far more vigorously than they appeared to.

This made me reflect on how much had changed in the time since I had managed services (pre-austerity). When I had been a Registered Manager of residential homes, someone other than me made decisions about legal action or giving notice when funding was not forthcoming from funders. I could be emotionally engaged with individuals, knowing the Business Manager would deal with the financial side of the charity's contracts with L.A.s. In this study however many of the service providers I spoke with were feeling pressure to play these dual roles themselves, to which they felt they were neither suited nor qualified. I realised what I had interpreted as passivity may have been that they did not feel they had the energy, qualifications or experience to perform this additional role as well as their own. I came to realise it may not have been that they were not fighting enough, but that they felt they had been fighting for so long, alone, without success that not pouring all their energy into continued fighting was a sound pragmatic decision from their perspective. I reflected that it may be that they felt they had seen the direct effects of years of cuts and could not bring themselves to give notice to people with intellectual disabilities who used their services for example, as they 'knew' funders would see this as an opportunity to stop services. Some service providers may have feared that losing funding would mean losing their jobs, others had been considering how long they could work in their services in the face of what they saw as uncaring attacks in the form of cuts. One provider resigned during the course of this study as she did not perceive that working for a charity with increasingly precarious funding streams provided the job security she needed. From the perspective of service providers, the goal of funders was to have no-one left to fund. Managers perceiving themselves as being as powerless and vulnerable as the people they supported came as a surprise and a dilemma for me in terms of understanding their situations and motivations. I am sure this is why powerlessness emerged as such a strong theme throughout this study.

I also have not been a funder of services so lack that perspective. If I had undertaken this research with that experience I may have been given different versions of service provider experiences. The lack of representation of funders' perspectives is a clear limitation. All but one funder I approached refused to engage or to allow access to any of their staff or people with intellectual disabilities using their services.

There is a lack of research which investigates managers' feelings regarding how cuts have affected their own identities, and their positions of power/powerlessness in relation to people with intellectual disabilities, parents, governments, L.A.s and funders. This PhD study has shone a light on this topic as a new area of study and highlights the importance of future research in the area of service provider identities and relationships in times of cuts.

Implications for Research, Policy, Practice and Families

Research, policy and practice implications raised by this study have clear implications regarding the ways in which research, policy and practice could be enhanced with the application of a care ethics approach. This includes service providers' need for partnership working in times of cuts, in order to build or rebuild positive working relationships with service providers as trusted, valuable people. The desire of service providers was that cuts not be made at all and instead that the needs of people with intellectual disabilities should be met. This too aligns with a care ethics approach. If cuts were to be made, service providers raised the desire that policy and practice should take account of the ways in which perceived attitudes towards cuts could negatively impact service providers. Service providers in this study described close and meaningful relationships with people with intellectual disabilities and felt they were ideally placed to support people with intellectual disabilities to navigate cuts and changes to their care. They felt the importance and strength of these relationships could be better included in policies and in practice regarding the ways in which cuts are made. Recognition that for these service providers, cuts could lead to real physical and emotional pain for providers and people with intellectual disabilities could be more widely researched. Any subsequent policy could then be written to work to build on strong and meaningful networks and thereby attempt to avoid causing this pain.

Recognition that at least some service providers understand the actions of funders as being detrimental to service providers' long held and previously valued identities, roles and purpose could provide new starting points for reciprocal relationships between funders and providers using care ethics as a basis for discussion. A care ethics approach would also enable service providers to work more closely with families to jointly explain and share their situations and experiences, which may enable both groups to be better equipped to work together with funders.

Conclusion

Insights have been provided into the ways in which service providers can perceive their own and funders' understandings of care. In times of austerity, a breakdown of their reciprocal social contract had been experienced. Funders were perceived to no longer value or understand care as a moral activity. The perceived change by funders to understanding care as an encumbrance rather than as emotion-in-action had significant negative impacts on the lives of many of the providers in this study. Impacts were loss of a certain future, loss of care, loss of identity and loss of power. The sense of loss identified in this study across a range of areas and the negative impact of poor relationships with funders suggests that it is not only people with intellectual disabilities and families who can experience loss when care is cut.

The suggestion has been made that a care ethics approach could be used to begin to shift focus from a culture of cuts to a culture of care. Further qualitative research which focuses on the views of service providers and the views of funders and considers the effects of lack of perceived reciprocity between providers and funders could add to our levels of understanding regarding the ways in which both groups experience cuts to services, support and care for people with intellectual disabilities. Research questions which consider the ways in which funders and service providers experience their relationships with one another, and whether funders also feel these relationships have changed since austerity policies were introduced would be helpful. The ways in which funders perceive their relationships with people with intellectual disabilities and whether these have changed since austerity policies were introduced would also be informative. Research questions which consider the ways in which service providers and funders could work together, in ways both felt were productive, could also illuminate differences and similarities in understandings and approaches. These research questions could lead to findings which may influence the creation of policies and practices which are perceived to respect, value and build the relationships which exist between service providers and people with intellectual disabilities, families and funders.

The ways in which austerity can affect the care and social networks of people with intellectual disabilities is an essential area of study when considering the ways in which service providers and funders can best meet needs in times of cuts. The effects that austerity can have on some people with intellectual disabilities, from their own perspectives, are therefore considered in the next chapter.

Chapter Six Results From Study Four: Quantitative Analysis of the Effects of Care Status on the Social Networks, Health, Finances and Activities of People with Intellectual Disabilities

This chapter will be used to consider the findings of Study Four. This fourth study consists of analysis of the responses of 150 people with intellectual disabilities to questionnaires. The main research question was "What are the views and experiences of people with intellectual disabilities around care and social networks in times of austerity?"

Data was gathered on participants' living situations, their care and support needs, how many people they saw, how often and in what contexts, on their anxiety levels and their self-esteem, and on their quality of life. Data on whether their care changed, stayed the same, improved or got poorer during austerity was also gathered. Analysis suggests that the care, social networks and relationships of people with intellectual disabilities could be negatively impacted by cuts.

The background section will be used to highlight the lack of research in this area and to make suggestions regarding the applicability of related research to this group and topic area. The methods used for data collection and analysis will be detailed. The results of the research will be presented, followed by a discussion regarding the analysis of the results. Conclusions and recommendations are suggested.

Analysis of the experiences of parents in Study Two and service providers in Study Three suggested that their own and the lives of people with intellectual disabilities could be negatively impacted by cuts to care. Analysis of the perspectives of people with intellectual disabilities themselves therefore adds depth and breadth to understandings of the effects of cuts on their care and social networks.

Background

Since the financial crisis began in 2008, cuts, often referred to as ‘austerity measures’, have been made to all adult social care including services, welfare and support (Clark, 2016). The effects of these cuts, combined with the effects of the Covid-19 pandemic on service provision (Forrester-Jones et al., 2021) have importance for future policy and practice.

Yet the effects of cuts on the care of people with intellectual disabilities is an under-researched area and little is known about the impact of any cuts on the social networks and social lives of people with intellectual disabilities. In addition, while there is some research which exists regarding the social networks of people with intellectual disabilities from the perspectives of parents and staff, very little of that research is based on the responses of people with intellectual disabilities themselves (Harrison et al., 2021). This study therefore aimed to investigate the ways in which cuts to care have affected the lives and networks of people with intellectual disabilities from their own perspectives.

The Importance of Social Networks

The review and synthesis of previous U.K. studies across 30 years undertaken in Study One suggested that the average network size of people with intellectual disabilities was 12 members, (with a range of 0-42 members) drawn mainly from staff, family and others with intellectual disabilities (Harrison et al., 2021). This is much fewer than the 150 members found in mainstream populations by Hill and Dunbar (2003). Harrison et al.'s study also showed that diverse networks were positively linked to quality of life and inclusion. They were perceived as important in the realisation of a desire for an 'ordinary' identity where people felt they had some level of power and control over their lives. Research has also shown that social networks can be fragile and affected by factors such as accommodation-type, location of accommodation, staff, and the amount, type and location of activities offered and undertaken. These issues are considered below, as are social networks, family and health.

Social Networks and the Role of Accommodation, Location, Activities and Staff

In the light of policies which aimed to end the institutionalisation of people with intellectual disabilities, research has suggested that accommodation can be an important factor in the lives and social networks of people with intellectual disabilities (Emerson et al., 2000; Forrester-Jones et al., 2006; Robertson et al., 2001).

Many research findings are nuanced and suggest that satisfaction with one's life and social network often relies on both internal and external factors such as family, staff and wider social attitudes towards people with intellectual disabilities (Beadle-Brown et al., 2016; Emerson, 2004; Wolfensberger et al., 1972). Cummins (2005) referred to the level of satisfaction with one's life and wellbeing as subjective wellbeing homeostasis, reporting that life satisfaction is typically described as generally positive by most people but as lower by disabled people due to the additional life pressures they face.

Opportunities for people with intellectual disabilities to build and maintain long-term networks and relationships are reported as limited when community integration focuses only on activities which do not involve relationship-building with community members who do not have intellectual disabilities (Ager et al., 2001; Cummins, 2005; Emerson and McVilly, 2004; Lippold & Burns, 2009; van Asselt-Goverts et al., 2015).

There is a small amount of empirical literature regarding barriers to social inclusion which involves people with intellectual disabilities as participants. That research has highlighted the need for robust policies and practices which support people with intellectual disabilities to undertake meaningful activities. These activities should support people to feel a sense of belonging and to learn enabling and empowering skills (Power, 2013). Staff have an important role to play in the development and maintenance of social networks. The importance of staff members understanding and using interventions which can aid the development and maintenance of social networks has been demonstrated in the U.K. (O'Brien et al., 2010), in the Netherlands (Blommendaal & van de Lustgraaf, 2006) and in Australia (Bigby et al., 2009). People with intellectual disabilities often rely on staff to teach them skills which can help to promote social networks, yet research has shown that staff often do not have sufficient time and/or ability to teach or value these skills (Abbott & McConkey, 2006; Cylus et al., 2012).

Social Networks and Family

Around half of the approximately 1.5 million people in the U.K. who have intellectual disabilities live at home with parents (Foundation for People with Learning Disabilities, n.d.). Of those, approximately 29,000 people with intellectual disabilities live with parents aged 70 or over, of whom 75% have no Local Authority alternative housing plans in place (Mencap, 2023b, 2023c). Living with parents is a reflection of numerous government policies which encourage family and community support (Borsay, 2004; Webb, 2013). Yet this can overlook the high levels of financial and emotional 'burden' that parents can experience when caring for their sons/daughters (Bauer & Sousa-Poza, 2015; Egan & Dalton, 2019; Glasby et al., 2021; Walmsley et al., 2017). Policies which promote the primacy of parental care may simultaneously neglect to provide the financial support needed for that care to be realistically achieved and maintained. These policies can also neglect the importance of the social networks, needs and views of people with intellectual disabilities, which may not align with the social networks, needs and views of their parents. The provision of care, the place in which care is provided, and the people who provide that care can become even more important in times of austerity when many household budgets of people with intellectual disabilities and their families are under pressure (Malli et al., 2018). Friends and family may therefore be essential in replacing lost services in times of cuts and working as "the social glue that holds many … networks together" (Hughes et al., 2011, p. 204).

Social Networks and Health

That people with intellectual disabilities experience more physical and mental health conditions, at an earlier age, than the general population has been demonstrated in several studies. McMahon and Hatton's (2021) recent findings concurred with those of earlier authors (Cooper et al., 2015; Finlayson et al., 2009; Finlayson et al., 2010; Robertson et al., 2017; Draheim et al., 2007) who observed that people with intellectual disabilities were more likely than the general population to lead sedentary lives, to have mobility problems, to be obese, to be prescribed multiple drugs which could negatively impact their health, to have mental health and behavioural disorders, and to experience difficulties accessing health services. McMahon and Hatton (2021) also reported that people with intellectual disabilities were less likely to exercise, to eat healthily and to have knowledge or understanding which would enable them to independently make healthy choices. Bollard et al. (2018) also found that people with intellectual disabilities experienced more health inequalities than non-disabled people.

Research on the health of people with intellectual disabilities has highlighted the importance of having people in one's network who can recognise and understand the range of health and wellbeing needs of people with intellectual disabilities and the inequalities they can face (The Money, Friends, and Making Ends Meet Research Group c/o Tilley, 2012). Cooper et al. (2015) concluded that people with intellectual disabilities needed significant and knowledgeable support from people who knew them well and could recognise their health conditions. This could lead to healthier lives and provide access to much-needed health care services. In their global review of hospital admissions for people with intellectual disabilities, Dunn et al. (2018) highlighted the “surprisingly limited” quantity and quality of existing research especially as people with intellectual disabilities experience higher levels of physical conditions, but poorer primary health care than the general population (Dunn et al., 2018, p. 6). The authors highlighted that within hospital settings, staff having an awareness of the needs of people with intellectual disabilities could positively impact those poorer outcomes. They therefore suggested prioritising the training and support of ward staff in meeting the needs of people with intellectual disabilities. People with intellectual disabilities could then have healthcare delivered by knowledgeable and helpful network members in hospital settings.

The research question regarding the views and experiences of people with intellectual disabilities around care and social networks in times of austerity included possible effects on health. In the U.K. specifically, as cuts to health services have affected access to hospital and community services and also negatively impact waiting lists for treatment (Robertson et al., 2017), the health of adults with intellectual disabilities may be being affected by cuts. The Care Act 2014, health policies such as the promotion of annual health checks for people over the age of 14 who have intellectual disabilities, and the promotion of stopping the over-medication of people with intellectual disabilities (STOMP) (NHS, 2016) had mixed levels of effectiveness (Javaid et al., 2020). The programme of annual health checks, brought in to reduce the burden on secondary health care services, began to increase the numbers of people with intellectual disabilities checked in 2015/16 to 2018/19, yet in 2019 this decreased significantly for adults aged 25 and over (NHS Digital, 2021).

Using pre-Covid-19 data, Truesdale et al.’s (2021) systematic review reported significantly higher rates of avoidable respiratory-associated deaths in people with intellectual disabilities than in the general population. While the authors did not cite austerity policies directly, they did conclude that improved public health initiatives and equitable access to healthcare could begin to address future avoidable deaths. The detrimental effects of a lack of focus on promoting equality of access and treatment regarding both the health and the wellbeing of people with intellectual disabilities has been raised as a fundamental issue for many years (Bollard et al., 2018). A lack of expertise or focus can have fatal consequences, as reflected in reports into avoidable deaths (Mencap, 2012).

Lack of appropriate health and social care support during the Covid-19 pandemic has also been found to have negatively impacted the physical and mental health of people with intellectual disabilities (Mencap, 2020). The emerging research regarding the treatment of people with intellectual disabilities during the Covid-19 pandemic has highlighted health inequalities further. This group were at higher risk of hospitalisation and death than the general population, particularly those with severe intellectual disabilities, or associated conditions including Down's Syndrome, Cerebral Palsy and/or those living in residential care (Williamson et al., 2021). Mencap (2021) suggested that figures which reported that people with intellectual disabilities were dying from Covid-19 at six times the rate of the general population were directly related to the systematic health inequalities this group faced as a result of not being prioritised for vaccination by the U.K. government. Loss of regular access to healthcare professionals in general (Flynn et al., 2021) and specialist intellectual disability nurses in particular (Heslop et al., 2021) have been highlighted as significant issues both before and during the pandemic. Concerns were also raised regarding 'Do not attempt cardiopulmonary resuscitation' (DNACPR) guidance and decisions during the pandemic (Heslop et al., 2021). Calls for real change to address these and wider health and social inequalities have again been made (Flynn et al., 2022; Schormans et al., 2021). The effects of austerity on health in relation to social networks are therefore worthy of further study.

Aim

As has been highlighted, there is some research which shows that social networks are vital for the positive health and wellbeing of adults with intellectual disabilities. The evidence which exists regarding the effects of cuts to social care and health services suggest cuts may be affecting adults with intellectual disabilities. Some of this current published literature relates to the wider study of which this PhD study is a part (Forrester-Jones et al., 2021). That wider study reported on some of the ways in which austerity measures had impacted the cost of service-use for 150 people with intellectual disabilities. This PhD study instead explored the social networks, relationships and care of those 150 participants with intellectual disabilities and the ways in which these may have been affected in times of austerity.

Method

Accessible information sheets and consent forms were provided to all potential participants directly prior to and at the time of interview. As required by the Mental Capacity Act 2005, an appointee was sought for those without the capacity to consent. Examples of information provided, consent forms and de-brief forms are included in Appendix A Forms A4-A6. As has been reported in the Methodology chapter (Chapter Three), questionnaires were administered face to face and additional qualitative comments were written down verbatim.

Recruitment and Sampling

Inclusion criteria were that participants had to be adults (over the age of 18) and be diagnosed as having intellectual disabilities. Participants had to be in receipt of some form of care, welfare, services or support. Participants were recruited through L.A.s, local and national service user organisations and independent service providers. Interviews took place at a time and location chosen by the participant. Some participants chose to be interviewed with a parent, friend or colleague, others with a staff member and some alone. This led to other individuals with intellectual disabilities being recruited through snowball sampling (Griffiths, 2020), which occurred when individuals with intellectual disabilities had been interviewed and told their colleagues or friends, who then also asked to be interviewed. One hundred and fifty participants took part in the study: 149 participants with intellectual disabilities and one consultee. Participants lived across the Midlands, Greater London, and the North and South of England.

Measures

Basic demographic data was collected from participants who were asked about their lives since austerity measures were introduced in 2008, using a range of five quantitative and mixed methods measures. Participants were asked open questions about whether their care had stayed the same or changed in any way (including support, services and welfare benefits) since 2008.

Responses were coded into one of four categories. *Poorer care* covered any loss of care which was not replaced. *Changed care* covered any change to care which was replaced by similar hours or level of service without detrimental effects. *Improved care* covered any rise in care. *Care stayed the same* covered participants who had experienced no change to their care.

The quantitative measures used in this study were chosen as they provided a range of questions which could be used to consider possible statistical links between different aspects of participants' lives and could be linked to care status and a range of aspects of participants' social networks. These questionnaires were also approved by the Health Research Authority as being appropriate for this study. The measures and their rigour are described below.

An adapted *Client Service Receipt Inventory* (CSRI) (Beecham & Knapp, 2001) was used to collect data pertaining to participants' living situation and contact with a range of professional services over the past year. This provided an overall view of the services which participants received. The Client Service Receipt Inventory has been used and positively reviewed as robust for over 20 years by authors such as Beecham et al. (2004), Curtis (2013), Beecham and Forrester-Jones (2019) and Yang et al. (2018). This measure has 11 key questions which relate to participants' living situation, any benefits they receive, their health and use of hospital services and whether or not they have seen and range of health professionals (dentist, optician, G.P., Learning Disability Nurse for example) or support staff (key worker, self-help group, advocacy worker for example) in the last year. It also gathers data relating to participants' use of the criminal justice system, their ethnic group and marital status. Questions are rated yes/no and if participants have engaged with health, support service workers or criminal justice workers, they are asked how many times in the last year this has occurred.

The *Glasgow Anxiety Scale* (Mindham & Espie, 2003) was then used to rate participants' anxieties. The Glasgow Anxiety Scale has been judged to be robust with good test-retest reliability (Mindham & Espie, 2003, p. 22) and has been successfully used by Young et al. (2016) and Bourne et al. (2022) amongst others. This measure is used to gather data on 27 questions related to worries, specific fears and physiological symptoms which relate to anxiety. Participants are asked whether they worry a lot, whether they are afraid of the dark, and if they get breathless for example. Answers are rated as zero for 'never', one for 'sometimes' and two for 'always'.

Dagnan and Sandhu's (1999) adaptation of Rosenberg's *Self-esteem Inventory* was used to collect data regarding participants' self-esteem. This has been used extensively in many international studies and was recently assessed as having robust internal consistency as well as strong content, convergent and discriminant validity (Syropoulou et al., 2021). This measure is used to ask participants six questions about their self-esteem, which includes questions such as 'I feel I am a good person, as good as others' and 'I am able to do things as well as most people'. A five-point Likert scale is used ranging from 'never true' to 'always true'. Accessibility is enhanced with face symbols with a sad face symbol at 'never true' through to a smiling face symbol at 'always true'.

The *Social Network and Employment Scale* (SONES) (Forrester-Jones et al., 2006) was used with participants regarding details of their daily lives, including their activities and social networks. This was used as it included asking participants how many people they knew across a wide range of personal, casual and professional areas of their network and how often participants saw those network members. It also included questions on what activities were undertaken by participants at what days and times throughout the week, and questions on employment. Questions on how many people supported participants with different aspects of their care and qualitative questions regarding each part of the SONES were also included. The SONES has been validated and successfully used previously by Forrester-Jones et al. (2006) and later by Bhardwaj et al. (2018) and White and Forrester-Jones (2019).

Lastly the *Personal Outcomes Scale* (Claes et al., 2012) was used to ask participants to rate their satisfaction with different aspects of their quality of life. 48 questions are asked: six in each of eight 'domains' which include Self-Determination, Interpersonal Relations and Social Inclusion. Participants are asked to rate their answers to each question into one of three Likert-scale categories: 'frequently', 'sometimes' or 'seldom/never' which are given a score of three, two or one respectively. Scores for each question are totalled within domains and then summed to produce an overall quality-of-life index score. Space for qualitative comments is provided. The Personal Outcomes Scale has been successfully validated as having reliably strong etic and emic properties across a range of international settings by Jenaro et al. (2005). It has also been widely used and positively reviewed for its validity, reliability and generalisability in a range of studies (Gómez et al., 2011).

Although all five measures were used, this study reports on the findings from three measures. Findings from the Glasgow Anxiety Scale and the Rosenberg Self-Esteem Scale have already been reported in Forrester-Jones et al. (2021).

In terms of using these measures, I had previous experience of working with and interviewing people with communication difficulties and/or intellectual disabilities. Most participants were able to answer questions unaided by additional support, but others had support from friends, family or staff. Some participants with intellectual disabilities who functioned at a level where they could state their first name but not their last name or contact details asked their support staff to give me these details.

Although it can be difficult for any research participants to recall specific years of importance when being interviewed, many participants in this study were very clear about the year their care changed, improved or got poorer. Over half of affected participants were able to pinpoint the year in which this happened. Often changes were reported as having occurred within the 14 months of the interview period (July 2017-August 2018) or in the 12 months previous to their interview. It may be that the creation of Bradshaw's (1998) suggested 'communication environment' using a Total

Communication approach was helpful here. This encouraged and supported a conversational style of interview by providing time, familiarity and a range of signs, symbols, photographs and other objects of reference, used as appropriate (Cambridge & Forrester-Jones, 2003). One participant used photos as an aide to questions about their family members for example.

Analysis

The statistical analysis software package SPSS 26 was used to analyse the quantitative data pertaining to the 150 participants interviewed as part of the main study. Data were analysed in order that any statistical links within and between quantitative responses could be calculated, analysed and reported. In order to reduce the risk of Type One errors, significance levels of $p < 0.001$ were set.

In contrast to the analyses undertaken for the wider study, the quantitative analysis presented below specifically focused on the ways in which participants' care status may be linked to their social networks and care.

Two thematic analyses of the qualitative comments provided by participants have also already been jointly conducted and published as part of the wider study. These presented themes of Lost care, Changed Care and Impact on People's Lives (NIHR, 2020) and Lost care, Loss of independence, and Loss of Future Aspirations (Forrester-Jones et al., 2021). A further thematic analysis of the qualitative comments was deemed beyond the scope of this PhD study, therefore qualitative comments are presented from participants across the range of care status groups in order to give context to the current quantitative analysis. Pseudonyms are used throughout.

Results

Between July 2017 and August 2018 150 participants with intellectual disabilities living in England were interviewed. Table 5 shows the broad geographic location of participants.

Sample characteristics

Seventy-two (48%) participants lived in a town, 34 (22.7%) in a city or city suburb, 23 (15.3%) in a village/ rural area, 20 (13.3%) in a London Borough and one participant's (0.7%) specific address was unknown.

Table 5

Participants with Intellectual Disabilities' Geographical Locations

Location	Number and percentage of participants living in that area
Greater London	20 (13.3%)
North and Northeast of England	4 (2.7%)
Northwest England	27 (18%)
South of England	86 (57.3%)
Midlands	13 (8.7%)

Eighty-nine participants (59.3%) were male and 61 (40.7%) were female. Participants were aged between 18 and 79 with a mean age of 42.05 (median = 40, SD = 14.101). One hundred and forty-nine participants gave their ethnicity: 141 were White British, two were Black African, two Black Caribbean, one was 'Black other' and three were Asian.

One hundred and thirty-two participants (88%) were single, nine (6%) were married, three were co-habiting (2%), two were widowed (1.3%) and four were divorced or separated from their spouse (2.7%).

All participants had intellectual disabilities as identified by themselves, their families or service providers. Of these, most (n = 124, 82.7%) had mild intellectual disabilities; five (3.3%) had moderate intellectual disabilities, 20 (13.3%) had intellectual disabilities which enabled them to state their first names but not their surname or address and in addition, one consultee was used (0.7%).

Care Status

Participants were asked about their care over the last 10 years. Their responses were coded into four categories which reflected their care status.

Of the 150 participants, the largest single group (n = 61, 40.7%) had poorer care, followed by 53 participants (35.3%) whose care had stayed the same. Twenty-three (15.3%) participants had had their care changed without detrimental effects and 13 (8.7%) had had their care improved. Of those whose care had improved, 11 (84.6%) of these related to now getting a service when they had not previously, as a result of moving out of the family home (n = 8, 61.5%) or moving from Child to Adult Local Authority services (n = 3, 23.1%).

Questions regarding the process of assessment and care status were not asked. However, during the interviews 57 participants commented specifically on their experiences of the assessment process. Negative experiences of assessment under austerity were common across all care status groups.

Table 6

Participants' Experiences of Assessment Processes by Care Status Group

Care Status	Experience of Assessment			
Group	Poor Experience	Good Experience	No Comment Made	Total
Poorer Care	34	0	27	61
Changed Care	5	0	18	23
Improved Care	6	1	6	13
Care Stayed the Same	11	0	42	53
Total	56 (37.3%)	1 (0.7%)	93 (62%)	150

Overall, 56 participants (37.3%) described their experiences of assessment negatively, 93 participants (62%) made no comment, and one participant (0.7%) described their experience as positive. Table 6 presents this data in tabular form.

The person who described their experience as positive was a consultee who explained he had spent several years planning for his son's assessment while his son was a child and had made links with important people in the L.A. so his son would be more likely to get a service as an adult.

Negative experiences included examples of assessments being undertaken and changes being made without the knowledge of participants (John, Bill, Graham, Harry, Ian), of having to "fight" (Sophie) by making complaints, lodging appeals or going to court to challenge changes (Eric, Emma, Sophie, Lauren, Colin), and of feeling "punished" (Robin) and "insignificant" (Tim) by the process of assessment. Elizabeth, whose care improved after she challenged cuts, was typical of many participants who felt despite asking for help, Social Workers were "not interested in helping me". Margaret, whose care also improved after challenging cuts spoke about her constant "fight" for support, recounting a "hideous, degrading" meeting with Social Workers. Ryan, whose care got poorer, explained his Social Worker visited him and cut his day service from three days to one day per week "She didn't ask me, she just told me".

Similarly, participants were not asked about their relationships with Social Workers, care managers or other professionals as part of this study. However, 71 (47.3%) participants voluntarily commented that their relationships with Social Workers in particular had deteriorated since austerity had begun. Table 7 presents this data in tabular form in relation to care status.

One participant (0.7%) described their relationship with their Social Worker positively and 78 (52%) made no comment. In addition to the comments above, some participants added that they did not know their Social Worker anymore, others did not know whether they had a Social Worker. Others described feeling not listened to by their Social Workers.

Table 7

Participants' Experiences of Deterioration in Relationships with Social Workers by Care Status Group

Care Status Group	Experience of Relationship with Social Workers			
	Poor Experience	Good Experience	No Comment Made	Total
Poorer Care	40	0	21	61
Changed Care	8	0	15	23
Improved Care	8	0	5	13
Care Stayed the Same	15	1	37	53
Total	71 (47.3%)	1 (0.7%)	78 (52%)	150

Accommodation and Care Status

Participants lived with family (n = 54, 36%), in Supported Living with others (n = 42, 28%), alone (n = 21, 14%) or in 24-hour residential care (n = 20, 13.3%). Nine people (6%) lived in Shared Lives accommodation, 2 (1.3%) lived in Sheltered Housing, one person (0.7%) lived in probation housing and one person's accommodation (0.7%) was unknown. There was no statistical significance between care status and accommodation type X^2 (21, N = 150) = 24.440, *p* = 0.272, or any accommodation change X^2 (3, N = 16) = 42.747, *p* = 0.471.

Year of Change, Government and Care Status

For 82 participants it was possible to date their most significant change to care status. For the bulk of the time which participants were asked to consider (2008-2018) the Conservative/Liberal Democrat Coalition was in power, yet it was under a Conservative government, in 2017, that most participants experienced some form of change to their care. In 2017, 29 participants (35.4%) experienced either a key loss (n = 24, 82.75%), change (n = 4, 13.79%) or improvement (n = 1, 3.44%)

to their care. More people experienced a change in 2017 than in any other year. This link between year and any change however was not statistically significant X^2 (2, N = 82) = 6.586, *p* = 0.037.

Participants across each care status group gave numerous examples of the cuts, attempted cuts and changes they had experienced. Many participants referred to cuts being attempted or made by others (‘they’): most usually Social Workers, care companies, L.A. workers or the government at the time of the cut. Illustrative comments suggested both that cuts felt unfair and that participants felt uncared about by those making cuts. Joan, whose care improved after fighting against cuts explained “I don’t feel protected by the Government. I am just a number”.

Comments about improvements to care most often related to participants feeling cared about by staff or being happier in comparison to previous accommodation or care. Ben, whose care stayed the same after he challenged proposed cuts explained “Consistency is really important”, but he felt this was not important to others who made constant staff changes, often without notice. This meant he could not “plan or cook like I used to”.

Networks, Health and Care Status

Of the 145 participants who responded, 34 (23.4%) had not seen a GP and of 142 participants 68 (47.9%) had not seen a nurse in the previous year. Of 124 participants most (n = 113, 91.1%) had not seen a Learning Disability Nurse team member in the last year. Analysis suggested there appeared to be possible inconsistencies between perception of health and actual health. Despite 67 of 145 participants (46.5%) having visited a hospital and 115 (79.3%) being prescribed medication in the past year, of 136 participants who answered the question, most participants described their health as good (n = 64, 47.1%), or very good (n = 61, 44.9%). A chi-square test of independence found there was no significant association between perception of health and care status (X^2 (6, N = 136) = 7.984, *p* = 0.239).

Participants reported a range of experiences related to their health and support. Illustrative comments suggested interactions were important: being treated as a capable individual adult was linked to feeling safe for example (Jane, whose care got poorer). However, despite describing their health as good or very good, many participants explained they were confused about the purpose of their medication and the nature of their health conditions. Some participants listed the ways in which their health and wellbeing had deteriorated due to cuts. Most often this related to no longer being able to undertake healthy activities due to lack of funds or staff and/or being supported by health professionals or care staff untrained in working with people with intellectual disabilities. Arthur, whose care stayed the same, was typical of several participants, explaining ‘cooking’ with staff usually meant “they put things in the microwave”. Amy, whose care got poorer, felt uncared about when a nurse and other health professionals “couldn’t decide what to do with me as I only have mild LD but I have mental health problems”. She explained she was sent away after being told to seek support from MIND. Hasan, whose care stayed the same, explained his difficulties with health staff when he had blackouts “hospital and ambulance sometimes believe me, sometimes not”.

Networks, Finances and Care Status

Of the 150 participants, 138 (92%) stated they were receiving benefits, 3 people (2%) stated they received no benefits, 5 people (3.3%) were unsure and 4 (2.7%) gave no answer. Of the 146 people who answered, 91 (62.3%) were able to list some or all of the benefits they currently received. The majority of those 146 participants (n = 119, 81.5%) across all care categories did not know if their benefits had changed at any time.

A chi-square test of independence was performed to examine the association between benefit clarity and having control of one’s money. The association between these variables was not significant X^2 (1, N = 135) = 4.738, p = 0.03). Of 146 participants, the majority (n = 91, 61%) were clear about all of their benefits. Of 138 participants who answered, the majority reported that they had at least some control over their money (n = 109, 79%). Of those who reported not having any control of their money (n = 29, 21%), slightly more than half were not clear about their benefits (n = 16, 55%).

For 127 participants who responded, the majority (n = 100, 78.7%) had two or less contacts who helped them with financial matters. For those who had support with finances, family or staff were key figures. Illustrative comments suggested family members, support staff or charity workers had regularly completed paperwork regarding benefits and financial matters such as Personal Independence Payments (PIP) paperwork and these social network members were essential in appeals against benefits cuts, such as with Universal Credit (Lily). Regarding welfare benefits systems and practice, Jo, who has Cerebral Palsy and whose care had improved, felt strongly "I think the Government needs to listen". Regarding PIP she explained that untrained staff undertaking medical assessments had told her they hoped her Cerebral Palsy would be "better" after three years. She felt it was hard work battling for services against people who "haven't got a clue". Hannah, whose care got poorer, described being supported to appeal against the decision not to be granted PIP. When she attended court alone, without any promised support staff, she stated the judge told her "to come back when my leukaemia gets worse". Leo and George both felt confused regarding their benefits when they lost their Social Workers from their networks. Eric, whose care got poorer, spoke about the advocacy group he attended, "If it wasn't for this place I don't know what I'd do".

Networks, Activities and Care Status

All participants were asked about their daily activities. The activities undertaken were then categorised as being: 1. at home alone; 2. at home with others; 3. out of the home alone and 4. out of the home with others.

Participants were encouraged to define their own ideas of what constituted an 'activity'. Many participants listed both active and passive, enjoyable and less enjoyable activities and tasks which they undertook throughout the week. For many this included going to a day service/specialist group only attended by others with intellectual disabilities and support staff, watching television alone, doing puzzles alone or seeing family members (most often parents). Activities at home with others often included undertaking household chores with a member of staff. Activities outside of the home alone tended to include going shopping to a particular local shop where the participant was known.

Activities outside of the home with others usually involved those where participants were taken by staff to an activity being undertaken solely by a group of other people with intellectual disabilities, and/or activities in the homes of parents.

The mean number of activities per week across all participants was 12 (N = 144, R = 0-68, M = 12.18, median = 11.5, SD = 7.583). Table 8 presents the mean number of different types of activities engaged in across different categories (with range and SD) and the percentage in each care status group who undertook no activities in each category.

Table 8

Mean Number of Different Types of Activities Engaged in by 144 Participants Across Different Categories (With Range and SD) and the Percentage in Each Care Status Group Who Undertook No Activities in Each Category.

	Poorer Care N = 58		Changed Care N = 23		Improved Care N = 13		Stayed the Same N = 50		Total Participants Undertaking no Activities by Activity Type
	Mean, *SD,* Range	% No Activities	Mean, *SD,* Range	% No Activities	Mean, *SD,* Range	% No Activities	Mean *SD* Range	% No Activities	
Activities Undertaken on own at Home	M = 2.155 SD = 3.138 R = 0-11	N = 27 (46%)	M = 2 SD = 2.54 R = 0-8	n = 11 (47.82%)	M = 3.53 SD = 2.93 R = 0-9	n = 2 (15.38%)	M = 3.89 SD = 3.895 R = 0-18	n = 14 28%	N = 54 (37.5%)
Activities with Others at Home	M = 2.29 SD = 3.03 R = 0-13	n = 23 (39.65%)	M = 0.58 SD = 0.74 R = 0-2	n = 13 (56.52%)	M = 4.5 SD = 6.54 R = 0-21	n = 5 (38.46%)	M = 1.55 SD = 3.78 R = 0-23	n = 29 58%	N = 70 (48.6%)
Activities Undertaken in the Community on own	M = 0.84 SD = 1.42 R = 0-18	n = 33 (56.89%)	M = 0.47 SD = 0.84 R = 0-3	n = 16 (69.56%)	M = 0.46 SD = 0.77 R = 0-2	n = 9 (69.23%)	M = 1.03 SD = 2.79 R = 0-18	n = 35 70%	N = 93 (64.6%)
Activities Undertaken in the Community with Others	M = 5.93 SD = 3.56 R = 0-15	n = 3 (5.172%)	M = 7.25 SD = 2.84 R = 0-11	n = 1 (4.34%)	M = 6.32 SD = 2.72 R = 1.75-11	n = 0 n/a%	M = 6.96 SD = 3.57 R = 0.5-20	n = 0 n/a%	N = 4 (2.77%)
Total Undertaking no Activities by Care Status		N = 86 (59.7%)		N = 41 (28.47%)		N = 14 (9.7%)		N = 78 (54.16%)	

Analysis of variance found that there was no significant difference between the four care status groups in terms of activities undertaken on own at home (F = 3.16, $p > 0.01$, df 3) and activities undertaken with others at home (F = 3.78, $p > 0.01$, df 3).

Analysis of variance also found that there were no significant differences between the four care groups in relation to number of activities undertaken outside of the home alone (F = 0.59, $p = 0.622$, df 3) nor for activities undertaken outside of the home with others (F = 1.21, $p = 0.306$, df 3).

Activities at home alone. Analysis showed 54 participants (37.5%) undertook no activities at home independently. The largest mean number of activities at home alone was reported by those whose care had stayed the same (M = 3.89, R = 0-18).

For those whose care had changed and undertook no activities at home alone (N = 11), the largest group had experienced changes to their accommodation (n = 6).

Lack of independent activities at home occurred for a variety of reasons. Some participants counted watching television alone as an ‘activity’, while other participants explained that lack of support and cuts to welfare and services meant they usually spent their time alone at home in their rooms, bored and doing ‘nothing’.

Activities at Home with Others. In relation to activities undertaken at home with others, almost half of participants (n = 70, 48.6%) undertook no activities with others. Participants whose care had stayed the same or improved experienced the largest range of activities (R = 0-23 and R = 0-21 respectively). Those who had experienced changed care experienced the lowest range of activities (R = 0-2). Illustrative comments suggested that ‘others’ with whom activities were undertaken were most often support staff. Participants who did not like the person/ people with whom they lived often stayed in their bedrooms alone rather than spend time in the same room or doing an activity with them.

Others felt activities were not age appropriate. Laura, whose care improved as her declining health needs were met, stated “They try to get me to do activities, but I’ve said it’s for children not for me”.

Activities Undertaken Outside of the Home Alone. The majority of participants (n = 93, 64.6%) across each care group undertook no activities outside of their home on their own. Illustrative comments suggested that participants could feel unsafe when out alone or were more used to undertaking activities with others, most often a member of their family or staff member. Some participants were afraid of being alone and had experienced negative reactions from others whilst outside of their home and alone, ranging from being stared at whilst shopping to hate crimes, including physical and sexual assault. Eric, whose care got poorer, advised that he now had taught himself to “Be aware. Don’t show fear” whilst in town alone.

Activities Undertaken Outside of the Home with Others. Participants across all care groups experienced more activities outside of the home with others than any other activity grouping (n = 140, 97.22%).

Illustrative comments suggested that although this was the category where the largest number of activities were undertaken when compared to the other categories of activity, participants now undertook less activities outside of their homes with other people than they had previously. Beth, whose care had changed, explained her weekend was now the worst part of her week as it was “boring …. I don’t want to be on my own, it’s not my choice”. She wanted to “go somewhere and do anything”. Many participants explained that as their services were cut, they had financial support from their families (most often parents) in order to still attend a reduced number of groups. The activities which participants chose to continue to attend were often chosen in order to maintain friendships with social network members also attending that activity. Those who had poorer care commonly lost access to work, volunteering roles, day services, slimming clubs, colleges and transport. Cuts to direct funding from L.A.s to service providers led to clubs and transport companies charging for activities which were previously offered free or at a reduced cost. Some participants suggested that this double cut, for some combined with a third layer of cuts to welfare payments, meant the number of opportunities they had to mix with others away from their home had diminished. Not seeing friends as often saddened many participants. Although overall Sam felt his care had improved after moving from a service where he had only medical support to a residential home, he explained that welfare cuts and rising day service charges meant he had had to choose between keeping his car or going to a day service where he could see his friends. He gave up his car, but further cuts meant "Now I do not have the car or go to [day service]" (Sam).

Activities and Times of the Week. The care status of participants who undertook no activities was considered in relation to days and times of the week.

Table 9 shows the numbers and percentages of people in each care status group who undertook no activities during daytimes and evenings through the week. There were no statistically significant differences between the four care categories on the number of activities reported at any time of the day (daytime weekdays F = 1.57, $p = 0.199$, df 3; evening weekdays F = 1.33, $p = 0.266$, df 3; daytime weekends F = 1.65, $p = 0.181$, df 3; evening weekends F = 1.53, $p = 0.21$, df 3).

Participants across all care status groups were though significantly more likely to report no activities in the evening at weekends (X^2 (1, N = 144) = 0.979, $p = 0.001$). At other times, they were significantly less likely to report no activities (daytime weekdays X^2 (1, N = 150) = 138.24, $p < 0.001$; evening weekdays X^2 (1, N = 150) = 49.307, $p < 0.001$; daytime weekends X^2 (1, N = 150) = 96.0; $p < 0.001$).

Table 9

The Number and Percentages of Participants Undertaking no Activities During Daytimes and Evenings Through the Week

	Poorer Care and Undertaking no Activities at This Time	Changed Care and Undertaking no Activities at This Time	Improved Care and Undertaking no Activities at This Time	Care Stayed the Same and Undertaking no Activities at This Time
Daytime Weekdays	N = 1 (0.7%)	N = 1 (0.7%)	N = 0	N = 1 (0.7%)
Evening Weekdays	N = 11 (7.6%)	N = 8 (5.7%)	N = 2 (1.4%)	N = 11 (7.6%)
Daytime Weekends	N = 9 (6.3%)	N = 4 (2.8%)	N = 1 (0.7%)	N = 1 (0.7%)
Evening Weekends	N = 39 (27.0%)	N = 18 (12.5%)	N = 5 (3.5%)	N = 34 (23.6%)

Regarding weekend activities Trevor, whose care got poorer, explained “staff can’t be bothered”. Others were aware that cuts had impacted on the levels of staffing and services which could be provided “The staff have to do less and less…. They don’t pop in anymore. That’s all gone” (Simon, whose care got poorer).

Social Networks and Care Status

Overall mean social network size was 37.819 (N = 144, R = 4-157, SD = 29.11, Mode = 24). Analysis of variance found that there was no significant difference between the four care groups and total network size (F = 2.11, *p* = 0.102, df 3). Mean network membership was largest for work/day centre contacts, followed by family, church and club contacts, staff and other people with intellectual disabilities within the participant’s household. Neighbours and professional or keyworker contacts made up the least membership. Details of social network make up are detailed in Table 10.

Table 10

Range, Mean and Standard Deviation for Each Network Member Type

Type of Network Member	N	Range	Mean	Standard Deviation
People in Household	144	0-21	3.72	5.51
Residential Staff Contacts	143	0-50	4.05	7.51
Professional/Keyworker Contacts	142	0-20	1.24	2.55
Work/ Day Centre Contact	142	0-78	8.02	12.93
Church/Club Contacts	139	0-85	5.52	10.42
Shops/Pubs/Cafe Contacts	141	0-36	3.11	6.21
Neighbours Contacts	141	0-26	1.20	2.76
Family Contacts	144	0-40	5.59	6.09
Other Friend Contacts	139	0-41	3.19	6.06
Social Acquaintances	139	0-70	2.917	8.55

Seventy-seven (53.5%) of 144 participants stated they were unemployed, three (2.1%) were reported as long-term sick, two (1.4%) were students and one (0.7%) was on a vocational/apprenticeship programme. Six participants did not report their employment status. For the 61 participants who stated they were in either paid (N = 16, 11.1%) or voluntary (N = 45, 31.3%) employment, most (N = 46, 75.4%) were either paid by or volunteered at the organisation which supported them.

Participants had a mean of two close friends (N = 132, R = 0-21, SD = 2.664, Mode = 1), with 24 (18.2%) participants stating they had no close friends. Table 11 shows the number, mean and standard deviation of the numbers of close friends reported by participants in each care status group. Analysis of variance found that there was no significant difference between care categories and number of close friends (F = 0.39, *p* = 0.755, df 3).

Table 11

Number, Mean and Standard Deviation of Close Friends as Related to Each Care Category

Care Category	Number of Participants in Each Care Category	Mean Number of Close Friends	Standard Deviation
Poorer Care	56	1.88	2.11
Changed Care	21	1.81	1.43
Improved Care	12	2.58	2.64
Stayed the Same	43	2.28	3.65
Total	132	2.06	2.66

When asked to consider reciprocal support, of 100 participants, 55 had either no reciprocal relationships (n = 30, 30%) or a reciprocal relationship with only one other person (n = 25, 25%). Illustrative comments suggested that participants wanted relationships with a broader range of people than they currently experienced, including wanting to maintain relationships with professionals and with their neighbours. Zac for example, whose care improved, explained he was told he no longer needed a Social Worker, although he felt strongly that he both wanted and needed one.

Participants who undertook employment valued having non-disabled colleagues as members of their social networks. Participants also considered long-term friendships, often over decades, to be valuable. Many listed family, staff or ex-staff or work colleagues amongst their friends, or as their only friend. Most often participants' close friends were described as also having intellectual disabilities. Important aspects of close friendships included seeing one another regularly, friends being helpful with tasks participants could not do themselves, and friends listening to participants. Having to see friends less often as a result of cuts was difficult for many participants. Jeremy for example explained he now wanted to move so he could see his family and friends as often as he had before cuts were made. Others described the ways in which they felt the results of cuts meant they were lonelier than previously (Steve, Jasmine). Some participants expressed the desire for 'ordinary' "adult" (Steve) relationships which did not require facilitation by or reliance on staff. Many participants explained that friendships were built on trust and seeing one another often. Simon was typical of this understanding of friendship, explaining regarding his closest friend "I can talk to her, like normal people are meant to talk".

Summary of Findings

In this study only 'type and timing of activities undertaken' was found to be statistically significant when considered in relation to care status. In relation to activities, most participants undertook no activities with others in their home, and most undertook no activities outside of their home alone. Participants who had poorer care undertook fewer activities at home alone than those whose care had stayed the same. Participants whose care had changed undertook less activities at home with others than participants whose care improved. Participants with improved care undertook more activities overall than those whose care had stayed the same. The least activities across all care groups occurred at the weekends in the evenings.

Mean social network size was 37.8 members which was not affected by care status group. Network members came primarily from work/day centres, followed by family, church contacts, staff and other people with intellectual disabilities within the participant's household. Neighbours and professional or keyworker contacts made up the least number of contacts.

Accommodation type, perception of health and social network size were not statistically significant when considered in relation to care status. This study has highlighted that rather than care status, it was the often quality of relationships with others in their social networks that participants found to be important. This was defined by participants in terms of being known well by others, being understood and having long-term relationships with people who were considered helpful, knowledgeable and trustworthy.

Discussion

This study extends the body of literature which values the responses of people with intellectual disabilities in research. It also enhances our understandings of the ways in which people with intellectual disabilities experience their care from their own perspectives. Areas for discussion are considered below. These are the effects of cuts, cuts and social network opportunities, cuts and family relationships, cuts and relationships with professional network members and cuts, networks and welfare systems.

The Effects of Cuts

This study augments the literature which considers the effects of cuts on the lives of people with intellectual disabilities since the beginning of austerity measures in 2008 in the U.K.. It is positive that more than half the sample had experienced no detriment to their care and support during the 10 years considered in this study. However, despite previous gains under policies such as *Valuing People* and *Valuing People Now* (DoH, 2001; DoH, 2009), this study provides the additional information that only 8.7% of participants experienced their care as having improved over the past ten years, while 40.7% had experienced poorer care. This study suggests that people with intellectual disabilities may have experienced cuts and changes to their care and welfare under all relevant political parties in power between 2008 and 2018. There may be many factors as to why participants in this study experienced a change or poorer care during this time. Often policies can take time to come into effect and have both intended and unintended consequences for example. It is also entirely possible that some as-yet-unidentified factors have interacted to cause these changes. Despite the hopeful perceptions of carers regarding the Care Act 2014 (Gant & Bates, 2019) social care funding was at its lowest in 2014/15, lower than at any other time between 2011 and 2021, which may have impacted on the rise in requests for care across all adult social care sectors in 2017 (NHS Digital, 2022). This study therefore also increases current knowledge about the timing and types of cuts and changes to care that people with intellectual disabilities may have experienced. It also broadens current knowledge on the importance of social network opportunities.

Cuts and Social Network Opportunities

Previous research findings that the social networks of people with intellectual disabilities are significantly smaller than the general population, ranging from 0-42 members with a mean of 12 (Harrison et al., 2021) are echoed by this study. Many of the studies reviewed used the reports of staff or family members to ascertain social network size. However, this study found that although still small, a larger than previously reported mean network size of 38 contacts was found across all care status groups. This study suggests therefore that it is possible that when people with intellectual disabilities themselves are asked to list their network members, they include more people from a wider spectrum of contacts than are included when professionals or families are asked to list the network members of the people with intellectual disabilities they support.

Of the network members listed in this study, most (a mean of eight) were known from day services or places of work, which builds on research which highlights the importance of these places as opportunities for social network development and maintenance, as has been previously reported by Forrester-Jones et al. (2004) for example. This PhD study echoes Forrester-Jones et al.’s (2004) work which asked 20 people with intellectual disabilities who were in supported employment about their networks, using a similar social network measure. It is perhaps unsurprising that people with intellectual disabilities who are able to access supported employment would have larger than typical networks. Participant numbers in this PhD study were larger than Forrester-Jones et al.’s study and included participants across a wider range of employment status groups. It may also be that when the social network measure used prompts, participants with intellectual disabilities considered more of the people with whom they interact. Therefore, their networks may be reported as larger than when different measures are used. The networks reported in this study however were not reported as reciprocal and the numbers of people listed as good friends remained small at an average of just two people. Interactions with others in one's network still required significant support from family and staff who were instrumental in network maintenance.

This study also concurs with Lippold and Burns' (2009) research which argued that without support for social network development and maintenance, people with intellectual disabilities have limited opportunities for reciprocal or wider community relationships because they are unlikely to meet new people from a wide range of backgrounds and settings. Participants in Lippold and Burns' study also valued long-term relationships and seeing social network members regularly. This PhD study was a snapshot of participants' experiences at one time period, in which participants stated their largest group of network members were mainly found in day service or work settings. Many participants however, explained that opportunities for attending day services and other regular social network opportunities (where staff could be instrumental in network development) had been cut. Networks were dense rather than diverse, centred as they were around others with intellectual disabilities in segregated settings. This study suggests then that although participants still saw network members in these settings, they saw them less often than previously, as staff support was cut and the number of services which participants could afford to access was reduced. This may threaten the future stability of networks which have often been built up over many years.

Importance of and Nature of Activities Undertaken

This study supplements previous research which has reported the numbers of activities undertaken by people with intellectual disabilities and with whom they were undertaken (Emerson & McVilly, 2004; Jahoda et al., 1990; Murphy et al. 2017). It provides details on the number of activities undertaken at different times of the day and week, with different people and in different settings, and the ways in which participants felt a decade of cuts and changes to care had affected them in relation to their activities more broadly. As previous research has measured activities in different ways it is not possible to provide a clear or accurate comparison with the findings of this PhD study. Mean number of activities undertaken by participants in this PhD study was 12, but even participants undertaking a relatively large number of activities often explained that the number of activities they undertook had been reduced due to cuts to care, support, services and welfare. This study has also added to previous literature by highlighting that although accommodation and care status were not linked to a statistically significant level, participants' care status could impact the number and type of activities they undertook.

Participants who had poorer care undertook fewer activities at home alone than those whose care had stayed the same. Participants whose care had changed undertook less activities at home with others than participants whose care improved. Participants with improved care undertook more activities overall than those whose care had stayed the same. The least activities across all care groups occurred at the weekends in the evenings. Care status could also affect the number of activities undertaken by people with intellectual disabilities, and despite policies which have promoted the need for people with intellectual disabilities to live in communities, most participants (64.6%) undertook no activities outside of their home alone.

Cuts and Family Relationships

Previous research shows that although smaller community settings in general have been found to have more positive effects on quality of life than larger institutionalised settings, all setting types can have both positive and negative impacts on wellbeing. These are often influenced by the expectation levels of people with intellectual disabilities moving from institutions to community settings, by staff attitude and by the heightened accessibility of supportive family members (Harrison et al., 2021). The findings in this PhD study concur with these findings. The largest single group of participants in this study (54 of 150) lived at home with parents. This differs from the national picture, which suggests that at least half of people with intellectual disabilities live with their families. Of the 11 participants who experienced improved care in this PhD study, eight stated this was due to leaving the family home. This may allude to the importance of families getting appropriate, timely, meaningful services. This study also enhances the literature by illuminating the ways in which families may be mediating cuts to care and threats to social networks for participants living away from the family home. In this study, care status was not significantly statistically linked to the size of one's social network or the number of close friends one had. This study suggests that where possible, participants were financially supported by families to make choices which attempted to mediate cuts and maintain the small social networks which participants had.

Cuts and Relationships with Professional Social Network Members

In this study, as in Bollard et al.'s (2018) and Giesbers et al.'s (2019) research, people with intellectual disabilities themselves highlighted the importance of positive relationships with professionals and others who understood them and their needs. In terms of social networks and health, whilst the majority of people with intellectual disabilities in this study had seen a GP in the previous year, almost a quarter (23.4%) had not. Although it is possible that participants who did not see a G.P. may have been feeling well and felt no need to visit, these findings suggest that almost a quarter of participants may not have had an annual health check or medication review. These findings therefore agree with the NHS' own reports that policies designed to improve the health and wellbeing of people with intellectual disabilities may not be fully successful. This study also provides detail regarding network members who were health professionals, in finding that the majority of participants had not seen and did not list a Learning Disability Nurse as part of their network. Given the broad definition of social networks and their members, this brings further detail to the literature which raised concerns about the lack of social network members who specialise in the needs of people with intellectual disabilities (such as Cooper et al. (2015), Dunn et al. (2018) and Robertson et al., (2017)), particularly as it was meaningful relationships with people who understood them which the participants in this PhD study valued.

This study also echoes Bollard et al.'s (2018) and Giesbers et al.'s (2019) research in relation to other professional social network members. Workers who had previously been perceived as generally supportive of the wellbeing of participants, for example Social Workers, Care Managers and other Local Authority staff who now made cuts to care, services and welfare were considered to be unhelpful. Workers in these groups and politicians more widely were often considered to no longer care about participants or about the impact of cuts on them and their lives. This study therefore strengthens the literature by suggesting that cuts to services have the potential to negatively affect relationships with professional members of social networks.

Cuts, Networks and Welfare Systems

There is little research regarding the ways in which people with intellectual disabilities manage their money in times of cuts and the research which does exist highlighted that this was extremely difficult without support (The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). The research findings of this PhD are compatible with that study as participants in both studies stated that support most often came from families and from staff in organisations which supported people with intellectual disabilities. This study has augmented the literature further by highlighting the link between learning and maintaining the skills of understanding one's finances and having at least some control over those finances. This study suggests that in times of cuts, even when participants did have a level of control over their finances, they often did not know whether or not their benefits had changed and also needed significant support to negotiate and challenge welfare systems. This study has suggested that having people in one's social network who were able to understand, negotiate and challenge welfare systems and decisions was beneficial for many participants who relied on this support.

This study has highlighted the ways in which adults with intellectual disabilities could experience cuts to care. Analysis of these experiences has suggested that cuts could have negative impacts on many areas of the lives of people with intellectual disabilities. Activities and social networks which were meaningful, which included people who knew them well and people who had a level of expertise in intellectual disabilities could be vital for the care, health, and wellbeing of people with intellectual disabilities in times of austerity.

Limitations

There are some limitations to this study. This study demonstrated that the L.A. area and the political leanings of L.A. in which participants lived did not impact on participants' care status. Yet the study did not include equal numbers of participants across all L.A. areas of England, therefore comparison of the impacts of cuts in relation to L.A. area could be being missed. Wider representation of more L.A.s would be helpful, especially as The Care Act was created in response to the 'postcode lottery' of care provision previously available. Some parents who acted as gatekeepers refused access to their sons/daughters, stating their son/daughters' intellectual disability meant they would not understand any questions I asked. This may account for the lower than national average numbers of participants who lived at home with family being included in this study.

Information about the cost of care and support and the savings thought to have been made by financial cuts would also be beneficial, in order to assess whether there were statistically significant differences between participants living in different L.A. areas. The study captured data at one point, so comparison of changes over time was limited, although participants were able to state clearly whether or not their care and support had changed and give information about the details of those changes. Although almost equal numbers of participants were found to have poorer care (n = 61, 40.7%) or had their care stay the same (n = 53, 35.3%), it is possible that as participants were accessed through gatekeepers they may have selected participants who had had recent changes to their care status. However, other participants who had experienced no changes, were also recruited via gatekeepers, and other participants with and without recent changes were recruited via their friends who had already been interviewed and reported the experience of being interviewed as positive. Gatekeepers may also have selected participants whom they felt were more able to answer questions asked by a researcher, which may have created bias in the sample away from those with significant difficulties in understanding.

The use of questionnaires in a face-to-face interview aimed to be as inclusive as possible to enable participants to give their responses regarding different aspects of their lives and to be supportive of people with a range of abilities. However, it may be that offering participants the opportunity to complete questionnaires in their own time with or without their choice of supporter may have suited the needs of some participants better. Certainly, one participant wanted his support worker rather than me to ask him the questions and write down his answers while I was there, which worked well for him. Other participants wanted to be interviewed in groups of two, three or four in friendship or family groups. This also worked well for them as the most 'able' participant would be chosen by the group to be asked and answer the first set of questions, through to the least able participant in the group. This enabled those who wanted extra time to think and process the questions and their possible responses to take part. When this happened, which was very occasionally, answers each person gave were different, which reassured me that the participants were not simply repeating what the previous person had said. However, offering this option from the start may have reassured and better met the needs of potential and actual participants with a wider range of abilities.

Nevertheless, the sample size was 150 participants with intellectual disabilities who were asked questions directly and did give detailed information about how cuts and changes to care had affected their lives. One hundred and fifty participants is a higher sample than other studies (Malli et al., 2018) and does add to our understandings of the experiences of people with intellectual disabilities.

In terms of methodology, limitations were also identified regarding the measures. Many participants stated their health was good or very good for example but had also had hospital appointments and/or been prescribed medication in the past year. It may be that health had improved as a result of these interventions, but this was not identified as a question on the measures and cannot be assumed. Similarly in terms of social networks, participants identified that they attended less activities than previously and saw friends less. Capturing data at one point meant that follow-up questions were not considered until data was being analysed. This data set could though be used as a baseline for future research which could consider these complexities in more detail.

This study was undertaken before the Covid-19 pandemic further affected funding for adult social care. The extent to which care status during and after the pandemic may further affect people's social networks is an area which requires further study.

Reflexive Considerations

Although I was asking participants about their welfare benefits and their support, often with interested parties such as workers or friends in the vicinity, the questions were mainly quantitative, and I had not anticipated any major difficulties regarding participants' responses. I had spent eight years previously working with people with intellectual disabilities and building a rapport in ways which I, and hopefully they, felt were respectful, warm and approachable. I felt this was key in relationship building. I am sure this is why I kept (and keep) referring to participants as 'people with intellectual disabilities' rather than 'participants in this study' (an issue which was raised when I submitted the literature review for publication).

I had not considered that my working so hard to be approachable would possibly be a factor in many participants telling me their stories of rape and other abuse. Abuse did not feature as part of the questions or measures I was using in any way. I found these accounts incredibly difficult to hear. The tipping point came when after five people in a row recounting their experiences of being raped as children, I interviewed a man who told me he had been sexually abused his entire life, had been homeless for 18 months and had in the previous week been placed in a hostel as he had been sectioned so many times he had been told he was costing the NHS too much money. The hostel housed people who dealt drugs (to which he was addicted) and the local mental health team had assessed the hostel as too dangerous for them to visit, even in pairs. He explained he was afraid of the dark as "bad things happen to me in the dark". Workers later gave me the same account and showed me an email from his Social Worker clearly stating she would not help him until he stopped using drugs. The workers had reported this situation to the L.A. and to the Police as Safeguarding issues.

Workers also explained that after our interview, he was “stunned” that I had believed him, as he was so used to being disbelieved. Many participants had told me that my writing down what they told me had been important to them. I had not realised how important this was until workers explained that many participants were used to being visited and asked questions by professionals as part of reassessment, and that not writing down responses was interpreted by participants as not being believed.

Another person told me she was being threatened with rape by her neighbours, which then involved careful discussion with my supervisors and my reporting this to Social Services and Police and following this up in meetings with the person, and relevant agencies. These and other encounters made me consider far more deeply the ways in which I was interacting with participants. I had already taken the approach that participants taking the time and effort to share their experiences was a gift and I understood our relationships in that manner. Several participants and workers had told me they expected a stereotypical ‘distant’ university researcher who knew nothing about intellectual disabilities and who would ask difficult questions which participants would not understand. I wanted to close the distance between us and build a meaningful (if brief) relationship.

After much reflection and discussion with my second supervisor, who regularly researches the topic of sexual experiences of people with intellectual disabilities, I realised that this was a part of the research relationship I needed to completely reconsider. I was advised to take a break from interviewing, to talk about and write down my feelings to ‘get them out’ of my head. I discovered that I needed to create some form of protective barrier not between myself and the participants but around myself. I started preparing an invisible ‘bubble’ around myself before I interviewed participants and I prepared myself to hear traumatic events. Balancing the desire to be close with participants, while also protecting myself without distancing myself was incredibly difficult. I used this ‘bubble’ approach with the remaining seven participants I later went on to interview. None of them told me about any sexual abuse, but one participant became upset when he told me about the significant antagonism he had experienced from members of his family when he married his long-term male partner. I took this to mean that despite my ‘bubble’ approach I was still being seen as approachable, and other participants told me details of their lives beyond what I had asked, but I do not know this was the case. I could not perceive any noticeable difference in the ways in which the interactions between myself and participants changed as a result of my new approach.

I have though learned that the next time I undertake research with people with intellectual disabilities I need to have a robust, proactive and ongoing way to protect myself from being overwhelmed by my reactions in order that I do not need reactive strategies. As a manager it was my role to work with people in the long-term to help them to access services in order to get support to deal with experiences such as previous or current sexual abuse. This would often involve advocacy services, counselling services and sometimes the Police. It was not my role to provide counselling, but I could ‘make a difference’ in my manager role by arranging these services. The situation where I am not able to offer this support has helped me to reflect that although I as a researcher am responsible for my actions, such as the questions I ask and the way in which I ask them, I am not responsible for what participants then choose to share or for offering/arranging long-term support. Feeling a meaningful connection with participants though remains an important part of my ongoing engagement with the ways in which relationships can affect the research process.

Implications for Research, Policy, Practice and Families

Findings suggest that policies which aim to promote wellbeing and social inclusion and prevent people with intellectual disabilities and their families sliding into crisis, do not appear to have been fully successful in achieving those aims thus far. Policies which actively promote and fund the development and maintenance of networks may provide some opportunities to enable people with intellectual disabilities to maintain or even enhance their networks, and by extension, aspects of their wellbeing. Findings suggest that the creation and delivery of policies which promote and protect social networks may become even more important if feared future cuts further affect the finances and care of people with intellectual disabilities and their families.

This study also highlights the importance of meaningful relationships with staff members and those professionals on whom people with intellectual disabilities may have come to rely for support. That participants in this study recognised and valued support staff having time for them, treating them as adults and providing consistent and knowledgeable care, may give hope to practitioners that their relationships are valued. It also highlights the importance of staff recognition of the importance for people with intellectual disabilities of having a range of social network members who can provide help and support, in different areas of their lives, as and when they need it.

Conclusion

This study aimed to investigate the ways in which cuts to care may have affected the care and social networks of people with intellectual disabilities. Meaningful relationships with others were found to be important to participants. Social networks were found to be important for health and wellbeing and for negotiating complex welfare systems. Services, including day services, which offered activities were important as places to access social network members and to access support. That most participants currently undertook no activities in the evening at the weekend hints that opportunities to develop social networking opportunities may be being missed. As activities were cut, so the opportunity to develop new relationships could be threatened.

Quantitative data analysis and illustrative comments in this study suggest it is the ability to maintain meaningful, helpful relationships with one’s social network members that may be of more importance to people with intellectual disabilities than one’s care status. The dream of having an ‘ordinary’ life in times of austerity may rely on support to maintain the “social glue” on which people with intellectual disabilities rely for their care, and for social network development and maintenance. Tensions between placing responsibility for services, care and support onto families and/or informal groups while cutting funding to these and other external essential services are thorny issues with which policy makers, practitioners and researchers could usefully further engage.

Chapter Seven: Discussion

The aims of this research study were to investigate the views and experiences of parents of adults with intellectual disabilities, service providers and people with intellectual disabilities around care and social networks in times of austerity. For this study, effects of austerity were defined as cuts to services, care, support and/ or welfare which affected people with intellectual disabilities, parents or service providers. For ease, all types of cuts are referred to as ‘cuts to care’ throughout.

This discussion chapter will present and consider the new data which is my original contribution to current literature on the experiences of care and social networks of people with intellectual disabilities, parents and service providers in times of austerity. Firstly, I will present a summary of the studies. I will then relate the findings of the studies (Chapters Four, Five and Six) to the review of literature presented in Chapter Two. Consideration of the robustness of claims made is then discussed, as are possible implications of this study and opportunities for further research.

Overview of Studies

To establish a baseline regarding the social networks of people with intellectual disabilities, a literature review was undertaken (Study One) which reported and analysed the experiences of adults with intellectual disabilities in relation to their social networks. Study Two was used to consider how ten parents of adults with intellectual disabilities experienced cuts to care, in their own lives and social networks and the lives and networks of their adult children with intellectual disabilities. Study Three explored the experiences of nine service providers in relation to care, relationships and social networks and the care and social networks of the adults with intellectual disabilities whom they supported. Study Four considered the experiences of people with intellectual disabilities in relation to their care and social networks. All studies related to experiences in times of austerity. The findings from each of these studies are briefly summarised below.

Study One (Harrison et al., 2021)

Analysis of the quantitative studies found a mean network size of 12 members for people with intellectual disabilities. Social networks were typically made up of staff, family, and other adults with intellectual disabilities. Accommodation and location played a role in social network size and membership, but other factors were also important. People with intellectual disabilities who had larger more diverse social networks were found to also have lower levels of support needs, were supported by organisations which had a culture of person-centred/ active support and undertook activities in locations which were not segregated (such as workplaces). Analysis of the qualitative research suggested that social networks and positive relationships were essential for the formation and maintenance of a positive sense of identity, but that a sense of powerlessness was common. Stigma and normalisation were important concepts in the lack of inclusion experienced. The role of parents could be experienced negatively or positively by people with intellectual disabilities. Parents were reported as not trusting the rhetoric of any policy which claimed to promote the independence of their sons/daughters.

Study Two

Findings from analysis of qualitative interviews with parents of adults with intellectual disabilities in Study Two found that parents reported their own lives had become harder as care was cut. They felt austerity as a concept had failed them and their sons/daughters in many ways. They reported that false assumptions about the identities of their sons/daughters had led to unjustified cuts. Parents felt they and their sons/ daughters were being strategically and practically distanced from having meaningful relationships with L.A.s and their workers.

Cuts had led to mistrust, lies and punishment for many parents. Previously many parents had enjoyed relationships with workers as part of their supportive social networks. Others had always found relationships difficult. Under austerity relationships had become characterised as (worsening) battlegrounds. Parents felt forced to change their identities to become fighters. Parents often felt powerless and had limited social networks, nevertheless they found social networks to be helpful in this fight. Working in partnership to build rather than cut social networks was suggested as a possible approach for the future.

Study Three

Study Three considered the qualitative experiences of service providers. Perceptions of different approaches to care emphasised that these participants felt there were fundamental differences between themselves and their funders in the way in which the concept of care was understood. Like parents, providers felt care for and about people with intellectual disabilities was regressing to historically very poor levels. Distancing in relationships with funders was reported. Lost and changed identities were also identified as issues by service providers who felt powerless in many ways. Physical and emotional pain, stress and worsening wellbeing were reported by service providers in relation to themselves and others, including people with intellectual disabilities. Policy and legislation were considered to be misused or misunderstood by funders in order that cuts could be made. The study concluded that policies and practice which respect, and value relationships and partnership working could improve experiences in times of austerity.

Study Four

Study Four considered the experiences of 150 people with intellectual disabilities. In relation to care status the largest single group (n = 61, 40.7%) experienced poorer care under austerity, followed by 53 participants (35.3%) whose care had stayed the same. Twenty-three (15.3%) participants had had their care changed without detrimental effects, and 13 (8.7%) had had their care improved. Overall mean social network size was 37.8 members. There was no significant difference between the four care status groups and total network size. Social network members were found to be crucial for financial management and control, health, wellbeing and accessing activities. These were all reported to have been negatively impacted by the effects of austerity.

There were no statistically significant differences between care status and accommodation type or any accommodation change.

The mean number of activities per week across all participants was 12. Participants across all care groups experienced more activities outside of the home with others than any other activity grouping. Participants across all care status groups were significantly more likely to report no activities in the evening at weekends (X^2 (1, N = 144) = 0.979, $p = 0.001$).

Cuts to care meant activities were not available, were no longer affordable or were delivered by people without experience of intellectual disabilities. Participants reported being assessed and having welfare and services cut by people with no knowledge of the nature of intellectual or physical disabilities.

Also important to participants was the need to feel consistently cared about.

Study Four concluded that policies and practice which actively valued the importance of long-term, meaningful social networks for people with intellectual disabilities would be essential for their current and future health and wellbeing.

Discussion

In relation to the research question *What are the views and experiences of parents of adults with intellectual disabilities, service providers and people with intellectual disabilities around care and social networks in times of austerity?* this chapter suggests that relationships appear to have been changed under austerity policies. Key aspects of these changed relationships will be considered. These are themes of: feeling distanced from governments, L.A.s and workers; of systems being designed in order to create this distance; of feeling uncared about; of having poorer wellbeing and of feeling the need to become fighters. Experiences and changes around eligibility, austerity and reassessment under The Care Act will also be considered. Care ethics, stigma and academic literature will be applied in order to provide context to the findings of this study.

Relationships with governments, L.A.s, Social Workers, other L.A. workers, welfare workers, and health service workers were examined from three different perspectives. One hundred and fifty people with intellectual disabilities were interviewed using a range of mixed methods questionnaires and additional comments were noted. Ten parents and nine service providers were interviewed in semi-structured interviews.

The issue of relationships will be considered from these three perspectives. The strength of evidence for claims made will also be considered. As it was a key issue in each of the three studies, the issue of relationships with Social Workers and assessors in particular will be related to the literature. Following this exploration, ideas around future data collection will be suggested, and key issues and implications will be highlighted.

People with intellectual disabilities, parents and service providers reported feeling that their relationships with L.A.s and workers had deteriorated. The loss of feeling understood by known, helpful Social Workers and other L.A. workers was reported. Under austerity, participants described feeling misunderstood by unknown, unhelpful L.A. workers. This study found this shift to be a crucial change in relationships. A feeling of being actively distanced from both Social Workers and assessors in particular was reported to now characterise these relationships.

Distanced Relationships and a Loss of Feeling Known and Understood

In this PhD study, loss of helpful L.A. workers and the introduction of unknown workers who were felt not to understand people or their needs was experienced not only by parents (as with Walmsley et al.'s (2017) and Hamilton et al.'s (2017) studies) but also by people with intellectual disabilities and service providers. All three of the studies within this PhD identified this loss as an effect of austerity policies. Similarities in experiences included feeling a sense of loss of previous relationships which had at times worked well and feeling powerless in relation to this loss. Hamilton et al. (2017) and Head et al. (2018) have previously reported this feeling of powerlessness in relation to people with intellectual disabilities in terms of accommodation and support staff. In Grant's (1973/1993) study, as a Social Worker joined a family's social network, a relationship with another social network member (such as a helpful neighbour) was lost. In contrast in this PhD study, under austerity, the loss was of a known, often helpful, Social Worker who was replaced by a new unknown worker who did not appear to understand the wide range of effects of cuts on people with intellectual disabilities, parents, or service providers. This PhD study suggests that the findings of previous studies can be developed to also be applied to relationships with Social Workers and assessors in times of austerity for people with intellectual disabilities, parents and service providers.

Across each of the three studies feeling insignificant and uncared about and that workers were uninterested in people and their needs was a common theme. In this study, when new and unknown Social Workers and assessors were involved in assessing needs, people with intellectual disabilities, parents and service providers reported these workers to be unhelpful and critical of them. This was the case whether they were perceived to be unqualified assessors or qualified Social Workers. These findings concur with Walmsley et al.'s (2017) and Hulbert-Williams et al.'s (2011) research which reported parents and people with intellectual disabilities feeling that L.A. workers were critical, rather than supportive, of them. In this PhD study, however, the process of trying to access early intervention and support was experienced negatively not only by parents and people with intellectual disabilities but also service providers. In addition, this PhD study has provided some insights into the views of people with intellectual disabilities about their experiences of new Social Workers and assessors, some of whom “haven't got a clue” (Joan, Chapter Six) for example.

These experiences also add to the sparse research on the views and experiences of Care Act assessors in terms of relationships. Under austerity Coderre-LaPalme et al. (2021) found that some welfare workers in the U.K. experienced increased pressure to sanction claimants and that others were given numerical targets for the number of sanctions they should make. Symonds et al. (2018) found that both qualified and unqualified, experienced and inexperienced assessors typically did not know their clients although they wanted to. It may be then that both assessors and those being assessed wanted meaningful relationships but that assessors were bound by the bureaucracy of budgetary restraints. That assessors may want relationships with their clients was not experienced by any participant group in this PhD study. Instead, distanced relationships were experienced by people with intellectual disabilities, parents and service providers as feeling misunderstood, disbelieved, untrusted and judged as having no legitimate claim to care. In addition, service providers felt assessors and service providers had fundamentally different understandings of the concept of care in times of austerity. Symonds et al.'s (2018) and Coderre-LaPalme et al.'s (2021) work may also go some way to explain why participants in each of the three studies in this PhD study described relationships with L.A.s and their staff as becoming aggressive and adversarial.

This PhD study suggests then that in times of austerity, feeling one is unknown and misunderstood may be related to experiencing negative effects on one's care and identity whether one has intellectual disabilities, is a parent or is a service provider.

In this PhD loss of known workers and associated feelings of being known, understood, trusted and believed were linked to the introduction and operationalisation of austerity policies beyond that already reported in the academic literature.

Not all the participants had the same experiences. Differences included three parents who had always experienced negative relationships with Social Workers and assessors. Although Forrester-Jones et al. (2021) were clear that relationships within social networks may or may not be considered helpful in terms of the provision of support, parents in this PhD study add that their negative relationships had worsened as austerity policies had been introduced and applied. For these parents, negative relationships with known workers were replaced by worse negative relationships with unknown workers.

Another difference was the ways in which some parents in this PhD study went further than Power (2008), Forrester-Jones (2021) and Walmsley et al.'s (2017) conclusions regarding difficult relationships between parents and Social Workers. All parents in this PhD study reported they felt they were lied to, and some felt lied about and punished when they complained about their treatment (see Chapter 4, Theme 3 An Ethos of Cuts has led to Active Mistrust, Lies and Punishment for example). This was also reported by them as being a result of austerity and added to their sense of powerlessness. This adds further detail to the existing literature regarding the ways in which austerity may interact negatively with feelings of powerlessness for some parents.

Systems were Designed to Create Distance

In this PhD study service providers and parents were clear that the changes they experienced in their relationships with L.A. workers were considered to be deliberate, systematic attempts to distance people with intellectual disabilities and parents from access to support systems. The introduction of access to support being available exclusively through almost inaccessible 'hubs'[1], of welfare systems being introduced which were inaccessible to people with intellectual disabilities unless they had considerable support, and of information about support being withheld from parents, suggested to service providers and parents that under austerity, access to support was being deliberately blocked. This perception goes beyond previous research which suggests that the systems which governments and L.A.s use for people to access to support could 'inadvertently' put off parents from applying for support (Forrester-Jones, 2021). It also suggests that the introduction of systems which are actively applied as barriers to block access to support for parents of children with mental health needs by stressed and overwhelmed charity and L.A. workers (Kiely & Warnock, 2023) may not be isolated to just those workers.

This study has found then that austerity was linked to feelings of being unknown and misunderstood within relationships which were characterised as distanced. Not only parents but also people with intellectual disabilities and service providers have found themselves distanced from governments and L.A.s and their workers. For some participants, particularly parents and service providers, 'governments' related to successive or particular political parties who were or had been in power. It was not only particular departments of government which were felt to not understand or care about participants and groups, but the people leading and running entire political systems who were considered to promote an ethos of cuts at any cost. People with intellectual disabilities did not

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[1] Parents in Chapter Four described a 'hub' as single point of contact which those seeking support or communication with their L.A. must use. These were felt by parents to be designed to systematically block access to support and to individual workers.

refer to particular political parties but referred to ‘the government’ in more distant, general terms. This distance and associated feelings of being unknown and misunderstood may have created a vacuum which became filled with feeling uncared for, experiencing poorer wellbeing, and feeling the need to respond to these changes by becoming fighters.

Feeling Uncared About

This study suggests that austerity can be considered to have created or deepened feelings of being uncared about. Although this is not a comparison study, and interviews were undertaken at one time point, feeling uncared about could be seen in the reports of loss or deepening lack of a sense of reciprocal relationships in this study. Parents in this study echoed the feelings of parents in Walmsley et al.’s (2017) work: that they were saving the State significant funds but being treated as burdens. This PhD study adds the feelings of people with intellectual disabilities, who also felt uncared about and that they had come to be seen as burdensome as Jo (Chapter Six) explained, “I don’t feel protected by the Government. I am just a number”. The three parents who adopted their children felt particularly aggrieved, and service providers too felt a loss of reciprocity in times of austerity, for themselves and others. This included when their own “good” nature and work was considered to be called into question and they felt they were treated as though they were untrustworthy animals “we’re all pigs in the trough now” (ST1, Chapter Five).

The finding that people with intellectual disabilities across all care status groups have also reported feeling uncared about by governments, L.A.s and workers (Chapter Six, Care Status) also provides new insights into the possible effects of austerity.

Wellbeing

There has been very little research globally or nationally regarding the well-being of people with intellectual disabilities in times of austerity (Malli et al., 2018). The literature review and synthesis which forms part of this study (Harrison et al., 2021) identified that the concept of wellbeing included social identity, social functioning, happiness, mental wellbeing, leisure activities and social inclusion. The Care Act (2014, c.23, Part 1) defines wellbeing as including: dignity; emotional wellbeing; control over daily life; participation in recreation; social and economic wellbeing; domestic, family and personal relationships; living accommodation and making a contribution to society.

Reduced wellbeing has been linked to reduced interaction with social networks for people with intellectual disabilities (Hamilton et al, 2017; The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly, 2012). This PhD study suggests that austerity measures have led to cuts across a range of areas of care including but not limited to individual welfare, parental welfare, services, staffing, and transport. The effects of the combination of these different cuts were reported by people with intellectual disabilities and parents as leading to them seeing their social network members less often. There were differences in the social networks of people with intellectual disabilities and those of parents, however.

For people with intellectual disabilities, social networks were clearly linked to social activities. In particular, the time people could spend building and maintaining relationships based on trust and where meaningful support could be obtained. People with intellectual disabilities reported for themselves, and parents and service providers agreed, that they had less activities to undertake and saw members of their social networks less often than they had before austerity measures had been introduced. Weekend evenings in particular have been shown in this study to be the time when the least activities and least engagement with social network members took place. The number, type and timings of activities in this PhD study provide greater detail than other studies (such as Murphy et al. (2017) for example) regarding the ways in which people with intellectual disabilities spend their time. For people with intellectual disabilities, seeing social network members less often was experienced negatively and parents were relied on to a greater extent in order that some engagement with activities in which social network members were seen could still take place. This was reported to have negatively impacted the wellbeing of both people with intellectual disabilities and parents.

For parents, social networks were clearly linked to emotional support and the gaining of information to enable them to understand their rights and the rights of their sons/daughters. Parents too saw social network members less often. Austerity policies were felt to have resulted in parents undertaking more caring tasks for their sons/daughters which left them too exhausted to engage with social network members. Having social networking opportunities such as advocacy groups cut by L.A.s was considered by parents to be deliberate and another result of the ways in which cuts across different areas could interact to reduce wellbeing.

Parents and service providers highlighted the irony that policy and legislation should promote wellbeing and protect people with intellectual disabilities and their parents from loneliness and isolation, but in times of austerity, policy and legislation appear to them to be having the opposite effect. As people with intellectual disabilities and parents felt uncared about, it may also be an ironic outcome of austerity policies that people in these groups also appeared to be less able to access informal support from elsewhere as they saw their social network members less often.

The language of feeling exhausted, screwed down, untrusted, degraded, not believed, unwanted and excluded was common in each of the three studies. Early deaths of parents and of people with intellectual disabilities were felt by parents and service providers to be an inevitable result of the lack of care and deteriorating well-being associated with austerity policies (Chapter Four, Theme One; Chapter Five, Theme Two).

The negative impacts of austerity on well-being for service providers, including high levels of mental distress and burn-out for themselves and their staff, appear to be new in the academic literature, as do reports that service providers can also feel uncared about and untrusted. Care being perceived as a commodity and the ways in which this can obscure inequalities and suffering for people using services and their families has been previously reported (Bates et al., 2017; Bowden, 1999; Clapton, 2008; Lolich, 2017). The higher levels of stress which staff can experience in non-reciprocal relationships with people with intellectual disabilities has also been researched. Relationships which lack reciprocity appear to be linked to higher levels of difference between staff members and the people with intellectual disabilities whom they support, particularly in relation to communication abilities and behaviours that challenge (Simons et al., 2021). This also includes wider issues such as the ways in which reciprocity can be improved by staff training, and the desire for lowered expectations around work-rate (Rose et al., 2010; Ryan et al., 2021; Thomas & Rose, 2010).

The difficulties managers have experienced trying to provide basic services in times of austerity has also been researched (see Bradshaw et al. (2018) for example). The ways in which relationships between staff and managers (Deveau & McGill, 2016) and relationships within organisational cultures (Gray & Muramatsu, 2013) can affect stress-levels have also been described, although this type of research rarely specifically considers cultures within intellectual disability services (Humphreys et al., 2022). That service providers in this PhD study reported feeling a link between austerity and feelings of increased stress and burn-out may add to Ryan et al.'s (2021) findings that managers experienced less stress than support workers and to Stevens et al.'s (2021) work which found that the most committed workers experienced the most stress. This may be related to service providers feeling the need to fight, which is considered in the next section of this chapter. Although comparisons of service providers' and workers' stress levels were not investigated in this PhD study, findings do offer further insights into the level of emotional connections and related stress which service providers can experience.

Having to Fight

People with intellectual disabilities, parents and service providers in this study have highlighted then the ways in which the effects of austerity could be perceived to be negatively influencing them, particularly in feeling uncared about and in reducing wellbeing. While parents have often felt the need to take on the identity of a fighter, feeling uncared about in this study was linked to a situation which created fighters not only of parents, but also of people with intellectual disabilities and of service providers.

Relationships between L.A.s and parents have often been reported in academic literature as adversarial, with parents feeling the need to adopt the identity of fighters (Power, 2008; Walmsley et al., 2017). Parents in this PhD study also gave examples of needing to change their identities to fight back against cuts, against feeling uncared about, and against the lowering of their wellbeing and the wellbeing of their sons/daughters. This PhD study adds the finding that service providers and people with intellectual disabilities too can feel the need to adopt roles of fighters.

The recurrence of the language of battle was noticeable in this PhD study. What appears to be new knowledge is the use of this language and associated feeling of needing to be fighters in times of austerity for people with intellectual disabilities and service providers. The eleven members of the Money, Friends and Making ends Meet Research Group c/o Liz Tilly (2012) stated they felt they could be “always in a battle” (p.131) regarding their attempts to use digital systems. This PhD study widens this battle to include people with intellectual disabilities feeling the need to be fighters in their relationships with Social Workers and assessors. Over a third of people with intellectual disabilities in this study reported negative interactions with workers in these groups for example (Chapter Six, Care Status). Rather than partners in care relationships, austerity appears to have resulted in the creation of wider adversarial relationships than previously thought. Tronto (2013) and Rogers (2016) argued in their work that people with intellectual disabilities should not be seen as passive recipients of care, but instead as active members of communities, having much to offer in reciprocal care relationships and in societies more widely. This PhD study appears to show that people with intellectual disabilities may also be demonstrating their lack of passivity by fighting back against cuts, against feeling uncared about, and against their lowering wellbeing. They did this by challenging assessors and Social Workers in meetings and by gaining support to appeal decisions to reduce their care. This study also highlights that this can happen across different care status groups.

As service providers felt less and less cared about and understood by governments and L.A.s, they too adopted fighting identities. This also appears to be new in the academic literature. Although parents have reported feeling the need to fight against service providers, and that feeling was echoed in this PhD study, service providers in this study reported their own battles with funders. These battles were against cuts to their own services and the services of people with intellectual disabilities, against their changing identities, and against the application of detrimental policies by L.A.s. The findings from this PhD study echo Courtney and Hickey’s (2016) findings regarding

Canadian staff feeling a sense of solidarity with the people with intellectual disabilities whom they supported and a decreasing sense of power in trying to advocate for them. Rather than adopting identities as fighters though, workers in their study worked at 'street level' with individuals. In Kerasidou et al.'s (2016) Greek study, healthcare workers did report feeling they were battling against austerity. This too however related to working to maintain a level of quality in their care of their individual patients rather than feeling they were fighting against governments and L.A.s. Culture may of course play a role in the ways in which service providers feel they can respond to austerity measures. However, findings in this PhD study do link to Stevens et al.'s (2021) work which concluded that the most committed workers were those most likely to experience stress and burn-out. Higher levels of stress and burn-out in this PhD study may be linked to committed service providers feeling the need to fight against governments and L.A.s.

Eligibility and Austerity

The Care Act 2014 brought in new eligibility criteria to attempt to reduce the impact of the previous 'postcode lottery' of care provision. It was intended to improve wellbeing, prevent crisis, and save money. Feelings already reported within this study suggest that under austerity, people with intellectual disabilities, parents and service providers felt they experienced lower wellbeing, were at greater risk of crisis and feared that austerity may save funds in the short-term but would be likely to increase them in the long-term. The experiences reported in this study were related by parents and service providers to the efficacy of austerity policies and the ways in which eligibility under The Care Act can be interpreted. This study then calls into question the purpose of reassessment under The Care Act.

There were commonalities reported in this study regarding the ways in which the purpose of reassessment under The Care Act was understood and experienced, how reassessment was experienced and how the results of reassessment were experienced. Reassessment, far from promoting wellbeing and preventing crisis, was found to be felt to disable those in need of care.

The Purpose of Reassessment. There was a key assumption by people within each study in this PhD that governments, L.A.s and assessors thought people with intellectual disabilities and parents were no longer eligible for previously assessed care because their levels of need were assumed to have decreased, or to be inflated. As people within each study could establish no evidence that any needs had decreased, and did not feel they had inflated their needs, this assumption was felt to be made as a direct result of austerity measures. Parents, people with intellectual disabilities and service providers reported stating clearly that needs had not decreased, and instead, that any skills demonstrated, or positive outcomes were as a result of continued support. Many people with intellectual disabilities, parents and service providers gave examples of the ways in which rather than decreasing, needs had increased, and they gave examples of decreased health and wellbeing when care had been cut. In this study, reassessment under The Care Act was felt to be being used not as a tool for assessing needs but as a tool to reduce eligibility and thereby cut care and costs. This aligns with the sparse academic literature available regarding assessment. Both Coderre-LaPalme et al. (2021) and Symonds et al. (2018) found reassessment could be a process which was unrelated to assessment of need and instead focused on reducing social care budgets using inaccurate assumptions as a basis for decision-making. Other authors suggested that barriers to support could be put in place as a way for workers to deal with stresses of overwhelming demand for children's mental health services for example (Kiely & Warnock, 2023), and cuts to care could be made as a result of false assumptions about the abilities of people with intellectual disabilities (Symonds et al., 2018). These assumptions can be seen to link to experiences of reassessment.

Experiences of Reassessment. Several authors have highlighted the dichotomy that exists between being required to assess need in a person-centred way under The Care Act whilst simultaneously experiencing pressure to reduce budgets (see Slasberg & Beresford (2017) for example).

Symonds et al. (2018) found that people with intellectual disabilities were likely to be disbelieved when they requested help and that their claims were likely to be considered illegitimate. They also found that assessors were angered by people who asked for support when those assessors judged claims to be illegitimate. Symonds et al. (2018) suggested then that assessors were tasked with undertaking needs assessments in a person-centred way whilst also saving money, but doing this possibly believing that if a person with intellectual disabilities was capable of asking for help, that person did not have intellectual disabilities and therefore did not need help. The findings of this PhD study may further illuminate Symonds et al.'s research by demonstrating the possible effects of the beliefs and actions of some assessors on people being assessed. People with intellectual disabilities, parents and service providers in this PhD study described what it can be like to be on the receiving end of assessment by assessors who are tasked with saving money and may be angered by requests for support. Participants in each of the studies reported that being given an identity of one who does not have intellectual disabilities was associated with having attempts made by assessors to have one's care cut. No participants in this PhD study described assessment as being person-centred during times of austerity. Many described the experience of assessment as instead being cuts-centred and adversarial.

Symonds et al. (2018) also found that unqualified assessors who did not know families were more likely to try to reduce demand for services. In this PhD study, findings differed from Symonds et al.'s research and add depth from the perspectives of those being assessed. In this PhD, parents and service providers reported losing care as a result of assessment both by assessors they considered to be new and unqualified and by those they considered to be new and qualified Social Workers. These assumptions of qualifications were based on whether assessors appeared to have any knowledge or understanding of the nature of intellectual disabilities or not and on whether assessors stated they were Social Workers. Assessors judged by parents to be new and unqualified were felt to make cuts without knowledge of outcomes. Assessors judged by parents to be new (qualified) Social Workers were felt to make cuts knowing that the results of those cuts would cause harm.

This study also suggests that despite government guidelines (DoH, 2016), Care Act assessors can be unqualified and inexperienced (Indeed, 2023a; Indeed, 2023b). This may be another reason for perceptions by parents, people with intellectual disabilities and service providers of assessors being unqualified, untrained and therefore incompetent in their role. Alternatively, it may be that assessors were qualified and experienced but assessed in ways that were different from expected or previous forms of assessment. Assessors may have been struggling to assess in person-centred ways whilst also making the cuts to budgets required by their role. It may be that the assessors whom parents experienced in this study did not receive the same level of training as Social Workers or that the role was not perceived by L.A.s to be important. Alternatively, L.A.s may have found qualified assessors were hard to recruit. Assessors may have believed, as in Symonds et al.'s study, that people with intellectual disabilities did not in fact have intellectual disabilities so were not entitled to the support they already had or were asking for. Assessors may then have extended this view to their interactions with parents.

Findings from this PhD add another U.K. perspective to the limited research regarding the effects of austerity on people with intellectual disabilities and their families. In this PhD study, being known by assessors was perceived to be preferable to not being known, even by parents who had negative relationships with assessors who knew them and their sons/daughters well. Previous, known assessors were felt to understand and accept the needs and perspectives of people with intellectual disabilities, parents and service providers (Dana, Chapter Four for example), even though some parents felt assessors did not want to fund assessed needs (such as Fred and Frances, Chapter Four). Needs had though been agreed in relationships with known assessors. With unknown assessors came reassessment with the perceived aim, not of getting to know people or of understanding their needs and perspectives, and not of meeting needs, but of changing and reducing previously assessed needs and associated care. Previously agreed assessed needs were now being “suddenly” (Dana, Chapter Four) disagreed and reduced by professionals who were felt to neither know nor understand people with intellectual disabilities, parents or service providers, and appeared to disbelieve not only them as people, but also the previous agreed assessments by other professionals. This left many participants in this study feeling they had lost relationships and agreed understandings they had with previous professionals regarding their needs and identities, and that these had been replaced by only negative experiences.

The Effects of Reassessment. Although it was not a direct question within this PhD study, no person reported themselves or others feeling 'less disabled' as a result of cuts to care. This aligns with the work of Walmsley et al. (2017) and Power (2008, 2013) who found that assessment which led to cuts did not result in the creation of more positive individual or social identities for those assessed. Instead, reassessment for welfare for example has been described as both traumatic and damaging to mental health of some claimants (Coderre-LaPalme et al., 2021, p. 363; Stewart, 2016).

Assumptions about our 'selves' relate to our relationships and the ways in which human beings understand themselves to be perceived by others within these relationships. Findings from this PhD study can be related to the works of Goffman (1990a, 1990b, 1991) and Edgerton (1993). By doing this it is possible to consider the ways in which people with intellectual disabilities, parents and service providers may understand themselves as being perceived by governments, L.A.s and workers. This appears to have changed in times of austerity. Despite the flaws of *Valuing People* (DoH, 2009), including unintended but preventable exclusion of some people with intellectual disabilities (Simpson & Price, 2010) and the marginalisation of the parent voices (Walmsley et al., 2017), parents and service providers in this study and authors more widely have reported feeling previously positive about the place of people with intellectual disabilities in society as slowly improving as a result of Community Care policies which moved away from institutionalised care (Gant & Bates, 2019; Shakespeare, 2013). This PhD study has suggested that in times of austerity, being assumed to be more 'competent' (able to live independently of State support) was instead associated with having care cut. Although advocates have long challenged the stigmatising negative assumptions about the skills and abilities of people with intellectual disabilities (Goffman, 1990a, 1990b; Wolfensberger et al., 1972), assumptions of the ability to live completely independently of State support can also be damaging (Edgerton, 1993; Power, 2008, 2013; Stewart, 2016). Although being assumed to be able to live independently may seem to challenge stigma, this assumption has been found in this study to instead be related to reducing people’s abilities to challenge stigma. Having care cut reduced abilities to develop and maintain the skills needed to live a meaningful ‘ordinary’ life with a meaningful ‘ordinary’ identity. This study appears to suggest that there is a difference between deciding to wear a ‘cloak of competence’ oneself and having an unwanted ‘cloak of competence’ thrown over oneself by others. Both acts impact on one’s identity. Having care cut in this study was associated with inaccurate assumptions of ‘competence’ and resultant negative effects on one’s care, identity and abilities.

However, the views of assessors were missing from this PhD study. Information on their experiences, perceptions and assumptions about reassessment are therefore not provided. Perceptions and experiences of people with intellectual disabilities, parents and service providers are reported. It is not possible to assess whether these feelings would have been the same if known assessors and Social Workers had made cuts, or whether this loss would have happened without austerity policies being introduced. However, the literature that is available can be used to try to illuminate possible explanations for the experiences reported in this PhD study. That very limited literature suggests that whether assessors are qualified or unqualified, experienced or inexperienced, they can each make inaccurate assumptions about people who are in receipt of or request support, and that cuts and attempted cuts can be made to previously agreed assessments (Forrester-Jones, 2021; Symonds et al., 2018; Stewart, 2016).

Reassessment and Associated Cuts Were Felt to Disable. People with intellectual disabilities, parents and service providers reported a range of common experiences related to feeling disabled by the reassessment process, and the cuts associated with the outcomes of reassessment in times of austerity. One clear theme was that of loss of the positive relationship experiences with social network members which enabled people with intellectual disabilities to live meaningful ‘ordinary’ lives. People with intellectual disabilities, parents and service providers reported feeling that people with intellectual disabilities were having opportunities to take part in meaningful activities and experiences cut under austerity. Although normalisation policies encouraged the use of social spaces and activities which were diverse and used by typical members of communities (Wolfensberger et al., 1972), the settings in which people with intellectual disabilities in this PhD study were undertaking activities were usually specialist services which did not tend to include opportunities to engage with non-disabled people. People with intellectual disabilities also reported seeing their network members less often than previously, which they, parents and service providers also felt was as a direct effect of austerity measures. Opportunities to work or volunteer were also reported to have been lost as a result of reassessment, again removing an opportunity to engage with non-disabled people, which Forrester-Jones et al. (2004) have demonstrated to be a key aspect of diversity and support opportunities within social networks. Fear of leaving one's home as a result of hate crime was reported by The Money, Friends and Making Ends Meet Research Group c/o Liz Tilly in 2012. Hate crime and fear of hate crime was also reported in this PhD study as affecting whether people with intellectual disabilities left their homes independently, after care which enabled them to safely leave their homes with a staff member had been cut. It may be then that austerity measures and associated reassessment and cuts to care could be related to people with intellectual disabilities, parents and service providers feeling more disabled.

Care Ethics

As outlined in Chapter Five, care ethics refers to an approach to individual, political and societal functioning which has its basis in feminist theory and celebrates the concepts of care and of caring as universal, meaningful, shared and based in ethically sound actions. It considers the ways in which societies can be overhauled on global, national and local levels to value human relationships and emotions and promote social justice in ways which are contextual and grounded in understanding care as an embodied experience.

The findings of this study contrast with the ideals suggested by care ethics authors such as Tronto (2013) and Rogers (2016) who have argued that in times of national and global financial difficulty, care ethics can be used to build capacity to meet care needs and to support those providing care. Partnership working, with all parties valuing the contributions of one another as part of reciprocal care systems, is key to the successful application of care ethics. When this way of working is adopted as an ethos, authors argue, it can lead to greater connectedness and more meaningful relationships, to improved political and economic functioning, and to global, national, social, community and individual well-being. It could be then that times of austerity could act as catalysts for improved relationships between States and their related systems and structures. Care ethics offers the opportunity for greater collaboration and greater levels of felt care for all human beings. Instead, this PhD study suggests the opposite can also occur. The perceived withdrawal of ‘life-sustaining webs’ which Tronto (2013, p. 19) argued were key to the successful application of care ethics, can result in wellbeing and competence being negatively impacted as people feel less and less cared about, feel the need to respond as fighters and feel reassessment is designed only to cut their care.

Critique of the concept of care ethics should be considered. Care ethics theories have been criticised for the range of different approaches they include, which can appear to be in opposition to one another. A focus on one-way relationships within care, whether or not care can or should be identified as a burden, whether care ethics focuses on parent-child relationships as a basis for understanding adult-adult relationships within care and whether a feminist approach excludes others within care relationships are all concerns within care ethics as a wider debate (Noddings, 2013; Rogers, 2016; Tronto, 2013). Similarly, the practicality of the introduction of care ethics as a global solution to the ways in which social, economic and political systems can and do function has been called into question by care ethics authors themselves. Care ethics approaches do though offer hope for approaches to care which benefit all.

Robustness of Claims

The robustness of the claims in this discussion chapter should be assessed in relation to the strength of the evidence gathered.

People with intellectual disabilities were asked how often they saw different L.A. workers but not about how they experienced their relationships with L.A. workers. Parents and service providers were asked a general question about their social networks and austerity but were not asked about the nature of their relationships with L.A. workers. Comments made about these relationships were all unsolicited. This adds strength to the claims made about deteriorating relationships for people with intellectual disabilities, who represented almost equal numbers of people who had poorer care under austerity (n = 61, 40.7%) and whose care had stayed the same or had changed without detrimental effects (n = 66, 44%).

In this study only one consultee was required. Different results regarding relationships and wellbeing may have been obtained if people with more significant intellectual disabilities and those with complex communication needs had been included.

A sample size of 150 people with intellectual disabilities is though larger than reported in other studies (see Malli et al., 2018, for example) and may be enough to make meaningful claims regarding relationships.

Parents who were interviewed had all been negatively impacted by austerity, and service providers had come forward asking to be interviewed, most with negative experiences of austerity and deteriorating relationships with L.A. workers. Sample sizes for these groups (ten and nine participants respectively) are not large and the sample does not claim to be representative of all parents or all service providers in the U.K..

Crucially, the views of L.A. workers, particularly Social Workers and assessors, were not solicited in this study. This is because the aims of this research were not to investigate the nature of relationships with L.A. workers, so L.A. workers had not been included as essential participants. Eliciting the views of L.A. workers then will be vital in providing another perspective to these claims regarding deteriorating relationships. Kiely and Warnock (2023) recently found that L.A. and charity workers deliberately distanced themselves from parents who had children with mental health needs, as a way to cope with overwhelming demand for services. Research which investigates Social Workers' and assessors' perspectives then could yield useful insights into their views regarding the nature of their relationships with people with intellectual disabilities, parents and service providers. It may also be that there are factors other than those identified in this study which interact to cause distancing in relationships, feelings of being uncared about and poorer wellbeing and false assumptions about identities and competence. Some parents for example have always had battles with L.A.s and Social Workers, certainly before austerity policies were introduced in the U.K.. It may be that expectation plays a role here, in that the positive moves forward under *Valuing People* (DoH, 2001) may not have been able to be realised indefinitely. It may be that needs had previously been inaccurately assessed, and funding and services been provided, to a greater extent than was needed, and that the reductions under austerity were simply a rebalancing act in order to meaningfully meet actual need.

The impossibility of assessing whether or not austerity could be a causal factor in poorer relationships and reduced wellbeing should also be considered. Austerity policies were applied across the U.K. so finding control groups of people with intellectual disabilities, parents and service providers who were not affected by austerity was not possible. What is reported is that participants in each of the three studies were clear that the changes they experienced were a direct result of austerity policies.

This PhD study has reported findings which may indicate that austerity can be felt to have negative impacts on relationships between L.A. workers and people with intellectual disabilities, parents and service providers, on identities and on wellbeing.

Implications

Austerity is a political choice (Burton, 2016). If austerity has caused distancing in relationships, feelings of being uncared about, poorer wellbeing, a greater number of people feeling they need to fight against these effects, whether or not these issues matter should be considered. The implications of the findings of this study are related to these issues and cover relationships in times of austerity, social networks in times of austerity, and care ethics.

Implications of the Findings of This Study Regarding Relationships in Times of Austerity

Relationships with professionals and between service providers and people with intellectual disabilities are considered as findings in this study has suggested these have fundamentally changed under austerity.

Implications for Relationships With Professionals. Participants in each of the studies in this thesis reported that their relationships with professionals, particularly assessors, had deteriorated.

The findings of this study have implications for understanding the ways in which austerity can affect relationships between people with intellectual disabilities, parents and service providers; and L.A.s and their staff. Bogdan and Taylor (1987) suggested that tackling the stigma around relationships between disabled and non-disabled people required a deep understanding of the ways in which these relationships work well, in order to create an environment where these relationships can flourish. Findings from this PhD study imply that relationships with professionals work well when people with intellectual disabilities, parents and service providers feel they include mutual trust, friendliness, knowing one another well, feeling understood and feeling professionals were knowledgeable advocates for their needs. Instead during austerity, this study has found that productive relationships with professionals had deteriorated into adversarial fights and previously meaningful environments had become battlegrounds. This study has added that it is now not only parents who can feel the need to fight, but also people with intellectual disabilities and service providers. This study implies then that austerity can not only reduce opportunities for the continuation or enhancement of the factors which maintain meaningful relationships. It can also create an environment which can negatively impact relationships which may previously have been instrumental in both meeting needs and reducing stigma, changing these from beneficial to combative. These negative relationships can then play a role in reducing wellbeing, having the opposite effect from that for which assessment under The Care Act was designed.

Implications for Relationships Between Service Providers and People With Intellectual Disabilities. This study also has implications for understanding the ways in which service providers make sense of their relationships with people with intellectual disabilities in times of austerity.

Stevens et al. (2021) found it was the most committed workers who can feel the most stressed. This is often found to be the case in studies which include the views of frontline workers. However, this PhD study suggests service providers at management level and above can feel stress when people with intellectual disabilities experience cuts and attempted cuts, feelings they described as painful. In this study this pain and a related sense of powerless was linked to service providers feeling the need to leave their roles. These findings imply that service providers may have far closer relationships with the people they support than has been previously supposed. Findings also imply that cuts may lead to service providers with the closest relationships being those who leave services. As this study has found that people with intellectual disabilities need support networks in order to maintain wellbeing, and that loss of known professionals was felt to be detrimental to their care and networks, the potential loss of service providers who know and care about them implies possible further detrimental effects on the care, networks and wellbeing of people with intellectual disabilities.

Implications of the Findings of This Study Regarding Social Networks in Times of Austerity

This study found that people with intellectual disabilities had larger network sizes than previously reported in other studies (Harrison et al., 2021). While this may suggest that austerity does not appear to affect network size or may even appear to increase it from the average, findings from this study also show that networks tend to be largely made up of others with intellectual disabilities, who are seen less often as a result of cuts. This study also found that the ability of both people with intellectual disabilities and parents to engage with their social networks was reliant on support. This support was found to be being cut as a result of austerity policies. This implies that austerity may be undoing previous progress regarding how often people with intellectual disabilities and parents have the opportunity to engage with others. This also implies that over time it is not only network size, and frequency of accessing one’s network that should be taken into account when considering the social networks of people with intellectual disabilities and of parents. Whether opportunities to access networks are available, whether support is needed and if so, is available and provided, and whether frequency of accessing network members has changed over time are implications for data gathering in future studies.

This study also found that people with intellectual disabilities had the least to do in the evenings at weekends. This information is new to the literature and has implications for those funding and providing services in terms of the ways in which the engagement of people with intellectual disabilities with weekend activities could be enhanced. Goffman (1990a, 1990b, 1991), Edgerton (1993), Wolfensberger et al. (1972), Scior et al. (2020) and Scior et al. (2022) have previously highlighted the importance of undertaking 'ordinary' activities in ways which were culturally appropriate to one's local community. They argued this was essential for tackling stigma and increasing inclusion. Academic literature has shown that social networks are essential for all aspects of wellbeing. Improving wellbeing and thereby preventing crisis is a key premise of The Care Act. For The Care Act to be successful in its aims, the findings of this study imply that support to start, build and maintain social networks, which includes support to engage with social network members regularly, may become even more essential as austerity policies continue.

Implications of the Findings of This Study Regarding Care Ethics

Findings of this study have implied that austerity can be perceived as causing deterioration in relationships, diminished social networks and poorer wellbeing. The application of a care ethics approach in the findings of this PhD study suggest however that a choice need not be made between valuing either making cuts or maintaining functioning relationships, social networks, wellbeing and skills. In this study not only people with intellectual disabilities and parents but also service providers have expressed the desire to work closely with L.A. workers. A care ethics approach would recognise, appreciate, and value that the groups of focus in this study wanted to be known and understood and feel cared about. Partnership working was suggested by some participants in each study as an essential way to consider funding assumptions and proposed budget reductions together far more productively and with positive outcomes for all parties. Although authors who espouse a care ethics approach argue for global systems change and the funding of universal care for all who need it

(Nguyen et al., 2017; Rogers, 2016; Tronto, 2013) this PhD study makes pragmatic suggestions which could be applied on a local scale. The findings of this study imply that by taking a care ethics approach it is possible that people with intellectual disabilities, parents, service providers and L.A. workers could have the opportunity to advocate together for one another, working in partnership to increase the importance of care across communities and societies. This could form a sound basis from which to work together in the event of either the wider adoption of a care ethics approach or the continued application of austerity policies.

Recommendations

In this section I will make recommendations with regards to policy and practice issues and future research in relation to austerity measures in a broad sense and specifically in regard to relationships. Recommendations include ways which may help in challenging current practice and changing future practice. I am however mindful of the ethical issues involved in making recommendations from the perspective of a researcher who does not belong to any of the groups interviewed and who has analysed and put her own interpretations onto the experiences of individuals. The recommendations I will make therefore are drawn from the findings of this study and reflect findings from other related research used in this study.

The findings of this study suggest governments and L.A.s would benefit from evaluating the effects of austerity policies on their budgets, their staff, people with intellectual disabilities, parents and service providers. This evaluation should include not only financial but also emotional and wellbeing cost/benefits of providing vs not providing care, and emotional costs on their staff. This could provide detailed information regarding the ways in which deteriorating relationships and social networks could be enhanced which may then positively affect outcomes for all involved. This may provide governments and L.A.s with missing/further information regarding the ways in which austerity policies can negatively affect the health and wellbeing of individuals, groups and staff beyond the little research which exists, to which this PhD study contributes.

It may be that governments and L.A.s and their workers care very much about the effects of austerity on people with intellectual disabilities, parents and service providers. If this is the case, they may benefit from sharing their views and getting this information across more effectively. Partnership working with people with intellectual disabilities, parents and service providers may then be initiated and funded with a shared understanding of differing roles, identities, pressures and perspectives.

Much of the anxiety raised by participants in this study related to be ‘suddenly’ surprised by changes in relationships, and cuts and attempted cuts being made as a result. This then was related to fear of the future for people with intellectual disabilities who it was felt would be left without much-needed advocates. Better communication from governments and L.A.s regarding the purpose of reassessment may at least give those being assessed time to prepare for and challenge new assessment regimes if governments and L.A.s choose not to work in partnership with those needing and delivering care.

A promise from governments and L.A.s that every individual with intellectual disabilities would have appropriate support from someone who knew them well both before and after parents die may allay some of these fears. This would require significant ring-fenced funding however, which links to the need for governments and L.A.s to better understand the needs of people with intellectual disabilities in both the short- and long- term. To this end, people with intellectual disabilities, parents and service providers providing training to governments and L.A.s about the nature of intellectual disabilities and the needs associated with people with intellectual disabilities, their parents and service providers would be beneficial. This training should demonstrate the falsity of the assumption that a person who can ask for help does not have intellectual disabilities and therefore does not need help. Governments, L.A.s, workers and assessors having a clear understanding of the fundamental need for support in order to maintain any skills a person with intellectual disabilities has acquired should also be included. Training and discussion regarding the ways in which people with intellectual disabilities, parents and service providers feel partnership working could benefit all parties, and the negative effects of changes to relationships which has made them feel poorer and more adversarial, could enable L.A.s and their workers to understand the perspectives of those being assessed and the lived experiences of the outcomes of cuts and attempted cuts.

People with intellectual disabilities, parents and service providers would benefit from working together in partnership to form a type of care advocacy collective. Forming their own social network which linked to other collectives could provide strength in numbers and information in order to better challenge not only cuts but also the assumptions behind the choice to adopt austerity policies. Forming alliances between parents, people with intellectual disabilities and service providers may also build strength and resilience in order to continue to fight against false assumptions and regain meaningful identities and relationships. This may also tackle the sense of powerlessness expressed by participants in each of the studies which form part of this PhD. In time this collective could include L.A.s and governments in order that a care ethics approach, where the universality of care and the need for care to be central to both policy and practice, could be applied collectively and with collective understandings. Policies such as The Care Act, or a new Universal Care Act, could then be enacted with sufficient funding to ensure that all persons who needed care would get that care and all who wanted to care would be enabled to do so.

Recommendations for Future Research

What is now known as a result of this study is some of the views and experiences of some people with intellectual disabilities, parents and service providers around care, relationships and social networks in times of austerity. Future areas of research could focus on enhancing knowledge regarding the questions which this study has created. For example, although people with intellectual disabilities, parents and service providers were able to relate their views and experiences over time, using the same measures in a longitudinal study would be beneficial in capturing snapshots of views and experiences over a longer period. Longitudinal studies can be a rich source of data. Measuring perceived impacts of different factors on people’s care and social networks over time and at different timepoints can be an effective way to better understand people’s lives and experiences. This would enable comparisons to be made across and between datasets. This has been undertaken in relation to different aspects of people’s lives, such as moving from institutional settings to community settings (Jahoda et al., 1990; Perry et al., 2011) and the cumulative impacts of Covid-19 on people with intellectual disabilities and their families for example (Flynn et al., 2021; Flynn et al., 2022). Measuring the experiences and views of people with intellectual disabilities, parents and service providers over time in relation to perceived effects of austerity could similarly create a rich data source which could be used to better inform policy and practice regarding funding priorities currently and in the future.

Although the views and experiences of some people with intellectual disabilities have been gathered and analysed in this study, the ways in which people with significant intellectual disabilities and those with complex communication needs experience austerity measures needs further investigation. People with complex communication needs and those with significant intellectual disabilities should therefore be included in future research. As has been discussed, gaining access to any people with intellectual disabilities without a national or local register of people in this group presents its own difficulties. Gaining access to those with higher levels of need presents even greater difficulties. However, judicious use of time to build trusting relationships with gatekeepers, parents, support staff and people with intellectual disabilities themselves may reap rewards in terms of gaining insights into a broader range of individual views and experiences beyond those reported in this study. Studies could include a wide range of communication aids, the use of consultees and/or observational approaches which have been successfully used in order to better understand the experiences of this group (Beadle-Brown et al. (2016) for example).

If perceptions that relationships with L.A. workers, wellbeing, identities and competence have deteriorated during austerity are to be further investigated, then undertaking research projects which also elicit the views of people with intellectual disabilities, parents and service providers who have not experienced any detrimental effects of austerity, including deterioration in their relationships with L.A. workers, will be important. Understanding more fully the exact nature of relationships with L.A. workers before austerity policies were enacted, including how often contact was undertaken, for what reasons, in what ways, and with what results would be helpful in order to compare these with those during austerity. This study was intended as a snapshot in time, so may be helpful in future comparison studies.

Questions also remain regarding the views and experiences of assessors in times of austerity. Although Symonds et al. (2018, 2020) Coderre-LaPalme et al. (2021) and Kiely and Warnock (2023) have begun investigating their perceptions, including assessors in future research will be vital in order to gain a range of more diverse perspectives and experiences regarding the effects of austerity on assessors themselves, and on how they view any effects of austerity on the groups of people included in this study. Interviewing a range of assessors nationwide could provide a level of illumination into key questions remaining from this study. This should include those who are qualified and unqualified, who have been assessing the same people and people who are ‘new’ to assessors, assessors who have and have not had experience of working with people with intellectual disabilities, those who work in relatively rich L.A.s and those who work in L.A.s with low income and high levels of social deprivation. How assessors approach assessment, what guidance they are given, their basis for making assessments, information regarding their feelings about relationships and their understandings of the role of care and social networks in the lives of the people they assess, all would enhance our knowledge about the effects of austerity on not only people with intellectual disabilities, parents and service providers but also on assessors.

Summary of Recommendations

Recommendations for Policy

Government and L.A. evaluation of the financial and emotional effects of austerity policies on budgets, their staff, people with intellectual disabilities, parents and service providers.

Policy to be written in partnership with people with intellectual disabilities, parents and service providers.

A promise from governments (with appropriate ring-fenced funding for L.A.s) that every individual with intellectual disabilities will have appropriate support from someone who knows them well, both before and after parents die.

Recommendations for Practice

Any concerns Government and L.A. workers feel regarding effects of austerity to be shared with people with intellectual disabilities, parents and service providers in order to enhance understanding of experiences.

Better communication from governments and L.A.s regarding the purpose of reassessment in order that all parties are clear before assessment takes place.

Training to be provided to governments and L.A.s by people with intellectual disabilities, parents and service providers regarding the nature of intellectual disabilities and associated needs in order that future policy and practice reflects lived experiences of these groups.

Formation of a care advocacy collective made up of people with intellectual disabilities, parents and service providers in order to challenge decisions and promote partnership.

Recommendations for Research

A longitudinal study using the same measures to understand experiences over time.

Greater inclusion of the experiences of people with significant intellectual impairments to enhance understanding of their experiences.

Inclusion of participants who have not experienced deterioration in their relationships with L.A. workers to better understand factors which influence positive relationships.

Inclusion of qualified and unqualified assessors making judgements about eligibility for care to better understand their experiences.

Chapter Eight Conclusion

This PhD thesis set out to explore the views and experiences of people with intellectual disabilities, parents of adults with intellectual disabilities and service providers around care and social networks in times of austerity. These are topics rarely considered in academic literature. This study used mixed methods research to consider these experiences and has made some contributions to the field of study.

The experiences of participants in this study suggest that austerity can have further-reaching effects beyond the creation or deepening of financial difficulties. Loss of relationships with known professionals and feeling professionals were actively distancing themselves from relationships was experienced as a fundamental shift and as a substantial loss. Even when pre-austerity relationships with professionals were considered to be far from perfect, austerity has been perceived as creating even greater difficulties. Relationships with professionals have been damaged during austerity, and the identities of people with intellectual disabilities, parents and service providers have been subsequently spoiled. Assumptions about social contracts, and the roles and identities of those within these contracts were also damaged. Relationships in this study have been reported as shifting away from a level of trusting partnership to those which were perceived to be characterised by mistrust and fighting at best, and lying, punishment and depersonalisation at worst. This has left some people with intellectual disabilities, parents and service providers feeling uncared about and misunderstood, with poorer wellbeing and diminished social networks. Apparent assumptions that participants did not need the help they were previously receiving did not leave participants in this study feeling less disabled or less stigmatised. Instead, the application of a ‘cloak of competence’ was felt to be neither wanted by, nor appropriate for, participants in this study.

Previous studies have suggested that adversarial relationships between parents and L.A.s and their workers can be typical. This study adds that this can also be the case for people with intellectual disabilities and service providers, with both groups also reporting diminished relationships and also feeling the need to fight. Previous research has also shown that front-line workers can experience high levels of stress when their relationships with people with intellectual disabilities and with managers are not considered to have a level of reciprocity and mutual understanding. This study has suggested that under austerity this can also be the case for service providers, who may experience high levels of stress and burn-out as a result of the pain they now experienced in their caring relationships with people with intellectual disabilities, and their newly adversarial relationships with professionals.

Under austerity, previous progress in policy and practice was felt to be regressing to levels experienced before the introduction of Community Care policies and deinstitutionalisation. The implementation, interpretation and perceived misuse of The Care Act was felt to be part of this regression. The finding in this study that people with intellectual disabilities, when they did see the majority of their social network members, saw them in large day services adds strength to the claim that the days of institutionalisation are not yet behind us.

The limitations of this study have also been considered and presented. Key amongst these is the need to understand the experiences of those making assessments which affect eligibility for care in times of austerity. Their insights will be invaluable in better understanding not only different perceptions of austerity and relationships but also any other effects on assessors themselves.

This study has made suggestions regarding the implications of findings to both policy and practice and has made recommendations for future research. Working in partnership to challenge stigma, and using and promoting a care ethics approach are suggested as key ways in which societies could be organised to better promote wellbeing, social networks and relationships for the benefit of all. These ways of being can then value every person and every relationship as important and meaningful. This may enable different choices to be made when financial decisions arise, avoiding or averting the need for austerity policies to make cuts to the care, welfare, support and services of those who feel they need it. Instead, when care is seen as the bedrock of a society, caring relationships can be recognised as fundamental to human functioning and prioritised as the key goal. The enhancement of social networks with and between people with intellectual disabilities, parents and service providers would be part of this goal. The dream of an ‘ordinary’ life may then be more likely to become a reality.

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Appendices

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Appendix A

List of papers published from research with thesis participants:

Forrester-Jones, R., Beecham, J., Randall, A., Harrison, R., Malli, M., Sams, L., & Murphy, G. (2021). The impact of austerity measures on people with intellectual disabilities in England. *Journal of Long-Term Care*, 241–255. https://doi.org/10.31389/jltc.59

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Appendix A

Form A1 Information Form for Parent/Carers

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ

[REDACTED]

Information Sheet for Carers

Title: **Becoming less eligible for care? Intellectual disability services in the age of austerity**

Dear Carer,

You are being invited to take part in a research study run by [REDACTED] at the Tizard Centre, University of Kent. Your participation in this study is entirely voluntary. Before you decide whether you want to take part it is important for you to understand why the research is being conducted and what it will involve.

What is the purpose of the study?

The purpose of this study is to examine how The Care Act 2014 with its eligibility threshold has impacted on the day-to-day lives and quality of life of individuals with Intellectual Disabilities and their carers. It also aims to provide evidence of the impact of the government policy. The project will enable the government, and social service departments in England, to see how the Care Act is being played out in practice and to make informed decisions about its future operationalisation.

Why have I been invited to take part in the study?

You have been invited to participate in this study as you are the principal carer of an adult with Intellectual disabilities.

Do I have to take part?

Your participation in this study will be entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time, without giving a reason (your answers will then not be included in the survey).

What will I be asked to do if I decide to take part?

If you agree to take part please sign the consent form enclosed in the information pack and return it in the prepaid envelope or to: [REDACTED], Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LZ.

All carers who take part in the study will be interviewed about their experience of losing services due to the implementation of the Care Act of 2014. More specifically we would like to know how, in your experience, this has impacted on your lives including how you now organise care for your loved ones. These interviews will last about 45 minutes and they will be audio recorded.

Will what I say in this study be kept confidential?

Material gathered during this research will be treated as confidential and stored securely. Only the researcher team will have access to the completed questionnaires and personal information of the adults with learning disabilities.

What are the possible disadvantages and risks of taking part?

The interview will require use of your time. We have, however, designed it to be as brief as possible. Furthermore, although we aim to make the interview a positive experience, some may find the discussion upsetting. However, the researcher will be available to offer support and refer you to an appropriate charitable organisation if you are feeling upset. Mencap and the Mencap / Challenging Behaviour Foundation Legal Panel are aware of this research and are able to offer support. Please keep in mind that you can stop participating at any time up to the point when the information has been analysed anonymously.

What are the possible benefits of taking part?

By discovering more about your experiences of eligibility and ineligibility, the research has the potential to inform the government, and social service departments in England, about how the Care Act 2014 has impacted the lives of people with learning disabilities and their carers. This will help make informed decisions about its future operationalisation.

What will happen to the results of the research study?

The information you provide us with will be published in a scientific journal. Specific individuals will not be identifiable from the results as no names will be used. At the end of the study the researcher will send you a summary of the results. Again, no individuals will be identifiable at all.

Who is organising and funding this research?

The research is funded by the School for Social Care Research, part of the National Institute for Health Research. The research is sponsored by the University of Kent under the Department of Health Research Governance Framework. The research has been reviewed by the Social Care Research Ethics Committee.

Contact

Please do not hesitate to contact the researcher [REDACTED]

If you wish to take part please complete the consent form enclosed in the information pack and return to [REDACTED].

Thank you for taking the time to read this.

[REDACTED] and Rachel Harrison

Appendix A

Form A2 Consent Form for Parent/Carers

Tizard Centre, University of Kent,
Canterbury, Kent, CT2 7LZ
[REDACTED]

Carers Consent Form

Becoming less eligible for care? Intellectual disability services in the age of austerity

Thank you for considering taking part in this research. If you have any questions please ask a member of the research team before you decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick and write your initials in the box to confirm

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without services being affected. ☐

I understand that the discussions will be voice recorded. ☐

Name of Participant (please print) ___________________________

Signed __________________________Date _________________

Appendix A

Form A3 Debrief Form for Parent/Carers

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7LZ

[REDACTED]

Becoming less eligible for care? Intellectual Disability services in the age of austerity

Debrief for Carers

Thank you for agreeing to take part in the study.

We hope that everything was alright during the study. However, if you have any concerns or wish to make a complaint please contact us to discuss this. My phone number is [REDACTED], and my email is [REDACTED]. Or you can email [REDACTED] at the following address: [REDACTED].

If you would prefer to talk to someone else first then you can phone my supervisor. Her name is [REDACTED] and her phone number is [REDACTED]. Or you can email her at the following email address**:** [REDACTED]. If you would like to speak to someone outside of the research team, you can contact the Tizard Centre Ethics Committee by contacting [REDACTED].

If you find it hard to make a complaint, you can ask someone else to do it for you or ask someone else to help you.

If something bad happened during the interview or during any part of the study, it will help us to know this. We want to learn how to stop this happening again. You will not get into trouble if you tell us.

Some complaints are big. Some complaints are small.

It's always ok to tell us about it.

Thank you for helping me with this study.

[REDACTED] ***and Rachel Harrison***

Appendix A

Form A4 Information Sheet for Participants with Intellectual Disabilities

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7NF

[REDACTED]

PARTICIPANT INFORMATION SHEET

Becoming less eligible for care? Intellectual Disability in the age of austerity (government cuts to funding)

We want to ask you about any support you are getting now.

- If you get support we want to know how this support helps you in your life.
- If your support has changed, how does this change your life?

We want to ask you about:

- ✓ yourself,
- ✓ your physical health
- ✓ your social relationships and the people you know
- ✓ how you are feeling about yourself and your life
- ✓ any worries you have
- ✓ any fears you have
- ✓ your independence

You can ask someone you know to help you if you would like that.

This could take up to 3 hours, but you can stop whenever you want to. If you get upset we will stop. If you want to talk to someone else we can put you in touch with other organisations such as Mencap.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm.

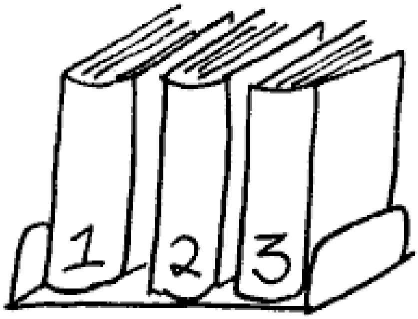
We would discuss this with you before telling anyone else.

At the end of the project we will send you a report about what we found out.

We will write about what we found out in a journal - a type of magazine for staff who work with people with learning disabilities.

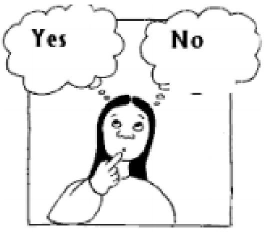
This is so that we can help Social Services know the best way to support people with learning disabilities.

We will not use your name when we do this.



All the information will be kept safely so no one else can see it.

We will keep the data securely because we might want to come back in the future to see how you are. If we do that we will ask you again if it's ok.



You can decide if it's ok for us to talk to you. Only you can say YES or NO and no one can decide for you.

If you say YES, a researcher will arrange to talk to you. It will be up to you how this happens. The researcher can visit you at home.

If you do not want us to talk to you it is ok to say NO. Nothing bad will happen if you say NO, and the support you get won't change.

If you say YES now, you can still change your mind later. Nothing bad will happen if you change your mind.

[REDACTED] If anything happens that you don't like you can complain to [REDACTED]

or to Rachel Harrison

[REDACTED] or to [REDACTED]

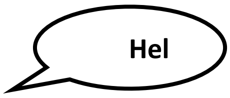
or to another member of the research team.

[REDACTED] If you're still unhappy you can contact [REDACTED], who is in charge of the research.

If [REDACTED] doesn't sort it out you can contact the University's Director of Research Services, [REDACTED].

If you think it would be ok for us to talk to you about the support you get please fill in the form you have been given.

You can ask someone for help to fill in the form.



If you have any questions you can ask someone to help you or you can contact us.

You can phone [REDACTED].

Write to [REDACTED].

THANK YOU

Appendix A

Form A5 Consent Form for Participants with Intellectual Disabilities

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7NF

[REDACTED]

Becoming less eligible for care? Intellectual Disability services in the age of austerity

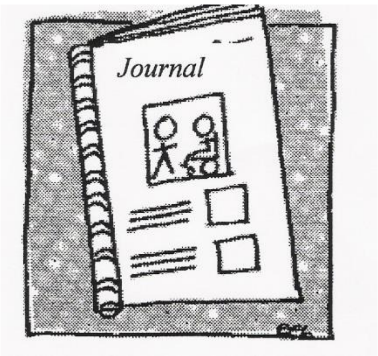
PARTICIPANT CONSENT FORM

Please tick

I have seen the information sheet about this study and talked about it with my family or carers, and the researchers. ☐

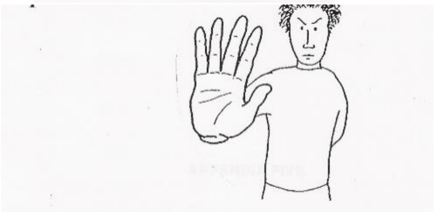
I understand that the researchers will talk to me about any support I am receiving. ☐

I understand that they will be asking questions about myself, my friendships and how I feel. ☐



I know that my answers will be written down and shared with other researchers, but they will not know my name. ☐

I understand that the information may be published in a professional journal, but no one will know my name. ☐



I understand that anything said will be private and confidential.

I know that it's ok to say NO to the researchers talking to me and that it won't change the support I get.

I know that if I say YES I can still change my mind about taking part later.

YES, I would like to take part in the research ☐

NO, I would not like to take part in this research. ☐

Name of participant:

Signed: **Date:**

If you cannot sign your name or mark the paper but have told the person helping you with the form that you want to take part then they should sign below to say that you have said "yes".

Name of person supporting you:

Signed by person supporting you:

Date:

After you have signed this form, please send it to the researchers or ask the person helping you to do this. The researchers will then contact you to arrange when to talk to you.

Thank you for helping me with our study.

[REDACTED] ***and Rachel Harrison***

Appendix A

Form A6 De-Brief Form for Participants with Intellectual Disabilities

Tizard Centre, University of Kent
Canterbury, Kent, CT2 7NF

[REDACTED]

Becoming less eligible for care? Intellectual Disability services in the age of austerity

Debrief for People with Intellectual Disabilities

This is [REDACTED]   This is Rachel Harrison   This is [REDACTED]

Thank you for agreeing to talk to [REDACTED] or Rachel and to help with them with this study.

We hope that everything was alright when you talked to [REDACTED] or Rachel.

It is [REDACTED] and Rachel's job to treat people properly. This means they should:

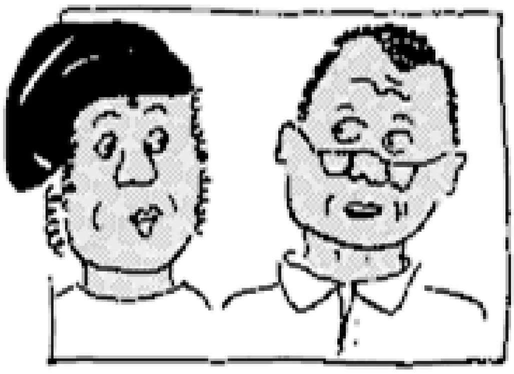
- Be polite
- Treat you as an adult
- Make sure you know what is happening

But if you did not like things [REDACTED] or Rachel did, you can complain.

This means you tell us and we will try to do something about it.

HOW TO COMPLAIN

- The first thing you could do is tell [REDACTED] or Rachel about it, if you can.



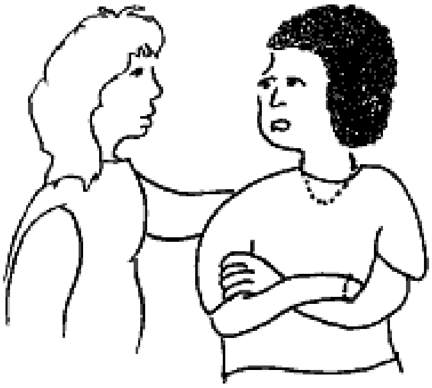
- If you would prefer to talk to someone else first, then you can phone [REDACTED] and Rachel’s boss. Her name is [REDACTED].

- Or you can write to her at the following address: Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, CT2 7NF

- If you find it hard to make a complaint, you can ask someone else to do it for you. Ask someone to help you.

- [REDACTED] will listen to you carefully. Then she will need to talk to other people. After a short while, she will get in touch with you to let you know what has happened.

If something bad happened when [REDACTED] was talking to you, it will help us to know this. We want to learn how to stop this happening again. You will not get into trouble if you tell us.



Some complaints are big.

Some complaints are small.

It's always OK to tell us about it.

Thank you.

[REDACTED] Tizard Centre

Appendix B

Memo B1 First Service Provider interview and analysis ongoing memo February 2020-August 2020

Memo NW7 Ongoing

Braun and Clarke for example Thematic Analysis (TA).

So, TA accepts that this is her view of the world and the way she interacts with it right then and only then. I am part of that as she is interacting with me.

TA makes sense as my PhD is about relationships and acknowledges that I am a researcher in a relationship with NWP7 for the time we are together and I'm interviewing her. So my analysis is what she said, embroiled in how she understood the world then, and the words she had to try to explain her relationship with the world then, all then tied up with the fact that she and I were in a relationship together then, so what she said would have been influenced by the fact that I was there. Then I'm analysing all of that, sympathetically, to try to understand her and her relationship with her world as it was at that time. I'm reflecting on relationships from the perspective of her engagement with relationships.

I'm looking for a third person account, so her as first, me as second, third is my reflection on first and second?? This is the first stage, trying to see the world as she sees it.

My interpretation can only happen because I exist in the world and understand it in my relationships with it. It is not perfect and cannot be.

She has meaningful objects with which she interacts to understand the world, so do I. I interpret using my meaningful objects and interpret her words in terms of my meaningful objects. It is therefore far from perfect but is at least open and honest about the limitations. Hermeneutic, I'm interpreting her interpretations.

I'm not saying I understand her inner experience.

TA needs to go further than just describing an experience. Difficult to work out where description ends, and interpretation begins.

I am the author of the analysis. I have a different position from the participant.

I'm not trying to find a theory of truth or the facts of reality. I'm interpreting an interpretation.

"interviews are complex social events" p115.

Redoing this I'm beginning to think transactional analysis. Victim and rescuer.

Also, I was thinking Wolfensberger- people with intellectual disabilities as objects of fear and of dread. NWP7 talks about people with intellectual disabilities as unable to cope without support. Eternal child? But also talks using the words fear and dread re how she feels personally about how people with intellectual disabilities are treated, about the systems that are failing them, about the future. Maybe I'm seeing this link because I know about Wolfensberger so anyone saying fear and dread when talking about people with intellectual disabilities in any way will always make me think of Wolfensberger?

I just re-read Braun and Clarke, re steps that I can use re TA. Now started going back through first section for linguistics. Lots of 'very very', 'massive', 'really high', 'there's nothing', 'nobody cares…'

extremes. Sign of stress or stressing to me the significance because she thinks- and says- that people do not know and do not care? Or is this me picking this up because I'm questioned about whether social care is really that bad? Perhaps of course she just uses this level of emphasis in all areas of her life? Is it because in the interview I was trying hard not to say anything on the tape which would look like I'm leading her, so I was not responding with the same vigour as in our discussions, so she felt she had to convince me?
She says vulnerable a lot, is she feeling vulnerable?
I have to be sceptical too.

Is she under siege?

Is she talking about people who have had no support? Nobody has ever cared? Nobody ever? Makes me think of the person I interviewed in the same location who was abused as a child, and nobody helped her despite them knowing she was being abused. So, she had nobody. Or support that has been inappropriate? Or that she thinks is inappropriate?

16.3.20
For third level themes Wolfensberger is a clear link.
There is an overall theme of perception, of seeing and not seeing, of fairness and morally just actions.
The participant enables a turning about of Wolfensberger's ideas around how societies perceive people with intellectual disabilities. She used the words that Wolfensberger used about people with intellectual disabilities, yet she used them about how she felt not about people with intellectual disabilities themselves but instead about the experiences and possible future lives of people with intellectual disabilities. The participant used the terms afraid, terrified, dread and there are links too to the view of people with intellectual disabilities as having only the abilities of eternal children. In this way in times of cuts to service provision, Wolfensberger's ideas can be extended. It is not people with ID who are to be feared, to be terrified of, or to be dreaded. Instead, it is their current life circumstances and their possible futures without effective support. It is not people with ID who are subhuman, it is their services which are substandard. As eternal children, this participant has highlighted the ways in which people with intellectual disabilities can learn and develop and gain independence skills, but that this requires effective support. She articulated her fears, dread and terror of an unjust future in which people with intellectual disabilities may return to an eternal child role, by being disempowered and deskilled by a reduction in their support.

Does caring about someone with intellectual disabilities involve a change of perception?

31.7.20 I am starting this again after a break to do the literature review article. I'm not reading the previous comments or this memo, I'm starting from scratch to see what I find, by reading and listening to the transcript again to get back into it. Already I realise I missed the number of times the participant refers to her working with voluntary services.
There is also a theme of suicidal people being talked about. And a fear for/of the future by people with intellectual disabilities and by the participant.
Finished the whole transcript now.
Links to Wolfensberger but not fear of, or dread of, fear FOR and dread FOR.
Dissonance between her ideas that people see but do nothing, or don't see, or don't want to see.
Does seeing link to action/ feeling for her?
Dissonance between her ideas that deaths of people with intellectual disabilities are all part of the plan and that nothing can be done?
The pressures of caring, burden, dissonance between wanting to care and knowing how hard it is.
Sense of responsibility.

I care but no-one else does.
She and people with intellectual disabilities isolated?

31.7.20
I am now going through and considering conceptual meanings. This is not just fear of the future, it's fear of an even worse future than the present. The worse future is imagined only as the deaths of people with intellectual disabilities and these deaths going unnoticed by society. The imagined deaths are initially considered as having a possible impact (making a difference is a clear theme throughout), but later deaths are considered as, "natural wastage" and part of a wider government plan to save money as they will no longer have to pay any costs towards those now deceased people with intellectual disabilities.
There is also fear of an uncertain future. Inability to be able to reassure people with intellectual disabilities that their futures are secure, or that things will get better, adds to the perpetual nature of feeling overwhelmed with no end in sight. There is no light at the end of the tunnel, or even an end to the tunnel. This then affects her views about her current and future identity. She repeatedly questions her role in a number of ways and refers back to previous roles where things were not perfect, but she felt she was making a difference in some way; to the lives of the people with intellectual disabilities whom she supported, and later also to the staff she worked alongside and those she manages.

The nature of care and the care role?
Caring is a responsibility which is overwhelming and unceasing. It is also an isolated role undertaken by isolated people for isolated people. This care which she provides is for people who have little or nothing and are often abused. She provides this additional, unpaid, unrecognised care so that people are safe at least from 9am-5pm on weekdays. The theme of safety is a strong one. Keeping people with intellectual disabilities whom she deems as, "vulnerable", safe from people who would, "take advantage" is a necessary daily task which she has set herself. She explains this is necessary as she works with so many people who have been abused and taken advantage of and deals with the aftermath of this several times per week in the form of people being suicidal and having mental health crises. These often require emergency services support; she also cares and worries about the medical personnel involved due to the negative emotional effect of these situations on them. Care for this person therefore means worry, stress, horror, fear, terror, not sleeping at night and the dream of living on a desert island where none of these situations must be seen and therefore faced and addressed.

What others see
Right, it's about if you see something you have to face it and if you face it you are then obliged to act. Can comprehend people not wanting to look, and people choosing not to SEE, but cannot comprehend people in power/ government choosing to plan for the deaths of people with intellectual disabilities in order to save money.

Commodification of care
Young carers save the state money. People with intellectual disabilities are not provided with even the basic amount of care needed to be safe. Even when organisations exceed expectations and target, this is no guarantee that further funding will be provided. No-one cares so no-one pays?
Eligibility criteria exclude.

'Nowhere else to go' keeps coming up, she says this 12 times.

3.8.20

Emotional overload linked to feeling overwhelmed? She is effectively talking about burnout and planning for it?

Layers in what people 'see' – oblivious to suffering of people with intellectual disabilities. Does more knowledge equate to treating people better? She does not think so.

Fear of uncertain future and fear of only negative future.

Things that should make a difference- knowledge, deaths, intelligence of people in government, do not actually make a difference. Shared powerlessness with people with intellectual disabilities but she knows she has more power than people with intellectual disabilities?

Senses- see, hear, feel.

Time- sense of history past and future generations making judgements on lack of action. Looking forwards and back- context?

These are all disaster words- current and future.

I have just completed another thematic analysis on NW7. This became much easier when I considered her words as a story, and narrative she was trying to get across. With this in mind the first key theme was about care: what it is, what it means to her, and how she sees and feels it. This starts with what is Care, then her role within this, then her perception that no one cares except her, that people have nowhere else to go but people just want to feel cared for, that society's expectations are unrealistic and there is no opportunity for reciprocity and that the current modification of care has had a detrimental effect. This continues to the perception of unjust treatment against people with intellectual disabilities which is exacerbated by lack of social networks. She's personally worried for others. This then leads to a feeling of being completely overwhelmed. To try to tackle these injustices and the overwhelming feeling of powerlessness she tries to make a difference, she goes 'above and beyond' and she breaks the rules.

Caring then acts as a link to the next theme which is seeing and not seeing and perceptions. She sees the level of care she is offering, which is 'above and beyond', as 'masking' the problem of people with intellectual disabilities not getting the support they need and deserve. This theme of seeing and not seeing and perceptions includes lots of descriptions of feelings the bulk of which are negative which are very much related to Wolfensberger's consideration of how society perceived people with intellectual disabilities. Part of what she is saying relates to how societies perceive people with intellectual disabilities. The key here is the flipping of that. So, she feels fear, not of people with intellectual disabilities, but for people with intellectual disabilities, dread for them, terror for them. Within this are many themes of vulnerability and of safety. She explains that cuts have made people unnecessarily vulnerable and that their safety is paramount but even basic safety needs are not being met. Linked to this is the idea of 'seeing': who sees and who doesn't see and what that means. Within this are several dichotomies. She knows that if she sees someone in need, that 'seeing' obliges her, and makes her responsible for her own actions in trying to help this person. She is also confused because there is an expectation that the more people know about a group- like people with intellectual disabilities- the more knowledge there is, then the more understanding there will be and the more support will be available. She really struggles that this is not the case. She is also torn between whether people see people with intellectual disability as struggling and chose not to help, or whether they choose not to see in the first place. So, people with learning disability are either invisible because people do not see them all, or they are (or will) be invisible by people who choose not to see them. She explains that some people perhaps pretend not to see people with learning disability struggling and in need.

The final theme is about the future. She makes many references to choosing to do this work from a very young age and references to the ways in which care was previously imperfect in terms of setting, but for the children she supported was like a family environment. She feels the current situation is that nobody cares for or about people with intellectual disabilities in any setting at all, as most of the people she supports are not eligible for support and she supports them anyway, this links to Wolfensberger's ideas about childlike and family. The future is also full of dissonance. She is fearful of an uncertain future, often stating that several years ago no one would've believed the situation could be this bad and no one would have allowed it to happen, and so the future appears uncertain and to be feared. There is also a feeling that the future will be disastrous. This will be as a result of people not caring, or of the government and people in power knowing the results of the cuts they are making and doing them anyway, and the results of these cuts will be deaths. She feels that even deaths and very visible deaths like people with learning disability dying on the streets will not be enough to make anyone fight for people with intellectual disabilities, so their deaths too will be unseen or invisible. She often describes these deaths as being perceived by those in power as natural wastage. These fears about the future are exacerbated by a feeling that there is no solution because we have all gone too far down a path of no resistance to now find a solution to these problems.

An overriding theme appears to me to be powerlessness. She is powerless to change society and powerless to change services, powerless to keep people with intellectual disabilities safe, powerless to change the present, and powerless to change the future. All she has is her emotional link and sense of responsibility to people without support, so she provides support despite not being paid to do so and the service she runs not being contracted or paid to do this. It may be that breaking the rules is the only way she feels she can make a difference and she knows she can only make a difference to some people some of the time in small ways.

The emotional burden of care is heavy indeed and without appreciation by a non-seeing and uncaring public and unseeing or uncaring government. Her desire to stop seeing people in need is manifested currently in her choice not to come into town when she is not working, so she does not have to see people who need support or not getting it, and in her future desire to retire to a desert island where she will not need to see and therefore act on unmet need.

Appendix B

Memo B2 Ongoing memo reflecting on parent and service provider interviews and analysis 9.4.21-9.11.21.

Memo For Self: Overall themes as I'm going through parent carer interviews (X, XX, XXX replaces parents' names before pseudonyms were assigned)

9.4.21

Parents are ageing and are concerned about that (X,XX,XXX)

Child does not deserve to be treated like this (X,XX)

No policy (X and SR2)

14.4.21

Identity- something here about relationships with Social Workers being expected to be cordial and helpful and joint working and reasonable. Relationships are not that by any stretch. Parents now feel treated as though they are thieves and con artists, to be treated with distain, and refused help at any turn. As if they are attempting to break in and burgle the personal homes of social workers, and if not them, then panel members who decide they cannot have the support parents feel their sons/daughters need. Links to distance between decision-makers and 'on the ground' practice of daily grind of care. Consequences of decisions are not seen or felt by decision-makers. Also, worthy/unworthy ideas about whether parents 'deserve' support. Who fights back and who just accepts this is the way of things and that there is no point fighting? Something about having knowledge = power and having networks of people who have knowledge = I have a bit more knowledge and can use it to fight my corner. Being walked over if you don't fight.

I'm part of the parent carer forum and the Local Implementation Group (LIG) so hear several times throughout the year about the frustrations of parents, who are very aware of budget cuts and are very concerned about trying to find appropriate, safe and secure care for their son/daughter after parents have died or are no longer able to provide care or challenge decisions.

I'm also not a parent, with all that that might entail.

14.4.21

I spoke with a colleague today about this beginning of analysis for these parents. I had forgotten that several parents had asked me to lunch, and I had had lunch with them just before or just after our recording of the interview (in the one visit). (3 parents) did this. In X's house you can hear her dog walking around on the wooden flooring tippy tapping. The dog was interested in our lunch.

Some of these parents said they either could see how parents killed themselves and their son or daughter or had contemplated it (X). Several said they had considered leaving their son/daughter on the steps of the council building or abandoning them in order to force the council to perform its legal duties. They stated then that they would not do this, they were clear about this, but had shared their thoughts about how desperate they felt at times.

I was far too talkative with X. She was very reserved and had to go to work so did not have long to talk. Several parents at the Tesco group had said they would like to talk to me but did not have time. X kept stopping talking and shrugging like she had nothing more to say. So, I asked another question or clarified a point but spoke over her when she agreed. If I had kept quiet she may have spoken more or she may have concluded the interview, but I’m now thinking that would have been, and should have been, her decision. I think I was eager to hear her views and to be encouraging so she would share her thoughts.

Most parents wanted to start by explaining who their son/daughter was. They would say how complex the son/daughter’s needs were and also include how lovely their son/daughter was – usually in relation to having to complete paperwork which focused on the deficits.

X said his son would be interviewed, then didn’t respond when I double-checked date and time. XX at the LIG encouraged him to be interviewed by me himself (not knowing he and I had discussed interviewing his son). I interviewed X and he stated he had not replied as he was concerned that his son would have become violent, at which point he was too difficult for his parents to manage. He could be violent towards them and as X’s wife had a long-term condition, this would be extremely difficult and distressing. After our interview X said he was glad it was me telling his story. I remain very moved by this and feel very privileged that someone with all this going on in his life, and being an ex-monk, would be so kind and generous with his feedback.

X’s house was not well-maintained, they lived on benefits. They made choices about where they went in the month depending on how much petrol they could afford and whether X’s wife was well enough to be left alone. They had adopted 2 disabled sons and he had set up a charity. XX had also set up a charity. Trying to make a difference?

10.5.21 (Parents)- overall themes for all/ many parents?

Not being believed, being ignored, cuts deliberately done, THE WAY IT WAS DONE, wanting honest conversations. Can’t get hold of any individual Social Worker (SW) to deal with your case ongoing. Assessment dressed as cuts.

Also stress killed husband – god this is awful.

Feedback sent to Jill on 13.5.21.

I've realised some parents wanted to be interviewed to tell me about one thing that has happened which they feel is unjust, so they have few themes but are now linking their poor experiences to having a Local Authority that 1. does not understand their life or the life of their son/ daughter and 2. when they are told how bad things are choose not to believe parents and make cuts anyway. So L.A. workers don't KNOW what it's like, then on top of that don't CARE. Parents are saying this ATTITUDE enables L.A. workers to lie, deceive, exclude and make decisions deliberately designed to wound. Two women who are widows have said it was the stress of cuts and fear of the future that caused their husband's strokes/ heart attacks which led to their deaths.

Other parents wanted to tell me the story of their family from the beginning, especially those who had adopted their children, so they have far more themes, which is taking more time. This parent group is still quicker than the provider group though as I feel more that I know what I'm doing. (I've gone and said it now, I can hear the gods chuckling as I write this!!).

29.5.21

(Parent) stress killed husband and parents from the North – X says she and other carers hope their children die before them because of lack of care. Northern parents said they were, in a way, pleased their son had not had to live through the current cuts.

Lots of parents have said they want rational conversations, and providers too.

31.5.21

X and XX Minute by minute is not seeing the holistic whole person

Also look at other parents. X says it's hard to know if it's austerity or personal vendetta because she complained. XXX said she thought she was on a hit list because she complains. Parent in tumbledown house said her payments stopped because she complained. Two at least sets of parents north and XXXX actively stopped from going to meetings because they complain.

Also look for Care Act.

Look for NHS as well as social workers. X says NHS so does NWP.

Say re X sending me copies of emails. And (Service Provider) up north re (participant with intellectual disabilities). And (service Provider) at (service) re 4 days to one hour/week.

18.6.21

X linked to ST1 'Do-goody'.

21.6.21

SM and SR1- constant assessment and assessed always as needing less support although needs had not changed.

Also, SM and SR saying everyone assessed as needing less hours although needs had not changed.

28.6.21 Overall themes from parents' memos?

1.7.21 changing SW identities??? Parent have had to change identity to fight, have SW changed identity from helper to obstructer?

Social Services picking on people who cannot fight back- people with intellectual disabilities and parents who are not articulate and/ or educated.

5.7.21

Lots here about fighting which is going to go across several wider themes. And issues as a result of such poor relationships with SW and LA and health workers. So, the issues are only there because of the attitude changes by SW which appear to be as a result of cuts.

Is it identity as defined by LA/SW/Health or is it relationships with SW etc deteriorating??

9.7.21

There's something here re SW just do not care about the effects of the cuts and do not care that parents cannot cope.

27.7.21

Parents desire for ordinariness for their children- and re social networks ordinary friends, linked to literature review desire for ordinariness?

29.7.21

Language and linguistics- language of battle, fight, drawbridge, ammunition.

13.8.21

Language and linguistics- ‘again again again’

Distance created between L.A.s and their decisions. Between L.A.s and parents. In relationships between people with intellectual disabilities and agency staff.

1.9.21

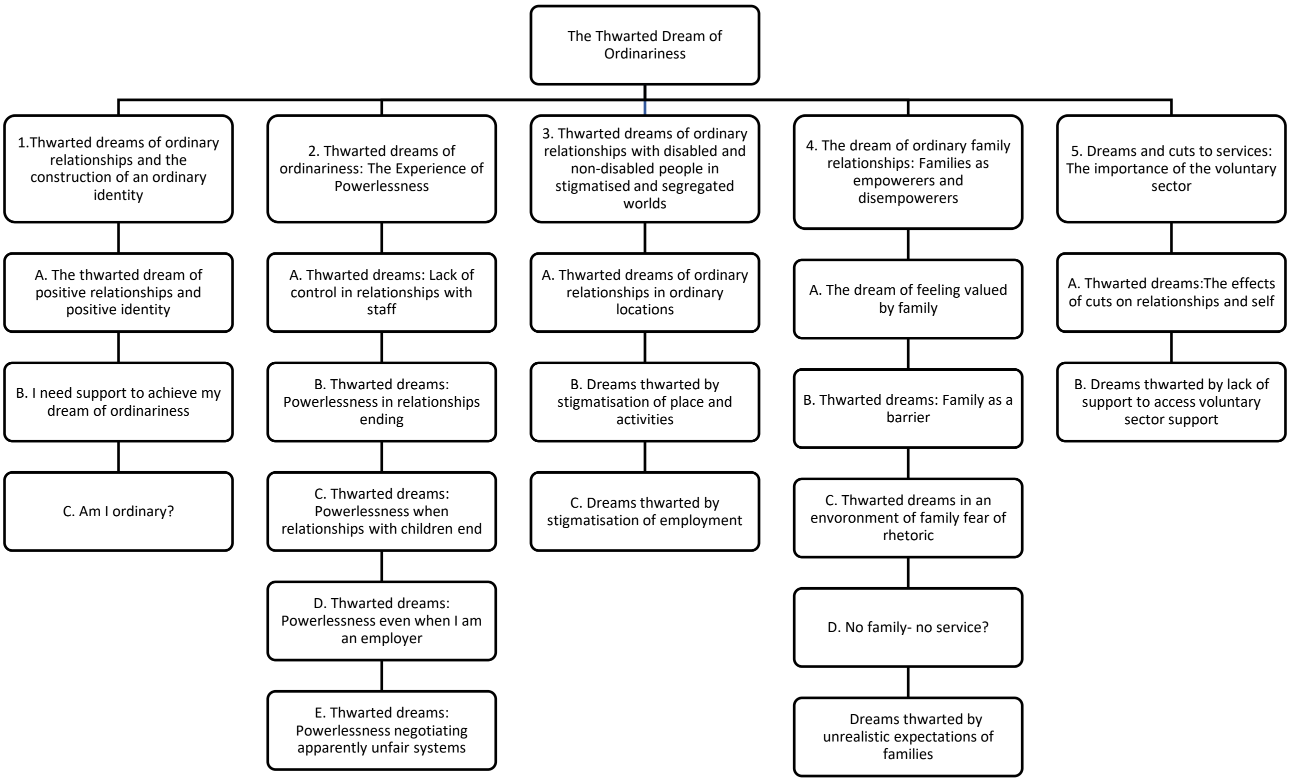
I’m re-thinking the above themes as they merge so much- perhaps it’s about the nature of Social Work has been affected? (I’m getting a bit lost it this section again. I’ve printed it off again and cut it all up into quotes and ideas again and gone back to the transcripts again). SO MUCH of what the parents are saying overlaps into so many of the themes. But I’m now thinking that the distance created is perhaps more about the fundamental shift from SW as helpers to SW as rejectors?

9.11.21

I’ve re-arranged and re-arranged and re-arranged and cut and cut and cut themes and subthemes. Discussion with supervisors has been so helpful as they are reading this as ‘outsiders’ to the research. They have said, as Braun and Clarke have said, you need to be able to let go of themes, plus, quotes are not self-explanatory! What I think is obvious really isn’t. I’m learning too about how many words per chapter, I thought it was 15k but it seems it’s 10k as I have 3 results chapters, heck that’s a lot more cutting. We have all agreed that all the stories are important and all need telling, but it has to fit into the PhD format, and even smaller if I’m to publish, so presenting a small but deep analysis is better than trying to do a large but deep analysis (which is how I started and have been working until now). I’m feeling it’s better to have too much and cut down than not enough. I hadn’t realised, or perhaps I had but I had moved away from it, how heartbreaking their stories were and how painful.

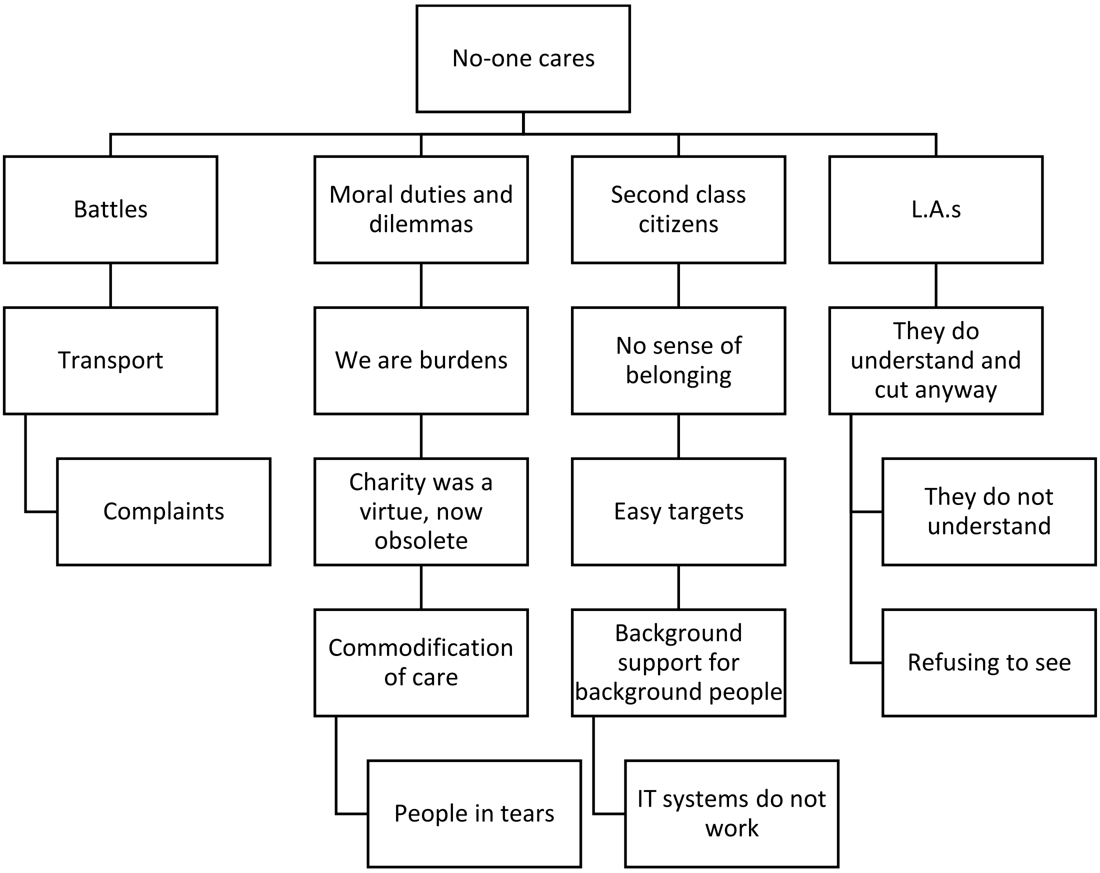
Appendix B

Figure B1 A Previous Version of Themes from the Systematic Literature Review and Synthesis



Appendix B

Figure B2 A Previous Version of Themes from Service Provider Interviews



Appendix C

Form C1 (Chapter Five) Indicative Interview Schedule for Service Providers

University of Kent | Tizard Centre

Becoming less eligible? Intellectual disability services in the age of austerity.

INDICATIVE INTERVIEW SCHEDULE FOR PROVIDERS

1. Has your organisation/ service been affected by cuts?
2. If it has, in what ways?
3. How does this affect the service you provide?
4. How does this affect the people who use your service and their carers?

Appendix C

Form C2 (Chapter Four) Indicative Interview Questions for Parent/Carers

University of Kent | Tizard Centre

Becoming less eligible? Intellectual disability services in the age of austerity.

INDICATIVE INTERVIEW SCHEDULE FOR CARERS

1. When did the person that you care for lose social care?
2. How did it make you feel?
3. How was your life before losing care?
4. How is your life now?
5. Has losing social care impacted on your social network?
6. Has losing social care impacted on your job?
7. How do you organise the care for your loved one?