



**Risk in Adult Social Care:  
Perceptions and experiences of risk  
in disability services in Ireland**

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## Abstract

The principles of autonomy, choice, and independence have been prevalent in the rhetoric used to initiate policy change in disability services in recent decades. As part of this rhetoric, it has been stressed increasingly that a rights-based approach to care must embrace risk and view it in a more positive light and that services and social care professionals should facilitate and promote a positive risk-taking environment. While these changes represent an optimistic view and emancipation for service users, this move toward increased choice and risk-taking also means more responsibilities for service users and social care practitioners. This shift in disability services, and social care in general, is informed by ideological visions in which risk and disability become a matter of individual responsibility within markets while the role of the state in protecting and providing for its disadvantaged citizens diminishes.

In practice, service users risk-taking leads to tensions, particularly as services and professionals attempt to balance their duty to safeguard service users with a service user's right to take risks. This situation is further compounded by a growing regulation of disability services and health and social care professions, heightening a perceived culture of blame. As such, professionals seek to avoid liability or being held accountable often through assessing, managing, and auditing risk in a defensive manner.

This study investigated varying perceptions and experiences of risk in disability services by exploring the perspectives of ten service users, five

social care workers, and five social care managers. This research was informed by a constructivist theoretical framework, which facilitated recognition of participants varying perceptions. Data was collected via qualitative interviews and vignettes, and the descriptive phenomenological research method designed by Giorgi was used to analyse the data.

The findings showed that service users, social care workers, and service managers perceive, assess, and manage risks differently and that different perceptions and interpretations of risk can influence how risk is approached in practice. While service users view taking risks as their choice, managers and practitioners are concerned with potentially negative consequences, often driven by concerns over blame and litigation. Within this climate, social care professionals find it hard to do 'the right thing', and service users feel that choices are often limited to 'safe options', as managers and social care workers try to manage out any potential ill consequences. The findings further indicate that service users are largely excluded from decision-making around risk, which is often solely the preserve of managers and clinical professionals through standardised processes, which do not reflect the individual needs and wishes of the service users. This study has implications for policy and practice and has the potential to inform risk research and social care education.

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## Chapter One: Introduction

### Background and context

Throughout the last century, disability services had been dominated by biomedical models of care, which were criticised for categorising disability with reference to conformity of body appearances and behaviour with mainstream expectations (Finkelstein, 1980; Goering, 2015; R. Hughes, 2010; Mulvany, 2000; Oliver, 1990; Thomas, 1999). Through such models, disability had been commonly treated as a bodily issue and perceived as a negative difference, abnormality or deviancy, which stigmatised disabled people<sup>1</sup> (Goering, 2015; R. Hughes, 2010; Mulvany, 2000; Susman, 1994). Within this lens, the main aim of care was treating, correcting, and curing bodily flaws (B. Hughes & Paterson, 1997), and good practice was viewed as one that protects service users and eliminates risks most commonly through segregation and institutionalisation of disabled people. Such models of care have been described as unsuitable for their controlling and oppressive practices that were unsupportive of disabled people's choices and rights (Carr, 2011; Independent Living Movement Ireland, n.d.; Rowlett, 2009)<sup>2</sup>.

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<sup>1</sup> The term 'disabled people' is used to emphasise the social model view of disability, which is considered to be a product of societies that disable individuals through societal barriers and norms (Barnes, 1991; Barnes & Marcer, 2004a, 2004b, 2004c; Brisenden, 1986; Finkelstein, 1980; Fisher & Goodley, 2007; Goering, 2010, 2015; Goodley, 2001; Health Information and Quality Authority (HIQA), 2019a; R. Hughes, 2010; Independent Living Movement Ireland, n.d.; Nisker, 2019; Oliver, 1983, 1990; Oliver & Barnes, 1998, 2012; Spandler, Anderson, & Sapey, 2015; Thomas, 1999; Tregaskis, 2002; Wendell, 1996).

<sup>2</sup> A movement initiated by disabled people called the Independent Living Movement developed in the United States in the 1970s as a response to the oppression experienced by disabled people. Later a European Coalition for Community Living and European Network on independent living were formed. In Ireland, there is the Centre for



Over five decades ago, disability rights movements began their campaigns, which challenged negative attitudes and stereotypes surrounding disability. Biomedical models of care were actively challenged and widely contested for their failure to recognise other than naturalistic aspects of disability, until finally, such models came to be considered outdated and oppressive (Barnes, 1991; Barnes & Marcer, 2004a, 2004b, 2004c; Brisenden, 1986; Finkelstein, 1980; Fisher & Goodley, 2007; Goering, 2010, 2015; Goodley, 2001; Health Information and Quality Authority (HIQA), 2019a; R. Hughes, 2010; Independent Living Movement Ireland, n.d.; Nisker, 2019; Oliver, 1983, 1990; Oliver & Barnes, 1998, 2012; Spandler et al., 2015; Thomas, 1999; Tregaskis, 2002; Wendell, 1996). Indeed, disabled people and activists have long called for the abolition of barriers produced by disabling societies and sought new models of care that would respect their rights and choices. They have emphasised that disability is not a personal tragedy, nor is it something that requires medical or other intervention in order to be corrected (Brisenden, 1986; Finkelstein, 1980; R. Hughes, 2010; Oliver, 1983, 1990, 1996).

Similarly, in Ireland, the suitability of segregation and institutionalisation of disabled people came to be questioned as biomedical models of care were increasingly viewed as paternalistic and “unacceptable” (Independent Living Movement Ireland (ILMI) & O’Duffy, 2018, p. 6). Following developed countries internationally, a move from institutional models of care was initiated and “a rights-based social model of disability” was advocated as a more suitable paradigm to inform the provision of disability services (Independent Living Movement Ireland,

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Independent Living Network Council, which includes 25 Irish Centres for Independent Living (Independent Living Movement Ireland, n.d.).

2018, p. 6). Thus, from the concluding decades of the last millennium, Ireland, like many other first-world countries, has undertaken a transformation of disability services with principles of choice, independence, and responsibility used as key terms to initiate policy change (Department of Health (EIRE), 2012, 2018; Department of Health (EIRE); Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, 2006; Department of Justice and Equality (EIRE), 2017; Department of the Taoiseach, 2006; Friedman & VanPuymbrouck, 2019; Gadd, Cronin, & Health Service Executive (HSE), 2018; Health Information and Quality Authority (HIQA), 2013, 2016, 2017b, 2019a, 2019b, 2019c; Health Service Executive (HSE), 2011b, 2012, 2016; National Disability Authority (NDA), 2010a).

Over the years, with the growing recognition of human rights, the importance of the involvement of disabled people in society and their care has become also rightly recognised<sup>3</sup>. It can be argued that in line with the aims of the ‘Value for Money and Policy Review of Disability Services’ (Department of Health (EIRE), 2012), disabled people have begun to be actively encouraged “to participate to their full potential in economic and social life” (Health Service Executive (HSE), 2014a, p. 52). Moreover, a rights-based social approach to care has now become widely accepted (Health Information and Quality Authority (HIQA), 2019a; Independent Living Movement Ireland, n.d.). Thus, services have been moving toward more self-directed, independent, and personalised care (Department of Health (EIRE), 2012, 2018; Department of Health (EIRE); Review Group on

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<sup>3</sup> This has been expressed through a range of legislation including the Disability Act 2005, The Citizens Information Act 2007, Equality Act 2004, Employment Equality Act 1998, The Equal Status Act 2000, The Education For Persons With Special Educational Needs Act 2004, and The UN Convention on the Rights of Persons with Disabilities (2006).

Health and Personal Social Services for People with Physical and Sensory Disabilities, 2006; Department of Justice and Equality (EIRE), 2017; Department of the Taoiseach, 2006; Gadd et al., 2018; Health Service Executive (HSE), 2011b, 2012, 2016; National Disability Authority (NDA), 2010a). This shift towards individualised services advocates greater control for service users and more positive risk-taking (Glendinning et al., 2008; Heath & Phair, 2009; Kettle, O'Donnell, & Newman, 2011). Positive risk-taking has become acknowledged as part of disabled people's lives and thus as an inseparable component of disability services (Carr, 2011; Department of Health (EIRE), 2018; Health Information and Quality Authority (HIQA), 2019b; Methven, 2009; W. Mitchell & Glendinning, 2008; Veselinova, 2014).

Nonetheless, the vision of disability services needs to adjust to support positive risk-taking to become a part of social care practice and 'protecting and shielding' should shift to 'enabling and empowering' (Carr, 2011; Methven, 2009; Rowlett, 2009). Service users should be supported to engage in positive risk-taking and make choices that are independent and autonomous. While earlier considerations have reflected on the past of disability services as rather prudent and risk-averse, it is evident that this transition to social care practice that approaches risk positively is not without its challenges. Indeed, services have begun to embrace a more person-centred outlook and begun to move towards self-directed, independent, and personalised care (Department of Health (EIRE), 2012, 2018; Department of Health (EIRE); Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, 2006; Department of Justice and Equality (EIRE), 2017; Department of the Taoiseach, 2006; Gadd et al., 2018; Health Service Executive (HSE), 2011b, 2012, 2016; National Disability Authority (NDA), 2010a). Moreover, they

can be seen to advocate greater control and choice for service users (Glendinning et al., 2008; Heath & Phair, 2009; Kettle et al., 2011). Yet, obstacles to implementing positive risk-taking in practice have been highlighted. Practitioners, for instance, do not feel entirely confident to promote service users' risk-taking (Robertson & Collinson, 2011). They feel that there is an onus on them to promote health and prevent disease or injuries when working with vulnerable 'at risk' people (Drennan et al., 2005; Leser et al., 2018). Social care workers also feel that positive risk-taking is fraught with balancing act in practice and that it needs to be considered against the backdrop of service users' "daily vulnerabilities, the concerns of staff for professional risk emerging out of a perceived blame culture, and the organisational context of services delivering on expectations of safety and well-being" (Morgan, 2016, p. 127). It is evident that while the emphasis on positive risk-taking has grown, the relationship between a service user's choice and a professional's responsibility for the management of risks is far from clear-cut (Carr, 2010, 2011; Hamilton, 2012; W. Mitchell, Baxter, & Glendinning, 2012; W. Mitchell & Glendinning, 2008; Scourfield, 2007).

While disabled people have long sought new models of care that would respect their right to live autonomously, social care workers and managers play a significant role in this transformation. However, the extent and contribution of this role are far from straightforward. Traditionally, the state was seen as responsible for shielding vulnerable adults from risks, which was historically performed through segregation of disabled people who were deemed "in need of protection" (W. Mitchell & Glendinning, 2008, p. 298). With the changing ethos of social care accompanying the move from institutional to community-based independent care (Department of Health (EIRE), 2018; Health Service

Executive (HSE), 2011b, 2016), many responsibilities have shifted to service users and professionals (W. Mitchell & Glendinning, 2008) and risks have been individualised (Scourfield, 2007).

In spite of the many positive aspects of this innovation in disability services and social care in general, it has been argued that the state's enthusiasm for more individualised models of care is not just a response to the disability rights movement and can also be seen to exist in tandem with conservative economic ideas of a more free-market provision (Burch, 2017; Ferguson, 2007; Fyson, 2009; Leece, 2004; Pearson, 2000; Stainton, 2002; N. S. D. Taylor, 2008). The calls for independence have occurred in an increasingly marketised environment leading to overlapping between economic and social policies. This has led to claims that the recent changes fall into the broader conservative market agenda, which has resulted in the state shifting and rearranging its responsibilities (Leece, 2004; Pearson, 2000; Scourfield, 2007; N. S. D. Taylor, 2008).

This conservative market agenda is about promoting the market as the primary means of provision and thus rolling back the state. While such policy drivers may have appeared to respond to the disability movement's calls for increased choice, most notably through the introduction of quasi-markets, the same policy drivers have increased the focus on risk management, private insurance, and litigation. As market deregulation and privatisation have colonised welfare spheres (Burch, 2017; Kemshall, 2002), social life has been "transformed by economic discourse", and the welfare culture has been changed into "an enterprise culture in which the supply side of a flexible workforce is emphasised, not the collective safety net of welfare provision" (Kemshall, 2002, p. 42). Security, once afforded through human solidarity and altruism, is now substituted for financial compensation and private insurance (Rose & Miller, 2010). In this climate,

many state responsibilities have been transferred to social care professionals and service users who are encouraged continuously to become responsible for the management of care and risks.

Against this backdrop, it has been argued that the “disabled peoples’ movement and governmental ideas on self-directed support, although superficially similar, are growing increasingly apart” and “that in the absence of adequate funding [service users] risk moving from a position of enforced collectivism to an enforced individualism”, which is a “characteristic of neo-liberal constructions of economic life” (Roulstone & Morgan, 2009, p. 333). In marked contrast to institutional care, in which disabled people’s responsibilities were largely overlooked along with their rights, marketised care influenced by the notion of responsible citizens places service users’ responsibilities at the centre of care. These responsible service users, however disadvantaged they may be, should not be seen as deserving a “solicitous expert proffering support and benefit cheques”, which has been portrayed as demeaning charity, but rather they should be viewed as in need of “ethical reconstruction as active citizens” (Rose, 1996, p. 60). As such, service users should be empowered to restore their rights and responsibilities and become responsible service consumers and managers of risk. In order to foster a suitable environment for this transformation in the social care sector, professionals and services need to recognise that “achieving a better quality of life may involve risk-taking in situations where clients and service providers are aware of exposure to potential loss or harm and accept the possibility of this in anticipation of potentially greater gains” (B. Taylor & McKeown, 2013, p. 164).

## Risk in the context of disability policy, legal frameworks, and social care governance in Ireland

The 1990s was a significant decade in the progression of disabled people's human rights. In 1993, 'The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities' provided governments internationally with a rights-based framework for policy and legislative reform. Against this backdrop of increasing awareness and recognition of the rights of disabled people internationally, a Commission on the Status of Disabled People was set up in Ireland "to ensure that people with a disability can exercise their rights to participate, to the fullest extent of their potential, in economic, social and cultural life" by recommending "changes, in legislation, policies, organisation, practices and structures" (The Commission on the Status of Disabled people, 1996).

In 1996, the Commission produced 'A Strategy for Equality', which is considered "a landmark document" in the changing the disability landscape in Ireland (National Disability Authority (NDA), n.d.para. 2). The core aims of this strategy were to advocate for the rights, independence and choice of disabled people and to maximise their participation and inclusion in Irish communities. This strategy was superseded in 2004 by the National Disability Strategy. The National Disability Strategy's primary objectives were to foster equality and inclusion for disabled people by creating plans and policy initiatives that built on relevant legislation, including the equality framework of the Employment Equality Act 1998, the Equal Status Act 2000, and the Equality Act 2004. The legislative components of the National Disability Strategy were the Education for Persons with Special Educational Needs Act 2004, the Citizens Information Act 2007, and key elements of the Disability Act 2005 (Department of

Health and Children (EIRE), 2009). The objectives of the National Disability Strategy to advance equality and social inclusion for disabled people have continued to be implemented through a series of actions and strategic plans, including the 'National Disability Strategy Implementation Plan 2012-2015', in which former Minister for Disability, Equality, Mental Health and Older People, Kathleen Lynch, emphasised how essential it is "to consider to what extent our society supports or restricts individual independence, choice and control" (Department of Justice and Equality (EIRE) & National Disability Strategy Implementation Group, 2013, p. 2).

In 2017, a 'National Disability Inclusion Strategy 2017 to 2021' was launched with a vision for ongoing improvement of the lives of disabled people in Ireland by further supporting their rights by committing policies to principles such as equality, choice, control, person-centeredness, and community-living (Department of Justice and Equality (EIRE), 2017). The National Disability Inclusion Strategy 2017-2021 currently sets a vital policy context for disabled people in Ireland as it provides "a significant framework for all activity across government departments and agencies which can support progress in delivering on the obligations in the United Nations Convention on the Rights of Persons with Disabilities" (National Disability Authority (NDA), 2019, p. 1).

Although Ireland was the last country in Europe to ratify the United Nations Convention on the Rights of People with Disability (UNCRPD), it nonetheless represents a significant aspect of the background of disability policy. The UNCRPD reflected calls for the rights and autonomy of disabled people and has fuelled a move in policy systems internationally toward person-centeredness, citizenship, and inclusion approaches. Article 19 of the UNCRPD 'Living Independently and being included in the Community' places an obligation on states to recognise equal rights for all disabled



people to live in communities with choices equal to others in all aspects of life (The United Nations (UN), 2006). This, of course, includes choices around risk. Nonetheless, the UNCRPD also stresses the importance of safeguarding and, in its Article 11, calls upon states to take all necessary measures to ensure the protection and safety of disabled people in situations of risk (The United Nations (UN), 2006). Thus, while choices should be free and independent, disabled people must also be safeguarded.

In line with the Convention, the Irish Government has committed to implementing capacity legislation<sup>4</sup>. In Ireland, supported decision-making<sup>5</sup> will also soon assume a formal legal dimension. This should bring more changes into how risk is managed in social care services, particularly as the Assisted Decision Making (Capacity) Act 2015 recognises service users as independent and capable of making decisions (Ni She et al., 2020). Incapacity will be determined only by examining a particular problem and attached only to a specific situation, context, and time, not to a person and their diagnosis (Health Information and Quality Authority (HIQA), 2019b; Ni She et al., 2020).

However, currently, there is no legislative framework to govern instances when capacity of a service user to make a particular decision is

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<sup>4</sup> In Ireland, to ratify Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD), which creates a state obligation to provide support for the exercise of legal capacity, the Assisted Decision Making (Capacity) Act was signed into law in 2015 and should be commenced in 2021. The Assisted Decision-Making Act 2015 is a central piece in Ireland's compliance with the UNCRPD (Inclusion Ireland, 2018).

<sup>5</sup> The UN Convention of the Rights of Persons with Disabilities (2006) employs the term 'supported decision making', while the Irish Act uses the term 'assisted decision making' (Ni She et al., 2020). It is a legal term used to place "the relevant person at the centre of decision-making" and "outlines the provision of appropriate assistance to maximise the decision-making capacity of a relevant person" (Ni She et al., 2020, p. 2).

absent, and in such cases, it is expected of health and social care professionals to act in the best interest of the service user (National Consent Advisory Group, 2013). Understandably, this can mean more uncertainty for social care professionals, and although guidelines around how the framework should be implemented in practice are pending, for now, it has been acknowledged that “training and guidance should be provided to staff on the practice of positive risk-taking, based on the principles of the Assisted Decision-Making (Capacity) Act 2015” (Department of Health (EIRE), 2020, p. 80). Certainly, it is essential to consider how this training and guidance will be provided and delivered to practitioners.

In Ireland, the configuration of the principles of choice and control set out in the UNCRPD contributed to the development of a set of rights-based policies and frameworks informing adult social care. These policies aim to initiate new, more positive ways of approaching risk but also continue to place obligations on services and professionals to protect service users. For instance, ‘A National Framework for Person-Centred Planning in Services for Persons with a Disability’ emphasises the rights of disabled people, including the right to take risks and guides services to promote “risk-taking that is calculated” (Gadd et al., 2018, p. 18). This document acknowledges that risks might increase for service users living more independently and outlines that organisations should never the less be proactive in enabling positive risk-taking. However, it also stresses that “robust risk management policies and procedures” must be followed in disability services (Gadd et al., 2018, p. 21) and that risks should be managed by “weighing up the potential benefits and risks of exercising one choice of action over another, identifying the potential risks involved, and

developing plans and actions” which would “minimise the potential harmful outcomes” (Gadd et al., 2018, p. 73).

In 2018, following the national safeguarding policy (Health Service Executive (HSE), 2014b) and in line with Article 11 of the UNCRPD, the ‘National Standards for Adult Safeguarding’ were launched. These Standards emphasised people’s rights and autonomy, as well as their protection and outlined that “each person’s welfare should be promoted...in an environment where every effort is made to prevent the risk of harm” and that “care and support should be balanced and proportionate to manage or mitigate risk in order for the person to live a safe and fulfilling life” (Health Information and Quality Authority (HIQA), 2019b, pp. 8-9). Furthermore, the document stresses that people should be “empowered to protect themselves from the risk of harm and to direct how they live their lives on a day-to-day basis according to their will and preferences” (Health Information and Quality Authority (HIQA), 2019b, p. 9). It also advises that professionals are responsible for “tak[ing] proportionate action which is the least intrusive response appropriate to the risk presented and takes account of the person’s will and preferences” (Health Information and Quality Authority (HIQA), 2019b, p. 9).

If the above considerations point to increased policy emphasis on autonomy for disabled people, then an intensification in the regulation and standardisation of social care services and health and social care professions means rather the opposite for professionals and service providers. While service users’ risk-taking choices are becoming recognised, accountability for the risks to organisations, such as liability to compensate or loss of credibility, is under-discussed (B. Taylor & Campbell, 2011; B. Taylor & McKeown, 2013). Nonetheless, services must act in accordance with the regulatory obligations and legal commitments,

including the safety and the rights of social care professionals and people using services. Thus “the focus of risk management, is [located] within its statutory and policy context and its public mandate” (B. Taylor & McKeown, 2013, p. 165) as “health and social care services are accountable for the care and support they deliver and for safeguarding people using their services” (Health Information and Quality Authority (HIQA), 2019b, p. 10).

In a similar vein, if professionals are urged to support service users to take risks, their role must be considered within the broader context of the relevant legislation and professional duty of care (B. Taylor & McKeown, 2013). The Social Care Workers Registration Board Code of Professional Conduct and Ethics (CORU, 2019)<sup>6</sup> clearly outlines that social care workers “must...comply with requirements for the protection of children and vulnerable adults (p. 6)” and “address health, safety and welfare risks (p. 7)”. Moreover, in order to “act in the best interest of service users”, social care workers “must” respect service users’ “privacy and autonomy”, but must also “do everything...to enhance the health, safety or welfare of a service user” (CORU, 2019, p. 8). In order “to address health, safety and welfare risks”, they “must” follow risk assessment

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<sup>6</sup> In 2010 many health and care professions came to be regulated by the Health and Social Care Professionals Council - CORU - the regulator of health and social care professionals, which was instigated under the Health and Social Care Professionals Act (2005) and established in 2008. Social care work will also soon be a regulated profession in Ireland, with the opening of the register suggested for late 2023. Coru has recently provided documents outlining professional codes and standards for social care work, including the Social Care Workers Registration Board Standards of Proficiency for Social Care Workers (CORU, 2017b); Social Care Workers Registration Board Criteria for Education and Training Programmes (CORU, 2017a); Social Care Workers Registration Board Code of Professional Conduct and Ethics (CORU, 2019).

policies and procedures” and “take any steps needed to minimise, reduce or eliminate the risks” (CORU, 2019, pp. 21-22).

Thus, managers and practitioners are expected to identify, assess, and manage risks in a manner that does not limit service user choices (Health Information and Quality Authority (HIQA), 2019c) while balancing rights with risks and responsibilities to both enable risk-taking and where appropriate safeguard (Health Information and Quality Authority (HIQA), 2016; Wallcraft, 2012). This is perhaps a tricky balancing act at the best of time, and social care practitioners can face particular challenges when they have to make often immediate decisions in dilemmatic situations (McLaughlin, Leigh, & Worsley, 2016; Reamer, 2006).

### The individualisation of disability services

Against the backdrop of marketisation in the health and social care sphere, many capitalist countries, including the UK and Ireland, have set out to transition toward self-directed personalised models of social care<sup>7</sup> (Carr, 2011; Christensen, 2010; European Union Agency for Fundamental Rights, 2014; Glasby, Le Grand, & Duffy, 2009; Glasby & Littlechild, 2002; Junne & Huber, 2014; Leece & Leece, 2011; Ratcliffe, Hutchinson, & Milte, 2019; N. S. D. Taylor, 2008). Although in Ireland, personalised budgets are in their infancy (Department of Health (EIRE), 2018), the Irish government has demonstrated a commitment to moving away from long-term residential settings towards community-based care (Department of Justice

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<sup>7</sup> This has been reflected in independent living and community integration programmes, including personalised budgets programmes; ‘direct payments’ and ‘personal budgets’ in England and Holland; ‘social insurance reforms’ in Germany; ‘cash and counselling’ and ‘consumer-directed care’ in the USA; and the ‘National Disability Insurance Scheme’ in Australia.

and Equality (EIRE), 2017; Government of Ireland, 2018; Health Service Executive (HSE), 2011b, 2016). It has been acknowledged that:

Congregated provision is in breach of Ireland's obligations under UN Conventions. The provision contradicts the policy of mainstreaming underpinning the Government's National Disability Strategy. We now know what needs to be done to change people's lives and why their lives must change. This knowledge brings with it an obligation to act (Health Service Executive (HSE), 2011b, p. 14).

Nevertheless, the process of de-congregation has been lengthy, and it has been noted that substantially more work is required to finalise the transition to more suitable community arrangements (National Disability Authority (NDA), 2019). A lack of funding and ongoing budget cuts have been reported as significant obstacles for independent living and community services in Ireland (Disability Federation of Ireland (DFI), 2019; National Federation of Voluntary Service Providers, 2019). While voluntary organisations, which are often primarily reliant on HSE funding, provide a majority of disability services (Department of Health (EIRE); Independent Review Group (IRG), 2018), they continue to struggle due to financial difficulties that were a particular feature of the recent austerity years. It is a situation further compounded by unremitting attempts to comply with HIQA standards (National Federation of Voluntary Service Providers, 2019). Indeed, disability organisations are faced with "intensive demands to deliver services whilst meeting extremely demanding regulatory compliance which has created a significant burden in both professional and reputational terms for those concerned" (National Federation of Voluntary Service Providers, 2019, p. 3).

If disability services are to change in line with changing policy and succeed in becoming rights-based and person-centred in any real sense,

then approaches to risk in practice must change. It has been noted that the recent changes that are concerned with advocating service users' choice and control through new models of care "impl[y] the need for changes in the way that risk is understood, managed, discussed and negotiated with the person using the services...Good practice in personalisation means balancing empowerment and protection, self-determination, independent living and safeguarding" (Carr, 2011, p. 123). Similarly, the National Disability Authority (2010a) has also called attention to the need for the abolition of over-protecting disabled people through risk-averse practices. However, the Authority acknowledged that challenges might arise if services that facilitate people to live independently overlapped with efforts to ensure safety and protection from risk against the backdrop of increasing regulation, standardisation, and accountability (National Disability Authority (NDA), 2010a).

As such, how risk is managed has come to be considered a determinant of the quality of service provision (Carr, 2011) and risk and its management have become central features in social care (Alaszewski & Manthorpe, 1998; Barry, 2007; Kemshall, 2010; Kemshall, Parton, Walsh, & Waterson, 1997; Macdonald & Macdonald, 2010; Munro, 2010, 2011; Parton, 1996; Stalker, 2003; Trevithick, 2014; Webb, 2006a, 2006b; Whittaker & Havard, 2016). Yet, as social care work has become increasingly individualised and self-directed, it is unclear who is responsible for monitoring, managing, and assessing risk (Glendinning et al., 2008; Manthorpe et al., 2009; W. Mitchell et al., 2012), and there is a corresponding vagueness around who is liable if something goes wrong (Glendinning, 2008; Hasler, 2003). Moreover, there is a dearth of research on how risk should be managed in a way that promotes positive risk-taking (W. Mitchell et al., 2012), and it is evident that some current risk

management practices can lead to disempowerment and constrain not only service users' choices, but also their rights (Hollomotz, 2012; Jingree & Finlay, 2008; Manthorpe & Moriarty, 2010; W. Mitchell et al., 2012; B. Taylor & McKeown, 2013; Warin, 2010; Waterson, 1999).

Thus, there can be little surprise that when examining risk management in individualised services, it was found that "policies of personalisation and safeguarding were not well aligned" (W. Mitchell et al., 2012, p. 29). On the one hand, increased independence and empowerment could be achieved through individualised models of care and could enable service users to attain more control of their lives and thus be able to manage risk better (Glasby & Littlechild, 2002). On the other hand, however, potential over-regulation in the area of safeguarding can hinder this opportunity to self-manage risk (Glendinning et al., 2008; M Henwood & Hudson, 2007; M Henwood & Hudson, 2008; Manthorpe et al., 2009; N. S. D. Taylor, 2008). Therefore, it has been suggested that safeguarding and empowering policies need to amalgamate if a balance between safeguarding and positive risk-taking is to be achieved (Carr, 2010, 2011). It has been recognised that if empowerment is to be effective in practice, it must incorporate autonomy, participation, and community involvement (World Health Organisation (WHO), 2006). The health promotion model of social care highlights empowering practice as "finding a balance between choice, control and flexibility for the services user while safeguarding security...or finding the balance between rights and risks in social care" (Canavan, 2013, p. 50). Indeed, finding this balance seems to be one of the central preoccupations of day-to-day practice (Carr, 2011; Carr & Robinson, 2009; W. Mitchell et al., 2012; B. Taylor & McKeown, 2013; Whitelock, 2009).



Moreover, against the backdrop of growing regulations, many practitioners feel powerless to fulfil the core values of their profession as social care work has become all too often dominated by adherence to guidelines and procedures (Foster & Wilding, 2000; Kemshall, 2010). Technocratic guidelines and regulations that shift responsibility and potential blame from the state to the individual professional frequently encourage assessing, managing, and auditing risk in a defensive manner (L. Brown, 2010; Carr, 2011; S. Donnelly, Begley, & O'Brien, 2019; Killick & Taylor, 2020; Munro, 2010; Stanford, 2010; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whittaker & Havard, 2016). This situation, compounded by negative media coverage and the consequential public anxiety (Kemshall, 2009), has led to claims that risk has come to be associated in the first instance with fear of potential negative consequences from enabling service users to take risks (W. Mitchell et al., 2012). As such, professionals “focus on what might go wrong rather than positive outcomes from taking risks” (Carr, 2011, p. 126).

In daily practice, professionals must manage the tension around conflicts between guidelines and providing care that involves caring (Hollomotz, 2012; Leece & Leece, 2011; Wallcraft, 2012; Waterson, 1999), and in doing so, they must also remain cognisant that the prediction, calculation, and minimisation of risk is now a defining characteristic of social care work (Alaszewski, 1998, 2011, 2013; Alaszewski & Manthorpe, 1998; Brearley, 1982a, 1982b; Ferguson, 2007; Hamilton, 2012; Kemshall, 2000, 2003, 2009, 2010, 2014; Kemshall, Kelly, & Wilkinson, 2012; Kemshall et al., 1997; Kemshall & Pritchard, 1996; Kemshall & Wood, 2008; Killick & Taylor, 2020; Lupton, 1993; Macdonald & Macdonald, 2010; W. Mitchell & Glendinning, 2008; Parton, 1998, 2011; Prebble et al., 2013; Shaw & Shaw, 2001; Skivenes & Skramstad, 2015; Stalker, 2003; Stanford, 2008, 2011; B.

Taylor, 2005, 2006a; B. Taylor & McKeown, 2013; B. Taylor & Whittaker, 2017, 2018; Waterson, 1999; Webb, 2006b; Whittaker & Havard, 2016).

In light of the above considerations, it may come with a little surprise that service users, service managers, and social care professionals can have different, or even conflicting, perceptions of risk and approach risk differently (W. Mitchell & Glendinning, 2008). While disabled people may value their autonomy and freedom to be respected above all else (Independent Living Movement Ireland, n.d.; Leece & Leece, 2011; Wallcraft, 2012), more often than not, managers and practitioners prefer to err on the side of caution (Barry, 2007; L. Brown, 2010; Carr, 2011; M. Donnelly, 2019; S. Donnelly et al., 2019; Killick & Taylor, 2020; Munro, 2010; Scottish Executive, 2006; Stalker, 2003; Stanford, 2010; B. Taylor, 2005; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whittaker & Havard, 2016). In addition to professional dilemmas, there can also be tensions between service users' aspirations and organisational views of how risk should be managed (B. Taylor & McKeown, 2013). Some service users wish to "avoid the protectiveness of social care staff" while providers feel under pressure to follow policies and guidelines (B. Taylor & McKeown, 2013, p. 164). Finally, disabled people's health, wellbeing, and quality of life are often compromised due to the decline in social determinants of health directly linked to a disability label (Frier et al., 2018). This interplay in social determinants can have "substantial flow-on consequences in all aspects of life for the individual and those close to them" (Frier et al., 2018, p. 538), which must be considered when managing and assessing risk in practice.

## Rationale, Research Question, and Study Objectives

Given the current emphasis on independence, choice and risk in disability services and the tension experienced by professionals who find themselves in limbo between respecting service users' right to make choices and enacting their duty to safeguard and protect (Hollomotz, 2012; Leece & Leece, 2011; W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008; Morgan, Basset, & Andrews, 2016; Robertson & Collinson, 2011; Robinson et al., 2007; Stalker, 2003; B. Taylor, 2006b; N. S. D. Taylor, 2008; Wallcraft, 2012; Waterson, 1999) this study appears well-timed. While some international studies draw attention to these challenges, research on perceptions and experiences of service users in this area is limited (W. Mitchell et al., 2012). More importantly, there is a dearth of research on perceptions and experiences of risk in adult disability services in Ireland. Yet, an understanding of these perceptions and experiences is essential for social care education, policy, and practice (Glendinning et al., 2008; W. Mitchell et al., 2012).

Consequently, the research question underpinning this research was:

How do service users, social care practitioners, and social care managers perceive and experience risk in adult disability services, and what are the implications of these perceptions and experiences for service users and social care practice?

Correspondingly, the objectives of this research were:

- To identify how disabled adults using disability services experience and perceive risk, including their perceptions and experiences of balancing positive risk-taking and protection from risk.
- To identify how disabled adults approach risk in day-to-day life.

- To identify how social care workers in disability services experience and perceive risk, including their perceptions and experiences of balancing positive risk-taking and protection.
- To identify how social care workers approach risk in practice.
- To identify how social care managers in disability services perceive risk, including their perceptions and experiences of balancing positive risk-taking and protection.
- To identify how social care managers approach risk in practice.

### Structure of thesis and outline of chapters

This thesis is divided into five chapters. Next is the review of the literature and existing studies of risk in social care work. The third chapter outlines the theoretical approach and methods used to collect and analyse the data. The findings are presented in Chapter Four, which is divided into five sections. The first section is dedicated to the findings from the interviews with disabled people solely, while the following four sections detail the four central themes of this study. This approach was included to support the voice of the service users, which has been identified in the literature as often absent. The final chapter discusses the findings of this research and concludes with recommendations for practice and further research.

### Conclusion

This chapter has provided the background to this study, as well as the study rationale, question, and objectives. It has set out the policy context of disability services in Ireland and has given an account of the changing social care climate in the developed world. It has outlined an overview of the legal frameworks that govern the management of risk in

disability services and drawn attention to the predicaments faced by social care professionals, service managers, and service users when they approach risk in practice.

## Chapter Two: Review of Literature and Background

Social care has developed “in a complex system that includes: a social dimension, that of risk society; a political dimension, that of advanced neoliberalism; and a cultural dimension, that of reflexive or late modernity” (Webb, 2006a, part 3).

### Introduction

The term ‘risk’ once represented chances with both positive and negative potential consequences (Shaw & Shaw, 2001). Until the onset of empirical enquiries in the sixteenth century, religion and fate had been the lead factors in constructing risk. The majority of events, including those involving risk or danger, were perceived as divine interventions rather than a result of human interference (Lupton, 1999) and risk was viewed as an inseparable part of existence (Bernstein, 1996). Within the modern era, new ways of thinking came to replace reliance on fate and traditional beliefs. Nonetheless, as with their predecessors, modern societies fear risk and aspire to control, measure, limit, or even prevent it (Beck, 1992, 1996, 1999, 2006, 2009a, 2009b, 2011, 2012, 2015; Beck, Adam, & van Loon, 2000; Webb, 2006b).

With the development of industrial and capitalist societies, people became concerned with often undesirable by-products of scientific and techno-economic revolutions. Natural hazards, such as earthquakes and floods, were augmented and sometimes even overshadowed by new dangers and risks that some viewed as manufactured through science,

technology, and politics (Burgess, Wardman, & Mythen, 2017; Ekberg, 2016). New developments also meant new worries, including pollution, ozone depletion, radioactive disasters, nuclear, chemical, or biological warfare, financial crisis, and other uncertainties. In light of these new risks, what has been described as traditional or classical modernity, characterised by confidence in science, has been replaced by reflexive modernity defined by uncertainty and increasingly a lack of faith in experts<sup>8</sup> (Beck, 1992, 1994, 1999, 2009a, 2009b; Beck, Bonss, & Lau, 2016).

In classical modernity, societies had been occupied with scientific and economic progress, often oblivious to gaps in knowledge and with little attention paid to possible consequences of new developments. In reflexive modernity, however, societies that have now been exposed to some of the implications of modern techno-economic advancements have adopted a more cautious approach to knowledge by accepting that it is not absolute and that science can be incomplete or even flawed (Beck, 1992; Beck et al., 2016; Ekberg, 2016). In addition to the consequences of industrial and capitalist expansions in reflexive modernity, people have become increasingly aware of additional risks that can emerge as a result of attempts to manage natural hazards (Burgess et al., 2017). Classic examples of these include the risk of antibiotic resilience.

In this climate, a susceptibility and mistrust in governmental bodies and scientific institutions to manage risks arose (Beck, 1992; Burgess et al.,

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<sup>8</sup> Beck distinguished between first and second modernity. The first modernity refers to classical modernity (including premodernity, primary modernity, and post-modernity (Ekberg, 2016), where science was seen to respond to risk. In contrast, the second (reflexive) modernity represents a reflection of the first modernity where concepts previously viewed as positive, such as knowledge, science, and technology, are now perceived in a less optimistic manner and, at times, as producers of risk (Beck, 1999; Burgess et al., 2017). In this sense, the term 'reflexive' should be understood as a reflex to previous activities (Aiken, 2000).

2017; Furedi, 2009; Giddens, 1990, 1991; Pollak, 1996; Stalker, 2003), and societies have become insecure and consumed by the uncertainty of what the future might bring (Furedi, 2009). Public doubts were further intensified and, in some cases, seen as justified by international scandals of ill-managed risks, including the Chernobyl nuclear disaster in the 1980s or the Mad Cow disease<sup>9</sup> crisis of the 1990s.

The scepticism about competence to manage risk has, amongst many other spheres, extended to welfare services. Alarming professional and system fiascos, such as the 'Baby P' case in the UK (Haringey Local Safeguarding Children Board, 2010) or the 'Roscommon Child Care Case' in Ireland (Roscommon Child Care Inquiry, 2010), left an indelible mark on the public psyche. Services were accused of "fail[ing] to recognise the risk indicators" and thus, "fail[ing] to respond appropriately to the needs of the children" (Roscommon Child Care Inquiry, 2010, p. 5). In disability services, the Aras Attracta scandal drew particular attention to risk management failures (Áras Attracta Swinford Review Group, 2016). In light of such failings, "recent abuse reports and the Ryan Report, in particular, are now warning signs etched in the consciousness of social care workers" (Howard, 2012, p. 38).

These anxieties, compounded by the rising capacity of the media to connect with individuals (Furedi, 2009; Slovic, 1999), have contributed to the construction of what some call a 'culture of fear' (Furedi, 1997, 2009). In this culture, the unknown is often associated with danger and risk is used to describe the dreaded "ambivalence" (Beck, 2006, p. 330; 2012). As such, communities became unified by the insecurity and the perceived

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<sup>9</sup> Bovine spongiform encephalopathy (BSE), commonly known as mad cow disease, is an incurable and invariably fatal neurodegenerative disease of cattle (Okada et al., 2012).



vulnerability to risk (Ekberg, 2016; Lash, 1994). Here, some authors subscribe to the view of living in a 'risk society' or a 'risk culture' influenced by reflexive modernity and the globalisation of risks (Beck, 1992, 1999, 2009b; Beck et al., 2000; Furedi, 2009; Giddens, 1990, 1991; Lash, 1994, 2000). In risk society, perceptions of risks are primarily influenced by mass media, which nurtures a politics of fear (Beck, 2012).

With fitness-to-practice cases in health and care professions, the role of media is significant in interpreting cases to the public (Byrne, 2016). In child services, for instance, media portrayals tend to focus on "cases where the danger has been under-estimated and cases where the danger has been overestimated" (Munro, 2010, p. 20). In disability services, similar reporting lines emerge, and it is either too much intervention and control over service users' lives or not enough protection. As a consequence, many professionals feel "damned if they do and damned if they don't" (Munro, 2010, p. 20), which can result in providers and professionals being overly concerned with the reputation of their organisation (Carr, 2011).

Newspaper headlines such as 'Dublin disability centre sanctioned over high-risk issues...HIQA says St John of God centre failed to protect all residents' (O'Riordan, 2019), or 'HSE deems it risky or not necessary for disabled people to make choices' (McCárthaigh, 2019) draw public attention and penetrate deeply to the consciousnesses of professionals working in disability services while creating "a climate of public blame, community anxiety, and challenge to the expertise of professionals" (Kemshall, 2009, p. 331). This atmosphere of increasing public concern has contributed to a notion that disabled people are at risk (Children's Rights Alliance, 2009; Commission to Inquire into Child Abuse, 2009; National Economic and Social Council, 2012) and has reinforced the idea that

disability services should be regulated more strictly (Health Information and Quality Authority (HIQA), 2019c; Irish Human Rights Commission, 2010). The Chief Inspector of Social Services within the Health Information and Quality Authority (HIQA) began to regulate disability services in 2013, and disability services now have to be registered by the HIQA (Health Information and Quality Authority (HIQA), 2019c). In 2013, inspections of designated centres providing services for disabled people began and in 2014, 41% of inspected services had been found non-compliant with the regulations; although this number decreased in the following years (Health Information and Quality Authority (HIQA), 2019c).

In the first five years (2013-2018), the HIQA conducted 3829 inspections, and one of the leading criteria was “the level of assessed regulatory risk in the centre” (Health Information and Quality Authority (HIQA), 2019c, p. 12). In order to be compliant, services must “actively consider risk management and health and safety” and must be “responsive to changing risks” (Health Information and Quality Authority (HIQA), 2019c, p. 45). Since inspections began, however, the HIQA has reported that risk management practices are unsatisfactory generally:

the absence of measures to assess, control and mitigate risks within many designated centres, and a failure by providers to ensure their approach to risk management reduced risks to residents and staff highlighted a lack of understanding of effective procedures in this area (Health Information and Quality Authority (HIQA), 2019c, p. 45).

## From 'Welfare Recipients' to 'Responsible Citizens'

In the aftermath of World War II, most governments globally endeavoured to revive their economies and rid their impoverished citizens of hardship and poverty by committing to wide-ranging welfare values. In this post-war consensus, many western governments followed Keynesian top-down economic rationality and centred their policies around employability (Saunders, 1999). The Eastern parts of Europe steered towards Marxist ideology while also keeping employability to the fore. A mutual ambition of many post-war states was “to restrain the economic power of the upper classes and for labour to be accorded a much larger share of the economic pie” (Harvey, 2016, p. 28). While post-war welfare states exhibited a commitment to equity and welfare, which were at the heart of many state policies (Saunders, 1999), they were criticised for overlooking individual choices and freedoms.

In the wake of the crisis of capital accumulation in the 1970s, which resulted in an acceleration of unemployment and inflation, many capitalist countries faced intense pressure from proponents of the socialist movement, which had by then been popularised across Europe for its apparent success in some post-war states (Gough, 1980; Harvey, 2016). This represented a concrete political and economic danger to the ruling upper classes, which had to act fast to suppress this threat (Harvey, 2016). Building on Hayek’s intellectual thought, welfare states started to be criticised for extending political control and accused of denying individuals their liberties and responsibilities (Hayek, 2011). Hayek’s main argument rested on the weakness of the inherent principles of socialism – solidarity and selflessness, for he argued that the economy could not be sustained under such principles alone, nor could political order ensure that citizens acted morally (G. Taylor & Power, 2011). Thus, drawing upon Hayek’s

work, by the 1980s, western politics had experienced “a powerful swing to the right” (Breathnach, 2010, p. 1182).

Conservative political parties, gaining public faith through promises of independence, freedom, and economic stability, sought to reform economic growth by minimising state expenditure (Gough, 1980) and thus, monetarist policies replaced the Keynesian approach (Breathnach, 2010). The conservative ideas that came to light in this era with the arrival of the New Right were often portrayed as a modern variant of more traditional conservative thought since they sought to marry socially authoritarian, morally conservative, and economically libertarian principles (Williams, 2015). Underpinned by these far from harmonious values, the New Right sought to achieve a free-market economy and minimise the need for state intervention in economic and welfare spheres (Williams, 2015). Although state responsibilities had been reconstructed in almost all spheres, in order to maintain or restore some traditional moral and cultural codes, the intervention of the state in some areas could be justified. This resulted, for instance, in Section 28 of the Local Government Act being enacted in 1988 to ban the promotion of homosexuality by schools and local authorities in the UK (Greenland & Nunney, 2008).

Welfare spending, including allocations for social services, was seen as unproductive and represented a financial burden and, as such, an obstacle to economic growth. Thus, by the 1980s, Thatcher’s government established firm control measures to address these growing concerns about the dependency on the welfare state, and the cuts to resources escalated (Culpitt, 1999; Gough, 1980). Not only did the welfare state represent a financial obstacle in Thatcher’s monetarist strategies, but it also “encourage[d] ‘soft’ attitudes” (p. 8) towards marginalised groups, which, of course, did not resonate with Thatcher’s authoritarian populist

ideology (Gough, 1980). Similar trends were observed in other Anglo Saxon policy countries, including many EU countries, as well as the USA, Australia, Canada (S. Brown, Shoveller, Chabot, & LaMontagne, 2013; Grover & Soldatic, 2012), and Ireland (Breathnach, 2010). These countries have replaced their orientation towards welfare state “by a decentralised neoliberal state wherein regional economies pursued their own economic interests through direct participation in the global economy” (Breathnach, 2010, p. 1181).

Indeed, the New Right’s ideology influenced politics globally (Williams, 2015) as the New Right sought to recuperate the role of the market while ending collectivist state policies (King, 1987). As states withdrew their responsibilities from regulating many domains and the privatisation of the public sphere took place, and what used to be public responsibilities were shifted to the individual (Scourfield, 2007). Thus, the relationship between individuals and the state was reconstructed, and policies began to focus on personal choices and the responsibilities of individual citizens (Kemshall, 2010; Scourfield, 2007; G. Taylor, 2009). What used to be a collective risk, once assessed and managed by the state, was now privatised risk, managed by the individual and controlled by the market (Ferguson, 2007; Kemshall, 2002; Scourfield, 2007). In this vein, “the individual becomes the primary site of risk management, not society, and the ‘good’ citizen is the responsible, prudential one” (Kemshall, 2002, p. 44). In this new relationship between citizens – service users and the state, social care workers can be seen as “mediators” (Hollomotz, 2012, p. 235).

Undoubtedly, the critical elements of the New Right project, such as deregulation, privatisation, an enhanced free-market, reduced state spending, an emphasis on individual freedom, choices, and individual

responsibilities, strongly resonated with the core principles of neoliberalism (Rose & Miller, 2010). Reagan's defeat of the air traffic controllers in the U.S.A. and Thatcher's destruction of the British miners in 1984 can be seen as ground-breaking events in the global shift toward the neoliberal project (Harvey, 2016). As such, it is argued that Reaganite and Thatcherite times provided a suitable context upon which a neoliberal hegemony could surface and become entrenched throughout the 1990s. Certainly, the International Monetary Fund and World Bank stimulated neoliberal reforms internationally through 'structural adjustment', a method that ensured that no money was loaned to another state without a firm commitment to neoliberalism (Harvey, 2016). The Washington Consensus in the 1990s and the negotiating rules set up under the World Trade Organization in 1998 can be viewed as critical moments in "the global turn toward neoliberal practices" (Harvey, 2016, p. 32).

In 1997, when the Labour party came to power in the UK after eighteen years of conservative influence, it brought high hopes for an end to neoliberal reforms and reconciliation with social justice. Instead, however, the Blair government further entrenched a neoliberal agenda into UK politics (Jessop, 2003), including within the spheres of health and social care (Ferguson, 2007; Scourfield, 2007). Succeeding the crisis that emerged in 2008, neoliberal deregulation and privatisation continued. While Cameron introduced some social reforms, such as the legalisation of same-sex marriage in 2012, remaining otherwise conservative, he further advanced the neoliberal agenda by continuous reductions of state spending, welfare decline, and independent living in adult social care (Burch, 2017). Although Cameron's 'Big Society' has officially been abandoned, the principles it followed remained in political rhetoric (Burch, 2017). Of particular significance is May's 'shared society' designed around

freedom and responsibility, in which economic costs were also valued over the needs of citizens (Burch, 2017). It has been stressed that “the UK’s austerity policies systematically violated the rights of disabled people, and this has resonance for Ireland” (Inclusion Ireland, 2018, p. 7), particularly in expenditure reductions between 2009 and 2016, which resulted in financial instability of many state-funded voluntary disability organisations (National Federation of Voluntary Service Providers, 2019).

Following the UK and the USA examples, countries worldwide embraced the neoliberal project, not only as a political or economic agenda but also as a way of life, and it has been argued that while so far neoliberalism has not succeeded in resolving the economic predicaments of defective capital accumulation, it has helped to restore upper-class power (Harvey, 2016). Perhaps most importantly for this thesis, it has affected how welfare is distributed in contemporary societies:

The assault upon institutions, such as trade unions and welfare rights organisations that sought to protect and further working-class interests was as broad as it was deep. The savage cutbacks in social expenditures and the welfare state and the passing of all responsibility for their well-being to individuals and their families proceeded apace. But these practices did not and could not stop at national borders (Harvey, 2016, p. 32).

Indeed, this was reflected in the development of social care (Scourfield, 2007), as market deregulation and privatisation colonised welfare spheres (Burch, 2017; Kemshall, 2002). Social life has been “transformed by economic discourse”, and the welfare culture has been changed into “an enterprise culture in which the supply side of a flexible workforce is emphasised, not the collective safety net of welfare provision” (Kemshall, 2002, p. 42). Once afforded through human solidarity and

altruism, security is now substituted by financial compensation and private insurance (Rose & Miller, 2010). State responsibilities, including those for the provision of disability services, have been transferred to service users who are continuously stimulated to become responsible for the management of their care and needs, often under the banner of choice and the freedom to choose the services and carers they want.

In such circumstances, disadvantaged, marginalised, and disabled individuals are reframed as responsible service consumers, who, by exercising their right to choose their service, can be titled as independent, equal, and free. These responsible service users, however disadvantaged they may be, should not be seen as deserving recipients of charity, but rather, they should be viewed as responsible citizens (Rose, 1996). Thus disabled people should be understood as active participants of the free market, in which they can purchase or manage the goods and services they require, including social care and, by extension, social care workers, which could ultimately lead to competition between workers. If disabled people feel excluded or marginalised, they should be empowered, educated, and reconnected with society so that they can fulfil their role as entrepreneur consumers. Meanwhile, these seemingly liberated individuals are stimulated to make choices deemed as acceptable and rational (Burch, 2017; Rose & Miller, 2010; Scourfield, 2007).

In contrast to the approaches of the welfare state that sought to compensate disabled people through varying benefits, the free market seeks to decrease the dependency of disabled people by empowering them to become independent through mechanisms such as direct payments (Scourfield, 2007). Through these new models of personalisation in adult social care, service users are encouraged to act as consumers purchasing their care from providers who should be responding to this free-market



stimulus by offering services that service users want. Nonetheless, this does not mean that supply matches demand, particularly as services are not arranged around the welfare consumers' needs, but around what the state can afford (Fyson, 2009; Glasby, 2012; Lymbery, 2012; Rummery, 2006), which can have devastating effects on service users (Lymbery, 2012). This has been demonstrated in service users' reliance on voluntary services in instances when the state does not meet needs (Sheldon, 2009). Indeed, the majority of disability services in Ireland are voluntary (Department of Health (EIRE); Independent Review Group (IRG), 2018), while child services and services for older people have been mostly privatised. Though the voluntary services rely on state funding, it is clear that the current budget allocation does not meet the needs of the services, which are experiencing severe financial difficulties (National Federation of Voluntary Service Providers, 2019). Undeniably, bringing free-market economics into disability services, adds to the oppression, social exclusion, and discrimination felt by disabled people (Barnes & Sheldon, 2010).

### Risk management and risk assessment in social care/disability services

Since the 1990s, disability services have undergone a paradigm shift from needs-focused to risk-focused services (Parton, 1998; Stanford, 2011; Trevithick, 2014; Waterson, 1999; Webb, 2006b) as risk was "brought into a social and legal context of responsibility" (Beck, 1992, p. 28).

In 2010, many health and care professions came to be regulated by CORU - the regulator of health and social care professionals, which was instigated under the Health and Social Care Professionals Act (2005) and established in 2008 in the midst of a global financial crisis. Along these lines, social

care will also soon be a regulated profession. This is a significant change from the post-war welfare state period when welfare professions were based on optimistic ideas of progress and rehabilitation (Stalker, 2003). Professionals were trusted in self-regulating services, and both the state and the academic literature paid little attention to how risks were managed (Alaszewski, 1998; Douglas, 1992; Foster & Wilding, 2000; Shaw & Shaw, 2001). With the growth of neoliberal ideas, however, and an emergent mistrust in experts, the self-governance of welfare professions “came under attack from the late 1970s” (Foster & Wilding, 2000, p. 143). In an increasingly privatised world, practice insurance, much like other types of insurance (Alliance For Insurance Reform, 2020), has become unsustainable, forcing the state to take over many previously self-governed areas and professions. This has meant that health and care professionals came to be viewed as a liability and a risk to the state, which could be seen in Ireland in the defensive approach of the state in high profile scandals such as the recent Cervical Check Tribunal (The CervicalCheck Tribunal, 2020). It has been suggested that the motivation of social care registration is related to state apprehensions and ‘moral panic’ that has been triggered by such scandals (Byrne, 2016; Howard & Lyons, 2014; M. Power & D’Arcy, 2018).

It has been argued that risk came to be used to assign blame to professionals in instances of adverse outcomes (Douglas, 1992; Waterson, 1999). Avoidance of liability and the costs of negligence litigation have engulfed welfare services (McDonald, 2010; B. Taylor, 2005; B. Taylor & McKeown, 2013), which have become preoccupied with assessing, managing, and auditing risk, most often in a defensive manner (L. Brown, 2010; Carr, 2011; S. Donnelly et al., 2019; Killick & Taylor, 2020; Munro,

2010; Stanford, 2010; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whittaker & Havard, 2016). Welfare professions thus came to be shaped by the manner in which risks are assessed and managed (Alaszewski & Manthorpe, 1998; Hollomotz, 2012; Kemshall et al., 1997; Macdonald & Macdonald, 2010; Waterson, 1999), and a focus on risk has replaced a focus on welfare (Parton, 1998; Stanford, 2011; Trevithick, 2014; Waterson, 1999; Webb, 2006b).

It is a set of circumstances in which many practitioners feel unable to empower service users to be independent in a climate that is driven by a strong focus on blame and accountability (Alaszewski, 1998; Manthorpe, 2007; Whittaker & Havard, 2016). As such, social care services can become obsessed with guidelines and procedures (Foster & Wilding, 2000; Kemshall, 2010), which can result in professionals feeling “trapped in risk-prone bureaucracies and technocratic response to risk” (Kemshall, 2010, p. 1256). In part, because technocratic risk assessments carry greater weight than professional judgment (Barry, 2007; Broadhurst, Hall, Wastell, White, & Pithouse, 2010; Manthorpe, 2007; W. Mitchell et al., 2012; Parton, 1998) or service users’ views. As such, the social care profession has been described as lacking confidence and under-utilising the skills of its professionals (Barry, 2007; Scottish Executive, 2006).

Against this backdrop, professionals can find themselves negotiating a balance between service users’ “right to self-determination” and “properly managed risk” (Wallcraft, 2012, p. 142). As such, services and practitioners are expected to identify, assess, and manage risks in a manner that does not limit service user choices (Health Information and Quality Authority (HIQA), 2019c). Thus, while there is a clear emphasis on balancing rights with risks and responsibilities (Health Information and Quality Authority (HIQA), 2016; Wallcraft, 2012), “the professional

challenge is to both proactively enable and where appropriate, constrain” (p.278), which can be rather tricky in practice (Waterson, 1999). It has been acknowledged that health and social care professionals “encounter complex situations in practice, where many factors need to be considered”:

an individual’s will and preferences and their right to autonomy versus the risk of harm from a particular decision. In some situations, there may be competing human rights, and staff need to consider the applicability and weighting of each right within that situation and their duty of care to ensure safety and fairness for all people using services (Health Information and Quality Authority (HIQA), 2019a, p. 5).

However, while technocratic guidelines and regulations are designed in a way that shifts responsibility, and potential blame, from the state to the individual professional, it is not uncommon for professionals to face moral dilemmas and feel vulnerable from a professional perspective when approaching risk in practice (Munro, 2010; Stanford, 2008, 2010, 2011; N. S. D. Taylor, 2008; Whittaker & Havard, 2016). The need for research into dilemmas of how to both empower and protect service users from risks was emphasised two decades ago (Waterson, 1999), yet the gap in evidence persists (S. Donnelly et al., 2019; W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008).

Indeed, it would be unrealistic to assume that rights-based social care can be realised through practice that has been described as defensive or risk-averse (Barry, 2007; L. Brown, 2010; Carr, 2011; S. Donnelly et al., 2019; Killick & Taylor, 2020; Munro, 2010; Stanford, 2010; B. Taylor, 2005; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whitelock, 2009; Whittaker & Havard, 2016). Such practice can lead to disempowerment and constrain not only service users’ choices but also their right to self-

determination (Hollomotz, 2012; Jingree & Finlay, 2008; Manthorpe & Moriarty, 2010; B. Taylor & McKeown, 2013; Warin, 2010; Waterson, 1999). Moreover, the legacy of previous care models must also be considered, and A report of a European study (2007) on deinstitutionalisation and community living warned that care staff who had worked in institutions long-term might present with institutional attitudes and be too risk-averse (Mansell, Knapp, Beadle-Brown, & Beecham, 2007). Nonetheless, trying to achieve harmony between the right amount of protection of service users and upholding their right to choose and live independently is a challenging task (Glendinning et al., 2008) that social care professionals embark on daily in disability services (Hollomotz, 2012; Jingree & Finlay, 2008; W. Mitchell & Glendinning, 2008; B. Taylor & McKeown, 2013). While research into if and how this balance is achieved in practice is limited, some studies have investigated the (un)changing practices in services for disabled people.

In 2019, for example, it was found that following the transition to an independent model of care in Spain, professionals' approaches in practice have not adapted, and service users' involvement in decision-making is still largely uncommon (Fullana, Pallisera, & Díaz-Garolera, 2019). Furthermore, while the discourse amongst practitioners is filled with a vocabulary dynamically supporting the empowerment of service users, this does not always translate into practice, and service users continue to lack control over their lives (Antaki, Finlay, & Walton, 2009; W. M. L. Finlay, Walton, & Antaki, 2008; Fullana et al., 2019; Jingree, Finlay, & Antaki, 2006). In Ireland, The National Disability Authority (NDA) (2010b) also viewed "the persistence of historical practices" as problematic. They found that while the staff that participated in their study "placed considerable emphasis on the rights of individuals", they were "reluctant to take risks"

(part 6), which caused impediments to the rights of disabled people (National Disability Authority (NDA), 2010b).

Research on disability services in Ireland identified that concerns over risk and safety could suppress the empowerment of service users in practice (A. Power, 2013b). While services and professionals openly discussed a rights-based approach, service users rights were often subdued by concerns over issues relating to risk and capacity (A. Power, 2013b), and risk was a critical factor in decision-making (S. Donnelly et al., 2019). Social care professionals and organisations were identified as a common barrier to service users exercising independent choices (Friedman & VanPuymbrouck, 2019), mainly due to risk-averse interpretations of risk assessments (Abbott & McConkey, 2006; Duggan & Linehan, 2013). It has been suggested that there is a link between power and risk in care services. Traditionally, care professionals were in control of many decisions, in particular those around risk, and they can be hesitant to give up this control (N. S. D. Taylor, 2008).

In addition, it was identified that some services concentrate “solely on keeping residents safe and making paternalistic decisions on behalf of the person” and that this approach to managing risks leads to “restrictive practices” (Health Information and Quality Authority (HIQA), 2019c, p. 46). For instance, if the risk of financial abuse was considered too high, the service user was not supported to manage their own money, or if the risk of using a kitchen was deemed high, the service user could not access this space (Health Information and Quality Authority (HIQA), 2019c). It was found that over-protective risk management practices can result in the service users’ rights being denied and the quality of their lives being compromised (Clarke, Keady, Wilkinson, & Gibb, 2011; Health Information and Quality Authority (HIQA), 2019c). Here, some literature distinguishes

between practitioners who employ empowering and supportive approaches to service delivery and those who apply a more traditional approach that is more about providing protection (Duggan & Linehan, 2013; Garcia Iriarte, Stockdale, McConkey, & Keogh, 2016). While service users strive to be empowered as opposed to being cared for in a traditional sense (Abbott & McConkey, 2006; Duggan & Linehan, 2013; Garcia Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014), many social care workers predominantly see themselves as care-givers (McConkey & Collins, 2010). Some professionals feel that making decisions for service users is acceptable because they perceive them as vulnerable (Parley, 2011). Indeed, professionals' attitudes and views of risk and vulnerability play a significant role in assessing and deciding about which risks are acceptable and which are not (Carr, 2011; Carr & Robinson, 2009; Ray, Pugh, Roberts, & Beech, 2008). Moreover, evidence suggests "that issues of perceived competence (or lack of competence) influenced both perceptions of risk and its management by different groups of people" and that stereotypes can effect service users risk-taking opportunities as well as their participation in risk decision-making (W. Mitchell & Glendinning, 2008, p. 309). In light of these considerations, risk management techniques used in social care are best described as "a continuum ranging from control at one end to empowerment at the other, with legitimate authority occupying the middle ground" (Stalker, 2003, p. 227), while the controlling paternalistic approach to risk management is the prevalent one (S. Donnelly et al., 2019; Stalker, 2003; Whitelock, 2009).

Although the research literature on risk experiences and the views of disabled people is limited, it has been noted that service users value their rights, independence, autonomy, and choices being respected above their protection (Leece & Leece, 2011; Wallcraft, 2012) and wish to engage

in positive risk-taking (Manthorpe, 2007). In the UK, participants identified empowering care as "being ready to take risks" (Keyes, Webber, & Beveridge, 2015, p. 245), while one of the key messages from service users conveyed through a document providing guidance on protecting vulnerable adults in care - 'No Secrets' - was that "safeguarding adults is not like child protection. Adults do not want to be treated like children and do not want a system designed for children" (Department of Health (UK), 2009, p. 6). Furthermore, while service users agree that the role of social care professionals is to safeguard vulnerable individuals, they are not entirely content with how professionals define vulnerability (Leece & Leece, 2011). A disabled person should not be automatically regarded as vulnerable and in need of protection from risks (Leece & Leece, 2011), and it has been suggested that an adult should be described with the term only if they feel vulnerable (Whitelock, 2009). More recently, for instance, the HIQA distinguished between persons who are at risk because of their inability to protect themselves and persons that choose not to (Health Information and Quality Authority (HIQA), 2019b).

If the above deliberations have sketched the tensions around risk in social care, then it is argued that while neoliberal policies may have appeared to respond to the disability movement's calls for increased choice and independence, the same policies have increased the focus on risk management, private insurance, and litigation (Burch, 2017). Since the state has retracted from its economic-regulatory responsibilities and much of the developed world has been privatised, the insurance trade has become a new way of how responsible consumers protect themselves from risk. In capitalist societies, the idea behind indemnifying risk was that although risks might not be preventable, their costs could be spread and, as such, the damage could be reduced (Ekberg, 2016). Through insurance,



risks came to be measured in terms of their probable losses versus their potential benefits (Ekberg, 2016). The losses are generally established by estimating “the sum of the probability of an adverse event and the magnitude of the consequences” (Ekberg, 2016, p. 343). In social care, positive risk-taking has been defined as weighing up the pros and cons of service users choices and minimising their negative consequences (Health Information and Quality Authority (HIQA), 2016).

Undoubtedly, risk has become prevailingly quantified (Pollak, 1996), “politicised, and contentious” (Slovic, 1999, p. 689). There has been a growing body of literature that has emphasised that an objectivist evaluation of risk, which ignores subjective perceptions and social context, cannot achieve an understanding of risk (Douglas & Wildavsky, 1982; Ekberg, 2016; Lash, 2000; Pollak, 1996; Ropeik, 2012; Slovic, 1987, 1999; Slovic, Finucane, Peters, & MacGregor, 2004; Tversky & Kahneman, 1974). Risk management practises based solely on quantitative cost-benefit analysis can be seen as lacking social and moral considerations, which is, of course, a biased concept with infinite probabilities and, thus, cannot be measured through a quantitative lens alone (Douglas & Wildavsky, 1982; Slovic, Fischhoff, & Lichtenstein, 1980). Moreover, it has been contended that some risks are unknowable and can be neither calculated nor insured (Anaïs & Hier, 2012).

Quantitative risk analyses fail to recognise that individuals do not comprehend risk from a purely analytical, rational stance, as they cannot simply abandon their intuitive awareness guided by experiences and emotions (Slovic et al., 2004). Perceptions of risk are “fundamentally different from the statistical calculations of actual risk” (Ekberg, 2016, p. 351). Evidence points out that not only do individual perceptions of risk vary, but the views of laypeople and experts differ considerably (Pollak,

1996; Slovic, 1987; Slovic et al., 1980). Laypeople perceive risk through the significance of its potential impact rather than its, often very low, probability (Slovic, 1987; Slovic et al., 2004).

Similarly, in social care, formal risk assessments often require quantitative calculations of risk (Kemshall, 2010) through which “risk is often normatively defined in probabilistic and mathematical terms as it relates to the expected losses that can be caused by a risky event and to the probability of this event happening” (Webb, 2006a, part 1). However, professionals do not assess risk in a purely objective manner in practice (Kemshall, 2010; Munro, 1999; Wood & Kemshall, 2008). When professionals evaluate risk they add subjective biases, including their perceptions of risk, their fear of certain risks, their concerns, and organisation beliefs (Broadhurst et al., 2010; Kemshall, 2003, 2010; W. Mitchell & Glendinning, 2008; B. Taylor & McKeown, 2013). When they consider risks, they also consider their duty of care and their responsibility to protect and safeguard service users (B. Taylor, 2005; B. Taylor & McKeown, 2013; N. S. D. Taylor, 2008). However, duty of care is often understood more traditionally as being in control and protecting as opposed to now a more accepted description - enabling service users to make free choices (Rowlett, 2009). Although it is clear that service users, social care workers, and managers view, assess, and manage risks differently (B. Taylor & McKeown, 2013), gaps have been identified in research studying the varying experiences and perceptions of risk, in particular those of service users (W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008).

When making rational decisions about risk, people are guided by their intuition, and evidence has suggested that “analytic reasoning cannot be effective unless it is guided by emotion and affects” (Slovic et al., 2004,

p. 311). Moreover, when responding to risk, individuals consider how risk influences unquantifiable social issues, such as, for instance, responsibility and morality (Ekberg, 2016). The extent of such confounding considerations is perhaps currently nowhere more obvious than in the worldwide debates over mask-wearing, vaccinating, and Covid-19. What was a public health issue has become politicised, often to extremes. Furthermore, it has been argued that similarly to laypeople, experts' assessments of risk can also be influenced by varying values and judgments (Slovic, 1999; Slovic et al., 1980). As such, shaped by social, cultural, and political dynamics as well as emotions, the perceptions of risk have been changing, and risk has been socially constructed and influenced by these perceptions (Burgess et al., 2017; Slovic, 1999). In light of such considerations, it is argued that risk assessments are of little benefit in understanding risk if they do not account for experiences and perceptions of risk (Ekberg, 2016; Lupton, 1993; Pollak, 1996; Slovic, 1987). Equally, risk assessment cannot be viewed as a purely rational, objective process and should incorporate the subjective lens of the individual (Lupton, 1993).

Against the growing backdrop of a dominating risk management agenda in social care, it is remarkable how scarce research is into service users' perceptions and experiences of risk (W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008; B. Taylor & McKeown, 2013). The views of disabled people are omitted frequently in risk research (W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008). Furthermore, there are gaps in research studying professionals decision-making around risk and the range of factors that influence the variances in approaches to risk in disability services (Barry, 2007; W. Mitchell et al., 2012; B. Taylor, 2005; B. Taylor & Whittaker, 2018; Whittaker & Havard, 2016).

If there are subjective elements in how risk is evaluated in practice, then prescribed risk assessments could be viewed as a tick-box exercise, used to cover professionals' backs, and often driven by social care workers' fears of being held accountable and litigation (Howard, 2012; McDonald, 2010; N. S. D. Taylor, 2008). Against this backdrop, there is a culture of distinguishing between acceptable and unacceptable risks and appropriate and inappropriate behaviour (W. Mitchell & Glendinning, 2008), in which different stakeholders define the acceptability and appropriateness of risk differently (Douglas, 1992; Waterson, 1999). This culture, supported by the general view that disabled people are vulnerable, silently justifies cherry-picking service users' choices. Service users' decision-making is often "obstructed by...professionals deciding on what is better for the individual" (Jingree & Finlay, 2008, p. 705). Choices are ranked based on the acceptability of risks involved, and service users are encouraged to make only the choices that are deemed as "good choices" (Health Service Executive (HSE), 2012, p. 76). Yet, judging the acceptability of risks and choices is a process founded on personal biases, and, as such, varying risks can be evaluated differently by different stakeholders (Barry, 2007; Waterson, 1999). Individuals' assessments of risk can be influenced by experiences, emotions, values, the principles at stake, as well as training, organisational, and professional cultures (Barry, 2007; W. Mitchell & Glendinning, 2008; B. Taylor & Whittaker, 2017).

An international review of approaches to risk assessment in social care showed that neither the understanding, training nor approaches to risk assessing are coherent amongst different organisations and individual professionals (Barry, 2007; W. Mitchell & Glendinning, 2008; B. Taylor & Whittaker, 2018). In addition, the varying risk management practices operated by different social care organisations have been identified as

lacking “accountability systems that are proactive, clear and which enable professional autonomy” (Barry, 2007, p. 43). Risk assessments were portrayed as impractical and inaccurate tools often used to replace professional judgment so as to avoid litigation (Barry, 2007; Manthorpe, 2007; W. Mitchell et al., 2012; Parton, 1998). In practice, much time is spent assessing risks and ticking boxes as opposed to managing risks in a meaningful and inclusive way (Barry, 2007; Methven, 2009). In an effort to avoid potential litigation, social care practice has been shifting towards a regulatory compliance approach rather than professional judgment (Howard, 2012). It has been argued that “in the face of risk”, the profession is “increasingly de-skilled and transformed into low-level functional administrative tasks” (Webb, 2006a, part 3).

Against this background of increasing defensive practice, the influence of the organisational and legislative environment in professionals’ day-to-day decision making has been emphasised (B. Taylor & Whittaker, 2018). Professional judgment can be limited by strict organisational policies and legislation and by the approach of their manager. Where managers execute risk-averse systems and regular audits, professionals are more likely to engage in the defensive practice (B. Taylor & Whittaker, 2017, 2018). Where the relationship between managers and social care professionals is supportive, professionals do not feel under such pressure and tend to over assess and over manage risks far less, which gives them the discretion to enact their professional vision (B. Taylor & Whittaker, 2018).

Nonetheless, with tensions between regulations, professional duty, and service users’ right to autonomy and personal choice (Manthorpe et al., 2009; W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008; Stalker, 2003; B. Taylor, 2006b; N. S. D. Taylor, 2008) professionals continue to feel

uneasy about service user's choices that may seem risky (Fyson, 2009; Hollomotz, 2012). As such, fear of litigation, defensive practise, uncertainty and a desire to comply with rules have become terms closely associated with social care practice (L. Brown, 2010; Byrne, 2016; Carr, 2011; Howard, 2012; McDonald, 2010; Munro, 2010, 2011; Richards, Donovan, Victor, & Ross, 2007; N. S. D. Taylor, 2008; Trevithick, 2014; Whittaker & Havard, 2016). Put simply, it can appear safer to follow the rules and administrative tasks to the letter while abandoning creativity, moral judgment, human interactions, and compassion. This can understandably pose problems for social care workers and managers, as well as service users (Howard, 2012; Howard & Lyons, 2014; Macdonald & Macdonald, 2010; Munro, 2010; Parton, 1998; Trevithick, 2014), particularly as professional knowledge, experience, and intuition, have been identified as key elements in the day-to-day management of risk (W. Mitchell & Glendinning, 2008). Moreover, although professionals often feel "strangled by bureaucracy and paperwork", they are nevertheless compelled to embed it as a norm in an attempt to cover their backs "at all costs" (Howard, 2012, p. 41). Thus, while the scrutiny, directly linked to the shift of responsibilities in social care, has been portrayed as having the noblest aim of protecting vulnerable individuals, it is increasingly voiced that social care workers "could one day be deemed as a group in need of protecting" (Howard & Lyons, 2014; McLaughlin, Leigh, & Worsley, 2016, p. 836).

At the same time, several authors have acknowledged that service users should be actively involved in the management and the assessment of risk (Killick & Taylor, 2020; Mantell, 2010; Ottmann et al., 2017; Stalker, 2003; B. Taylor & McKeown, 2013; Whitelock, 2009), as "they have valuable knowledge and experience of their own situation" (Stalker, 2003,

p. 228). Although some services include service users in risk discussions (B. Taylor & McKeown, 2013), service users' involvement in risk decision-making remains uncommon (Fullana et al., 2019) and "the person or group taking the decision is not always the person or group affected by the risk" (Neill et al., 2009, p. 18). As such, risk assessments that are often performed in the absence of service users play a significant role in deciding who is and is not at risk (Carr, 2011). More often than not, risk is the preserve of professionals and is managed defensively in order to protect the organisation or the professional (Munro, 2010; Stanford, 2010; B. Taylor & Whittaker, 2017, 2018; Whittaker & Havard, 2016), even if it means imposing on the rights of the service user (Jingree & Finlay, 2008; Ottmann et al., 2017). It is essential for organisations to employ approaches to risk that actively involve social care workers as well as service users (Barry, 2007). Nonetheless, gaps have been identified in knowledge around how to involve service users in the management of risk (Ottmann et al., 2017; Wallcraft, 2012) and in the experiences of involving disabled people in assessing and managing risks (B. Taylor & McKeown, 2013).

### Risk in individualised social care

The last few decades has been described as an unprecedented transformative era in disability services (Health Service Executive (HSE), 2011b, 2012, 2016). Internationally, adult disability services abandoned segregated institutional models and embraced rights-based and personalised supports (Christensen, 2010; European Union Agency for Fundamental Rights, 2014; Glasby et al., 2009; Glasby & Littlechild, 2002; Junne & Huber, 2014; Leece & Leece, 2011; Ratcliffe et al., 2019), which

was a move strongly supported by the disability movements' calls for equality (Shakespeare, 2006; Vanhala, 2011). An emphasis on individual autonomy and control in disability services intensified across all EU member states (European Union Agency for Fundamental Rights, 2014). Whether the motives behind these recent reforms are of economic or moral character has been the centre of long and, at times, controversial debates in disability literature (Burch, 2017; Ferguson, 2007, 2008; Fyson, 2009; Ni She et al., 2020; Scourfield, 2007; Yates, 2015).

On the one hand, the recognition of the rights, choices, and responsibilities of disabled people, initiated by disability campaigns, can be seen as a core driver of changes in disability policy (Department of Health (EIRE), 2012, 2018; Department of Health (EIRE); Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, 2006; Department of Justice and Equality (EIRE), 2017; Department of the Taoiseach, 2006; Friedman & VanPuymbrouck, 2019; Gadd et al., 2018; Health Service Executive (HSE), 2011b, 2012, 2016; National Disability Authority (NDA), 2010a) and as care moving towards greater control for service users, including more positive risk-taking (Glendinning et al., 2008; Heath & Phair, 2009; Kettle et al., 2011). On the other hand, many scholars have found the independent movement in adult social care to be positioned within a neoliberal discourse and have argued that the recent changes fall into the broader conservative market agenda of the state shifting responsibility to the individual (Leece, 2004; Pearson, 2000; Scourfield, 2007; N. S. D. Taylor, 2008). It has been suggested that although calls for individualised care may fit well with the rhetoric of moving away from overprotective services (Ferguson, 2007), primarily through the use of the vocabulary of choice and freedom, "the value of independence transpires to the economic advantage of less people



receiving social support” (Burch, 2017, p. 102). As such, empowering vocabulary can be seen as a smokescreen for the real motivator of personalised care – budget cuts (Fyson, 2009). Such arguments have led to the claim that, much like other spheres, social care is being marketised and that the independent movement has given into an:

uncritical acceptance of the marketisation of social work and social care; in its neglect of poverty and inequality; in its flawed conception of the people who use social work services; in its potentially stigmatising view of welfare dependency; and in its potential for promoting, rather than challenging, the de-professionalisation of social work, the philosophy of personalisation is not one that social workers should accept uncritically (Ferguson, 2007, pp. 400-401).

In this vein, choice and control have been portrayed as “the buzz words” of the independent movement (Christensen & Pilling, 2014, p. 492). With concepts such as social inclusion and empowerment to the fore, international and domestic policies promote the social and economic participation of disabled people. While for many the move represents a revolution in a fight against the oppression of disabled people (Morris, 1993; Oliver, 1990, 1996; Silvers, 1995), such calls can be easily co-opted into neoliberal rhetoric and reforms, in the manner of a Trojan horse, involving responsabilisation and privatisation of risk (Ferguson, 2007). Thus, risks and responsibility for their management are individualised in social care (Hamilton, 2012; Scourfield, 2007).

While it has been noted that through personalised care service users may learn how to manage risks independently (Glasby & Littlechild, 2002), it has also been argued that the approach transfers many risks from service providers to service users (Alaszewski & Manthorpe, 1998; Junne &

Huber, 2014; Kemshall, 2010; Kemshall et al., 1997; W. Mitchell & Glendinning, 2008; Roulstone & Morgan, 2009) and can put pressure on service users to assume and manage numerous and diverse risks and responsibilities (Junne & Huber, 2014). This approach requires that service users become “calculative rational risk-takers” (Scourfield, 2007, p. 116), which is not something that all service users desire or can appropriately manage (Scourfield, 2007). To promote independence above dependence is at odds with some of the core principles of welfare professions, which were developed to care for and protect marginalised and dependent individuals (Scourfield, 2007).

In addition, although it has been acknowledged that individualised services transfer onus for care to service users and that this “could put service users at risk of abuse and neglect, in particular, if the user purchased unregulated services”, there are evident gaps in the literature on how these risks should be managed (Department of Health (EIRE), 2018, p. 49). Along these lines, a report of a European study on deinstitutionalisation and community living highlighted that the individualised models of care would place a significant amount of responsibilities on service users and increase the risk of exploitation and that “if the right services are not available for individuals to purchase, then a system of self-directed care could be highly constrained” (Mansell et al., 2007, p. 85). Moreover, if disability services are being marketised and free markets often overly penalise bad choices, then disabled people are knowingly placed in the position of having to make choices, some of which may undoubtedly involve risks or poor outcomes. Some of these risks may include feeling excluded or isolated as a result of the new care environment (Glendinning et al., 2008; A. Power, 2013a; Roulstone & Morgan, 2009); possible higher risk of harm or abuse (Glasby, 2012;

Glendinning et al., 2008); inability to manage finances and financial abuse (Gilbert & Powell, 2011; Glendinning et al., 2008; M Henwood & Hudson, 2007; M Henwood & Hudson, 2008; W. Mitchell et al., 2012; Rowlett, 2009); risk of being excluded from services due to what may be perceived as problematic behaviour (Glasby, 2012); and risks related to a service user's failure to managed appropriately new responsibilities (Junne & Huber, 2014). Moreover, it was found that practitioners worried that personalised models of care would result in leaving service users already at risk with little or no protection (Glendinning et al., 2008).

Other studies have found challenges surrounding professionals attempts to balance increased choice with duty of care and have argued that over-regulation in the areas of safeguarding could impede service users opportunities to self-manage risks (Glendinning et al., 2008; M Henwood & Hudson, 2007; M Henwood & Hudson, 2008; Manthorpe et al., 2009; N. S. D. Taylor, 2008). However, the research on individualised services has focused on the perceptions and experiences of professionals, while service users were not represented (W. Mitchell et al., 2012). It was emphasised that the attitudes of staff and organisations needed to change in order to foster genuinely personalised services and that research into the perspectives of all stakeholders was necessary to inform this shift (Glendinning et al., 2008). It was further noted that stakeholders perspectives might vary or even contradict one another and that such insight could advance discussions of risk in individualised services (Glendinning et al., 2008; W. Mitchell et al., 2012). It has been suggested that the voice and the individual choices of disabled people should play a central role in how policies are developed and designed in individualised social care (Souza et al., 2021).

In Ireland, a recent study highlighted the experiences of disabled people with high dependency needs living independently and provided an alarmingly long list of profound “pitfalls and shortcomings” (O'Donnell, 2019, p. 220). This study pointed to inadequate personal assistance, limited funding and resources for disabled people, which left them at risk of poverty, social exclusion, alienation, and discrimination (O'Donnell, 2019). In this study, a disabled person argued that both policy and praxis still have a long way to go before independent living services can be called rights-based (O'Donnell, 2019).

### Construction of disability; risk, a tool used to govern?

Until recent decades, disability had been dominated by biomedical models, which were rooted in objectivist epistemological paradigms. These models have been widely contested for their failure to recognise other than naturalistic aspects of disability and for defining disability in the realm of bodily flaws (Barnes, 1991; Barnes & Marcer, 2004a, 2004b, 2004c; Brisenden, 1986; Finkelstein, 1980; Fisher & Goodley, 2007; Goering, 2010, 2015; Goodley, 2001; R. Hughes, 2010; Nisker, 2019; Oliver, 1983, 1990; Oliver & Barnes, 1998, 2012; Spandler et al., 2015; Thomas, 1999; Tregaskis, 2002; Wendell, 1996). Biomedical models categorise disability with reference to the conformity of body appearances and behaviour with mainstream expectations (Finkelstein, 1980; Oliver, 1990; Thomas, 1999). They commonly view disability as a bodily issue (Goering, 2015; R. Hughes, 2010; Mulvany, 2000) and perceive it as a negative difference, abnormality or deviancy, which can stigmatise disabled people (Susman, 1994). Through these models, the main aim of care was seen as treating, correcting, and curing bodily flaws (B. Hughes & Paterson, 1997),

and good practice was viewed as one that protects service users and eliminates risks.

Over the course of more than five decades, opponents of biomedical approaches to disability have called for an abolition of barriers produced by disabling societies. They have emphasised that disability is not a personal tragedy, nor is it something that requires medical or other intervention in order to be corrected (Brisenden, 1986; Finkelstein, 1980; R. Hughes, 2010; Oliver, 1983, 1990, 1996). In the 1970s, The Union of The Physically Impaired Against Segregation (UPIAS) (1976) in the UK produced a document called Fundamental Principles of Disability, and a social model of disability emerged. This paper held that society is responsible for disabling and oppressing individuals with impairments, which was a notion then reinforced by disability writers who further criticised disabling societies for longstanding impediments to the inclusion of disabled people (Barnes, 1991, 1992; Finkelstein, 1980; Goering, 2010, 2015; Hahn, 1985; Kemple, Ahmad, & Girijashanker, 2011; Liggett, 1988; Mulvany, 2000; Oliver, 1983, 1990, 1996; Thomas, 1999; Zola, 1982). Within the social model perspective, disability was separated from impairment and became viewed as a by-product of disabling society, not as a matter of pathology (Barnes, 1991; Oliver, 1996). Through this lens, disability has been socially and politically reconstructed and reformed to draw attention to the societal barriers that disable people (Bolt, 2005; Finkelstein, 1980; Oliver, 1983; Sisti, 2015; Thomas, 1999).

The social model has influenced the image of disability in media, academia, legal systems and public policies and has become a future vision for disabled people (Tregaskis, 2002). This model has emphasised that disabled people should not be viewed in the realm of the medical or as helpless individuals in need of protection; instead, they must be

understood as citizens oppressed and disabled by a discriminating capitalistic society (Oliver & Zarb, 1989; The Union of The Physically Impaired Against Segregation (UPIAS), 1976; Tregaskis, 2002). As such, rather than preventing risks, disability services should provide care that respects service users rights, autonomy, and choice. Recognising this need for change was a pivotal event in often altering paternalistic approaches to risk in disability services. Through the medical model lens, risk-avoidance and the limitation of service users' independence had often been normalised and labelled as 'protecting the vulnerable', while service users views of risk were largely overlooked (Guess, Benson, & Siegel-Causey, 1985). Although the social model has been highly influential in altering the manner in which disability has been constructed and consequently how risk is approached, some writers have pointed out its limitations and the need for revisions (Allan, 2010; Crow, 1996; French, 1993; Levitt, 2017; Morris, 1991; Oliver, 2013).

It has been argued that it is "an outdated ideology" (p. 9) and that in separating impairment from disability, the social model failed to adequately account for many important aspects of disability, such as the lived experience, individual identity and the body (Shakespeare & Watson, 2001). Many social and post-social model writers criticise what they call the medical model of disability for regarding disability as pathology and overlooking other factors (Goering, 2015; Nisker, 2019; Oliver, 1983; Owens, 2015). Yet, at the opposite extreme, the social model does not consider other critical aspects of disability. This has led to the charge that the "disabled subject is not an individual with a full set of properties (biological, psychological, social) but, at best, a half-person with only social properties; a half-man, biologically naked and only subjected to social values and roles" (Anastasiou & Kauffman, 2013, p. 445). Here, it is

maintained that a dichotomy between the biomedical components of disability and its social construction is not possible, as both components interact in creating disability (Anastasiou & Kauffman, 2013; Hasler, 1993; B. Hughes & Paterson, 1997; Wendell, 1996).

Undoubtedly, much has changed in how risk is approached in disability services, to no small degree because of the enlightenment brought about by the social model. Since the 1990s, disability movements equipped with 'the Big Idea' of the social model have challenged oppression and revolutionised how disabled people were perceived, and consequently, the amount of choice in taking risks they have (Barnes, 1991; Hasler, 1993; R. Hughes, 2010; Oliver, 1990, 1996; Tregaskis, 2002). However, it was only before the closing of the last millennium that disability has escaped from being perceived merely as purely a medical issue and entered political debates (Oliver & Zarb, 1989).

More recently, disability came to be studied from a subjective positionality as a socio-political phenomenon influenced by much more than physical impairment or a product of discriminating societies (Gillies, 2014; Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019). Building on the substantial body of disability studies literature produced by scholars challenging dominant biomedical approaches to disability (Barnes, 1991; Barnes & Mercer, 2003; Barnes & Mercer, 1997; Barnes, Mercer, & Shakespeare, 1999; Charlton, 2006; L. J. Davis, 1995; Garland Thomson, 1997; D. Mitchell & Snyder, 2006; Morris, 1996; Oliver, 1990; Oliver & Barnes, 2012; Thomas, 1999, 2007; Wendell, 1996), critical disability studies emerged (Goodley, 2014, 2016; Goodley et al., 2019; Liasidou, 2014; Liddiard, 2018; Mallett & Runswick-Cole, 2014; Meekosha & Shuttleworth, 2009; Moeller, 2015; Shildrick, 2004, 2007; Slater, 2015; Vanderkinderen, Roets, & Van Hove, 2014). Critical disability theorists

have emphasised that “disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; rather, it is a question of politics and power(lessness), power over, and power to” (Pothier & Richard, 2006, p. 2).

In this sense, critical disability scholars have argued that the evolution of disability has been contemporaneous with the growth of neoliberalism and that risk has been used as a tool of governance. They maintain that how neoliberal societies define ‘normal’ deepens inequalities and further disempowers already marginalised communities, including disabled people (Sleeter, 2010; Yates, 2015). It has been suggested that neoliberal hegemonic ideology endorses ableism (Fritsch, 2015; Scuro, 2017), primarily through the notion that only those that are independent, whether it is economically, physically, or lawfully, can be truly happy (Goodley, 2018). This neoliberal ableism combines economic independence with individual autonomy (Goodley, 2018). It has been described as a “state of economic, cultural and political life” where only those that can “manage to demonstrate normalcy and abilities to become part of the capitalist marketplace, ready and willing to work” can fit into society (Goodley, 2016, p. 177). It has been suggested that neoliberal systems use physical appearances and body as instruments determining economic productivity (Fritsch, 2015; Harjunen, 2016) and that, in this sense, disabled people are perceived as a financial burden (Grover & Soldatic, 2012). In this realm, neoliberalism has been described as “a theory of political economic practices proposing that human well-being can best be advanced by the maximisation of entrepreneurial freedoms within an institutional framework characterised by private property rights, individual liberty, unencumbered markets, and free trade” (Harvey, 2016, p. 22).



These neoliberal and biomedical trends have shaped how disability has been perceived and constructed and continue to shape how disability services are delivered both nationally and internationally. Indeed, it has been argued that neoliberalism uses “tactics” that are “sophisticated, frequently masked by ideological gambits, but devastating for the dignity and social well-being of vulnerable populations and territories” (Harvey, 2016, p. 39).

Since the end of the last millennium, neoliberal trends and policies have penetrated much further than economic spheres (Goodley, 2017; Hamann, 2009; Harvey, 2016; Yates, 2015), including welfare systems, social provision, and the lives of disabled people (Yates, 2015). Neoliberal political rationality can be seen to execute a form of governmentality<sup>10</sup>, which governs through the market and stimulates people to become individual entrepreneur consumers (Hamann, 2009; Harjunen, 2016; Yates, 2015).

It has been argued that risk is reconstructed and used in a way that produces fears and, consequently, norms that govern individuals through self-regulation and superficial freedom (Burch, 2017; Kemshall, 2010; Lupton, 1999; Rose, 1993). Risk is used to name economically undesirable concepts, such as obesity, poor health, disability, and responsible citizens are encouraged to manage, or prevent, these risks by opting for a healthy lifestyle or avoiding elements that may compromise good health, for instance (Burch, 2017). As such, in this superficial freedom, responsible citizens are stimulated to make only economically viable choices (Harvey, 2016). Otherwise, they are framed as irresponsible and perceived as an

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<sup>10</sup> This concept was first developed by Michal Foucault who argued that liberal forms of government can still exercise control (Foucault, 1991).

outcast. This has led to claims that the neoliberal agenda uses risk to “advance ideals such as rational choice and individual responsibility” (S. Brown et al., 2013, p. 333). This form of governance can be achieved by standardising norms of acceptable risk, acceptable behaviour, and acceptable status (Parton, 1998). If a society produces polarised norms and labels human life, behaviour, and choices as good and bad, then “individuals can be governed through their freedom to choose” (Rose & Miller, 1992, p. 201). Following this rationale, being independent, for instance, is more normative than being dependent<sup>11</sup>, and being employed is more acceptable than being unemployed. It is a sophisticated way, or as Rose (1993, p. 294) called it, an “advanced liberal” way of exercising control while maintaining the rhetoric of freedom and liberty (Burch, 2017; Harvey, 2016). Many responsibilities, including risk management, previously the preserve of the state, have been transferred to individuals within this process. Though the official regulatory power of governments may have decreased in economic spheres, the power of authorities in achieving their neoliberal goals has by no means diminished and has extended to many previously autonomous areas (Rose & Miller, 2010), such as social care.

### Risk, choice, and health promotion in modern disability services

To date, the literature has pointed to the underlying connection between the core concepts of the individualised movement in adult social

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<sup>11</sup> A recent European study distinguished between social care that operates from within a ‘care’ approach, which implies caring for, and thus suggests the person is dependent, and an ‘assistance’ approach, which is preferable as it represents assisting a service user to become independent (Christensen, 2010). Thus, through the use of such language, there is a clear message transmitted - that it is far more valued to be independent rather than dependent.

care and risk and responsibility (L. Brown, 2010; S. Brown et al., 2013; Burch, 2017; Burchardt, Evans, & Holder, 2015; A. Davis, Ellis, & Rummery, 1997; Department of Health (EIRE), 2018; K. Ellis, 2005; Ferguson, 2007; Foster & Wilding, 2000; Glasby, 2012; Hamilton, 2012; Kemshall, 2002; Kemshall et al., 1997; Lupton, 1999; W. Mitchell et al., 2012; Rummery, 2006; Scourfield, 2007). It has also been acknowledged that while the move from a medical to a social model of disability has contributed to moving away from perceiving disability purely in biological terms and seeing disabled people as in need of being 'cured', many people with the label of disability continue to experience many more health difficulties than non-disabled people (Brown, 2017). It has been found, for instance, that people with a label of intellectual disability face challenges closely linked to poor nutrition, lack of physical activity, and obesity (Heath & Fentem, 1997; Hsieh et al., 2018; Janicki et al., 1999; McDermott et al., 2007; McDermott et al., 2012) and are almost three times more likely to develop diabetes (Brown, 2017). Indeed, disabled people "often are at greater risk for health problems that can be prevented. As a result of having a specific type of disability, such as a spinal cord injury, spina bifida, or multiple sclerosis, other physical or mental health conditions can occur" (Centers for Disease Control and Prevention, 2020, para. 'Secondary Conditions' section 1). It has been stressed that social care workers play a significant role in the lives of disabled people and thus have the capacity to influence their health behaviours (Leser et al., 2018). Along these lines, it has been emphasised that social care practitioners ought to empower service users to help prevent and self-manage health issues such as obesity or diabetes (Brown, 2017; McDermott et al., 2012).

Undoubtedly, social care can be seen as closely aligned with health promotion. This natural relationship is founded on mutual values as it is

apparent that health promotion principles, including empowerment, participation, and a holistic approach, underpin social care practice. Empowerment can be seen as “having a measure of control over one’s life, of being able to choose what one wants to do or be” (Downie et al., 1990, p. 18). One very recent study found that service users view being empowered and able to make independent choices as the most critical determinant of service quality (Frounfelker et al., 2020).

The key health-promoting areas for disabled people include “choice for individuals, opportunities for integration in the community, opportunities of active participation as equal members of the community and local neighbourhood, the ability to form and maintain relationships with others and the acquisition of competence and skill” (Dines & Cribb, 1993, p. 121). Nonetheless, empowering individuals and enabling them to make healthy choices and take risks often means enabling them to become responsible for these choices and their potential repercussions (Hollomotz, 2012; Scourfield, 2007; B. Taylor & McKeown, 2013).

An Irish study of the health and health promotion needs of people with a label of intellectual disability found that the views of service providers and carers differed from the views of service users (Boland et al., 2008). While service providers and carers emphasised the need for speech and language therapy, counselling, physiotherapy, and occupational therapy, service users talked more about creative therapy, relaxation, and social and physical activities (Boland et al., 2008). Although perceptions of how health should be promoted vary amongst different stakeholders, the study recommended that policymakers and services enable service users to make healthy choices, including healthy eating and physical activity (Boland et al., 2008). Nonetheless, while promoting healthy choices can influence positive outcomes, service users choices are often limited by what is

readily available, which can be seen clearly in the area of food choices. Nutritious foods, for example, are not always easily accessible, as they are often less convenient and more costly than less nutritious alternatives (Kelly, Callaghan, & Gabhainn, 2021).

While there is general agreement that empowerment and promotion of independence are fundamental principles of both health promotion and social care practice (Social Care Institute of Excellence (SCIE), 2005, p. 7), empowering practice can bring associated risks (Adams, 1996). There is an increased risk of choices with potentially risky outcomes being made in an environment that is more autonomous and less controlled. It can be inferred that with increased emphasis on empowerment, participation and individual choices, there are increased risks and thus, “achieving maximum independence may involve risk-taking where potential losses are great, but potential gains greater” (Waterson, 1999, p. 278). While this seems an equivocal point for the delivery of individualised services in adult social care, it is largely omitted by some key national policies informing the independent movement in Ireland, including ‘Time to Move on from Congregated Settings A Strategy for Community Inclusion’ (Health Service Executive (HSE), 2011b), ‘Value for Money and Policy Review of Disability Services in Ireland’ (Department of Health (EIRE), 2012), National Disability Inclusion Strategy 2017-2021 (Department of Justice and Equality (EIRE), 2017), and ‘Sharing the Vision – a Mental Health Policy for Everyone’ (Department of Health (EIRE), 2020).

More recently, it has been acknowledged that all service users have the right to make even the choices that may not appeal to others and that services should recognise the positive aspects of risk-taking (Health Information and Quality Authority (HIQA), 2019b). Thus, the need for a “cultural shift towards positive risk-taking and risk enablement” has been

highlighted (Department of Health (EIRE), 2018, p. 49). Moreover, services should support service users in assessing risks and considering the pros and cons of choices that may involve risk (Health Information and Quality Authority (HIQA), 2019b). Risks should not be avoided; rather, they should be managed in a manner that empowers service users to make informed choices (Health Information and Quality Authority (HIQA), 2019c). Indeed, ensuring that service users are autonomous in all aspects of their lives requires supports around active decision-making (Burchardt et al., 2015) so that disabled people can be independent and make (even unwise) choices (W. M. L. Finlay et al., 2008; Hollomotz, 2012). While the literature is generally concerned with the negative aspects of risk (Macdonald & Macdonald, 2010; W. Mitchell & Glendinning, 2008), with some exceptions acknowledging the positive aspects of risk (W. Mitchell & Glendinning, 2008), to achieve care that is truly empowering, potential gains from risk-taking should also be considered (B. Taylor & McKeown, 2013; B. Taylor & Whittaker, 2017). As such, when assessing or “measuring risk...the positive aspects or outcomes of that risk should be considered “against the negative effects of attempting to avoid [that] risk” (Manthorpe & Moriarty, 2010, p. 8).

When it comes to discussing positive risk-taking and service users’ decision-making around risk, the importance of ‘informed choices’ is often emphasised, which means that service users should be fully informed about risks (Health Information and Quality Authority (HIQA), 2019a, 2019b, 2019c; National Consent Advisory Group, 2013; Rowlett, 2009). The ‘National Consent Policy’ stresses that for “consent to be valid, the service user must have received sufficient information in a comprehensible manner” (National Consent Advisory Group, 2013, p. 23). However, where professionals should seek information about each risk and how it should be

presented to service users remains vague. Thus, although it is a professionals' responsibility to ensure that service users are supported around independent decision-making (Arstein-Kerslake, Watson, Browning, Martinis, & Blanck, 2017), they "can feel overburdened if they are expected to adopt new practices in an environment that is not adequately resourced or supportive for a change in practice" (Davies et al., 2019, p. 10).

Recent studies have highlighted just how challenging supporting changes in practice can be given deeply embedded cultures of paternalism. For example, Johnson et al. (2020) found that adults with a label of intellectual disabilities using social care services face significant difficulties in having their choices supported due to practices that continue to be paternalistic and restrictive. In a similar fashion, Richardson (2020) echoed this point, observing that personalised social care for adults labelled with learning difficulties frequently means "giving them choice which is controlled choice":

people are continuing to have to fit into services rather than have services shaped around their needs. Choice is limited, information on quality is based on subjective opinion, lacking or is complex to contextualise and assimilate meaningfully. Personalisation in the era of austerity is offering empty promises to people with learning disabilities, where choice, whilst fleetingly present, does not lead to control or opportunity for self-determination. There is an important opportunity in the face of these challenges for change and to focus on new ways of working (Richardson, 2020, pp. 2079-2080).

While the existing accounts of risk in adult physical disability services pay little attention to assisted decision-making, it falls within the arena of increased control, choice, and independence. As such, it is essential to recognise the potential effects of the Assisted Decision Making

(Capacity) Act on how risk is approached and viewed in disability services in Ireland. As in most developed countries, in Ireland, supported decision-making will soon assume a formal legal dimension to maximise individuals' independence, which can bring revolutionary changes in how risk is managed. Similarly to choice and control (Christensen & Pilling, 2014), supported decision-making has also been described as "one of the newest buzzwords in the disability field" (Arstein-Kerslake et al., 2017, p. 2). Although the literature links the concept predominantly to people with the label of intellectual disability or people with mental health difficulties, it also acknowledges that its application is wide-ranging, from the ageing population to people with acquired brain injuries, developmental or psycho-social disabilities, or people with fluctuating capacity (Davies et al., 2019; M. Donnelly, 2019; Ni She et al., 2020; Simmons & Gooding, 2017; Wade & Kitzinger, 2019). A study in Canada, for instance, found that while disabled people could have benefitted from supported decision-making, the framework had been implemented only in settings used by people with the label of intellectual disability (James & Watts, 2014). Reasons for the requirement of assistance with a decision can be wide-ranging, including lacking confidence and lost or never-learnt life skills caused by institutionalisation (Mansell et al., 2007). More than addressing why a person requires assistance with decisions, the Assisted Decision Making (Capacity) Act is concerned with changing culture in health and social care services by placing an obligation on professionals to recognise service users as independent and with capacity to make decisions (Ni She et al., 2020). Indeed, this legislation should necessitate new ways of providing care by ensuring less risk-averse and more person led services (Department of Health (EIRE), 2018; S. Donnelly et al., 2019; Ni She et al., 2020). This framework has the potential to challenge outdated approaches employed



by some health and social care settings, such as mental health services, which continue to “rely on a medical model of care where the healthcare professional is positioned as the dominant decision-maker” (Simmons & Gooding, 2017, p. 275).

However, while this new legal framework can emancipate service users, it also brings challenges for health and social care practice and potentially more risks for service users (Department of Health (EIRE), 2018; M. Donnelly, 2019). Concerns have been raised that without proper consideration of how supported decision-making will be enacted in practice, it could turn out to be “another tick box exercise” (Arstein-Kerslake et al., 2017, p. 14). Certainly, the implementation of this complex legislation in practice will require a multidimensional approach focusing not only on policy but also on education and practice (Davies et al., 2019; M. Donnelly, 2019). Yet, not only has there been little attention paid to how supported decision-making will be implemented in practice (Arstein-Kerslake et al., 2017; Davies et al., 2019; Ni She et al., 2020), its very real connection to risk has been largely overlooked in the literature.

## Conclusion

This review of the literature has identified an underlying connection between risk in disability services and the broader economic, political, and social context. Firstly, it reviewed the literature on risk society, which identified how dominant risk had become globally, nationally, and in social care. It identified how these developments influenced the social care profession and disability services in particular by outlining the impact of risk on how welfare professions have been remodelled throughout the past decades to form the social care profession as it is today. This review

evaluated risk assessment and management in social care practice and identified variances in approaches amongst different stakeholders. Next, it reviewed how risk falls into the discourse of the changing principles in adult social care toward choice and empowerment. It also examined the evolution of 'disability' through the changing socio-political climate and outlined how the neoliberal project has shaped the relationship between risk and disability. It provided an overview of the literature on the shift of state responsibilities, including risk management and presented an argument around how social care professionals' struggle both to empower and safeguard service users in technocratic blame orientated climates.

Although the literature points to a tension between professional responsibility and service users right to autonomy, there is a gap in the research literature around how this tension influences risk decision making in social care practice. In particular, this review identified gaps in research into how different stakeholders perceive and experience risk in social care.

## Chapter Three: Research Approach and Methods

### Introduction

This thesis was informed by a constructivist theoretical framework, which facilitated recognition of participants varying perceptions and the multiple subjective meanings assigned to their experiences (Creswell, 2003). Data was collected via qualitative interviews and analysed using the descriptive phenomenological research method designed by Giorgi (Giorgi, 2006a, 2006b, 2008a, 2008b, 2009, 2012; Giorgi, Giorgi, & Morley, 2017). This method, influenced mainly by the philosophical works of Husserl (Husserl, 1931, 1969, 1970, 1973, 1980, 1982, 2000, 2001), was tailored specifically for human sciences and caring research, and thus, provided the most suitable tool for examining risk in disability services.

Phenomenology seeks to study human experiences through descriptions (Creswell, 2003). It is concerned with learning how individuals perceive the world and how researchers can make sense of those perceptions (Bryman, 2012). Phenomenology acknowledges that human consciousness of the surrounding world is ever active (Husserl, 1982, 2001) and that consciousness is the most fundamental quality of a human (Husserl, 1982). It is the mediating channel between humans and the world (Giorgi, 2005).

This chapter presents a rationale for the constructivist theoretical approach and the phenomenological method chosen for this research. It also elucidates phenomenology as a research method and details the approaches to participant recruitment, data collection and analysis. Central to achieving harmony in applying constructivism and

phenomenology in this study was their close connection (Avramidis & Smith, 1999; Berger & Luckmann, 1966; Crotty, 1998; Lather, 1992; Neuman, 2014). Proponents of both domains emphasise that reality is not independent of its external, often subjective factors. Rather, through phenomenology as well as constructivism, social sciences recognise social reality as experienced and perceived by subjective actors (Schutz, 1964). The critical difference, however, is that here constructivism represents a worldview and, thus, a theoretical underpinning for this research, while phenomenology signifies a philosophical movement and, once adopted, a scientific method used to collect and analyse data.

### Constructivist theoretical approach

Current knowledge and understanding of risk and disability are embedded in the cultural, historical, political, and social processes which have shaped their formation over time (Barnes, 1991, 1992; T. J. Beck, 2013; Beck, 1992, 1994, 1996, 1999, 2006, 2009a, 2009b, 2011, 2012; U. Beck, 2013; Beck, 2015; Beck et al., 2000; Beck & Grande, 2010; Berger & Luckmann, 1966; Finkelstein, 1980; Goering, 2010, 2015; R. Hughes, 2010; Lupton, 1993, 1999; Mythen, 2004; Nisker, 2019; Oliver, 1983, 1990; Shaw & Shaw, 2001; Stanford, 2011; Thomas, 1999; Tregaskis, 2002; Webb, 2006b; Wendell, 1996). Thus, both disability and risk are social constructs and as a consequence, how these concepts are perceived varies amongst individuals and stakeholders. In this sense, risk can be understood only through appreciating perceptions, experiences or as an expression of human consciousness. Consequently, risk had to be investigated as embedded within the context, which both shapes and is shaped by that context. Service users, social care professionals and service providers

experience risk in disability services first-hand and therefore create and recreate knowledge about the phenomenon. To reflect this, the main aims of this study were to examine participants' perceptions and experiences of risk in disability services and to explore if and how these meanings shape social care service provision for adults with physical disabilities.

This research has had a subjective epistemological orientation and anti-foundationalist ontology. It recognises that reality, knowledge and understanding are shaped, interpreted, and constructed by individuals seeking to understand and navigate the world they live in (Creswell, 2003; Crotty, 1998; Gergen, 1985). Galbin (2014) compared perceptions to "differing maps of the same world" (p. 82), which are created in each distinct mind influenced by various discreet factors. Constructivists respect this subjective value of individual perceptions and resist the idea that all knowledge is measurable and can be standardised or generalised (Crotty, 1998). Constructivists believe that reality cannot be studied or explained in a purely objective manner but rather that knowledge is created by social actors influenced by their environment and must be studied with that in mind (Creswell, 2003; Crotty, 1998; Gergen, 1985).

Societal perceptions, cultural representations, and attitudes toward disability have evolved and changed profoundly throughout different eras (National Health Service (NHS) North West, 2013). A striking example is the industrial era, where work and employability played an essential role in constructing disability. Cultural values at the time regarded employment and pride synonymously with the inability to work seen as a burden. Thus, disabled people that were employed were frequently perceived in a more positive light than unemployed disabled people (Turner, 2018). Since then, perceptions of disability have evolved from discriminatory and oppressive attitudes, through mixed views influenced by civil rights movements, to

finally accepting disabled people as emancipated and valuable members of society (National Health Service (NHS) North West, 2013).

In Ireland, a series of surveys since the turn of the millennium highlight that public attitudes and perceptions of disability have changed significantly (National Disability Authority (NDA), 2001, 2007, 2011, 2017). Between 2006 and 2017, for example, there has been an increase of 16% in the number of people who now feel “that people with physical disabilities can participate fully in life” (National Disability Authority (NDA), 2017, p. 2). Although attitudes toward disability, in general, have improved, there are some areas, such as sexual relationships of adults with mental health issues or intellectual disabilities, where stigma persists (National Disability Authority (NDA), 2017). The survey points out, for instance, that “only 56% of respondents agree that adults with mental health difficulties should have children if they wish compared to 85% for vision or hearing disabilities” (National Disability Authority (NDA), 2017, p. 8). As such, while a timeline plays a significant role in constructing disability, it is not the only factor influencing the way individuals perceive it. In the USA, for example, perceptions of disability vary among families with different cultural and linguistic backgrounds (Sanchez & Wood, 2016). As such, disability has been and continues to be socially constructed and is contingent on social, historical, and political processes.

Given the social construction of both disability and risk, this research sought to understand risk in disability services, and thus studying the lived experience of disabled people was essential. By acknowledging that risk and disability are socially constructed, this research acknowledged both concepts’ dependency on social, cultural, historical, and political factors. It recognised that a great deal of the social world exists as it does

due to social and interpersonal influences (Gergen, 1985), and these influences must be considered when studying social phenomena. Thus, through the constructivist paradigm, the importance of investigating the phenomena from the perspective of those directly involved in their formation was kept at the heart of this research.

In contrast to some naturalistic sciences, constructivists challenge the traditional views of the positivist outlook. They respect the genetic, physical, or naturalistic aspects of realities, such as impairment being a part of how 'disability' is constructed or probability estimation being a part of how 'risk' is understood. These aspects alone, however, cannot represent the full truth, and through these aspects alone, disability or risk cannot be understood. Constructivists emphasise the importance of investigating social, cultural, and historical processes and individual interpretations of these realities in order to gain meaningful knowledge. However, a distinction has to be made between constructivism and what has been labelled as 'radical' (Schwandt, 2003; von Glasersfeld, 2007) or 'strict' (Burningham & Cooper, 1999) constructivism. There are radical forms of constructivism that have a strict relativist orientation and do not recognise any part of reality as objective. Nonetheless, constructivism recognises both objective and subjective reality and knowledge as subjective reality becomes viewed as objective phenomena over time (Berger & Luckmann, 1966). Humans, their culture and environment change dynamically and give meaning to new social realities. People institutionalise habits and routines progressively until these routines become perceived as objective norms. These norms are never static as they change over time and vary between different cultures, which can be observed through many concepts that were once culturally accepted and perceived as norms, including

slavery, gender discrimination, ableism, or institutionalisation. Not only are these concepts now perceived as unacceptable, but people worldwide have aspired to replace them by new norms such as race and gender equality and social inclusion. In this manner it is acknowledged that any reality that is deemed as objective at any precise moment in any given culture has been constructed over time and remains ever-dynamic. Thus, this research recognised the phenomenon of risk in disability services as created not discovered and thus investigated it from that perspective.

### Data collection

#### *Recruitment process, sample, and ethical considerations*

To facilitate understanding of the phenomenon from diverse perspectives, three different groups of participants were interviewed, including five social care workers, five social care managers and ten service users. Triangulation is valuable, where service users, social care workers and service managers are all involved in the research process because it facilitates understanding of the phenomena from three distinct but related perspectives. Uncovering in-depth meanings required a detailed investigation of a small sample (Boddy, 2016; Dukes, 1984). In a phenomenological study, while a large sample is not required, the richness of data is necessary (Giorgi, 2009), and because the main aim was to understand experiences and perceptions, participants must know the phenomenon well (Englander, 2012). As such, it was a requirement that all participants had either worked in disability services or have used disability services for at least three years. Historically, disabled people were excluded from research (Goodley, 1996, Hollomotz, 2018). This research also fully acknowledged that disabled people must be included in research



that affects them (National Disability Authority (NDA), 2002; Hollomotz, 2018; Office for Disability Issues. HM Government, 2011; Rios, Magasi, Novak, & Harniss, 2016). In this study, the final number of participants was guided by meaning saturation, which was accomplished when the researcher understood the data (Hennink, Kaiser, & Marconi, 2017). This was achieved when data from five social care managers, five social care workers, and ten service users were analysed. This also ensured a balance in understanding risk from the perspectives of both of those employed in disability services and those utilising them.

All three groups of participants were recruited through three national organisations providing social care services across Ireland. Both purposive and snowball sampling were used to recruit participants. Initial contact with potential candidates was made personally by visiting organisations providing services for disabled people. The first six participants were recruited during these initial visits, and these primary contacts were then used to expand the sample through snowballing (Bryman, 2012). Each organisation was HIQA registered and provided individualised social care services<sup>12</sup> and supports for disabled people in their own homes<sup>13</sup>. These social care supports included home management, budgeting, personal and health care, shopping, cooking, accessing the community, education, and employment. Disabled participants were adults living in their own homes using individualised social care services. Service users were enthusiastic about taking part in

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<sup>12</sup> The term 'Individualised services' refers to any services for disabled people that identify themselves as 'individualised' either in their mission statement or in their vision and values.

<sup>13</sup> The term 'own home' refers to any self-owned, rented, or council-owned accommodation, in which a person is either solely responsible or shares responsibilities for the household with other occupants/tenants.

the study, and thus recruitment proceeded quicker than had first been anticipated. Social care workers and social care managers also responded positively but had concerns about finding the time to partake. In order to facilitate participation, interviews were arranged around days and times that suited participants.

Ethical approval was granted by the Research Ethics Committee in NUI Galway prior to the commencement of the study. Given the nature of the subject matter, there was the potential for some emotional discomfort to occur for participants. In order to minimise the potential for this, interviewees were monitored for signs of distress. Additionally, social care interpersonal and communication skills were employed throughout the research. A list of appropriate supports was prepared in case of an interviewee becoming distressed, which, ultimately, was not observed. Furthermore, to assure the protection of privacy, anonymity and confidentiality, the data has been anonymised, and random pseudo-names have been used.

### *Interviews and vignettes*

Data was collected both via semi-structured interviews and vignettes. Since this study aimed to investigate risk from diverse perspectives, individual interviews were chosen over focus groups. Moreover, one-to-one interviews have been suggested as the most suitable data collection method to collect participants descriptions of a phenomenon (Giorgi, 2009; van Manen, 1997). One pilot interview was conducted. This revealed that some questions in the interview schedule were repetitive, and the language in the vignettes required minor

alterations as it proved to be overly academic and therefore less reader-friendly in some parts. Here, it was of a particular benefit that the researcher is a social care professional working in disability services and thus was familiar with more frequently used terminology. Furthermore, the pilot identified that the three vignettes were suitable as they induced a more nuanced discussion around dilemmatic issues concerning risk in disability services. In addition, prior to the interview process, the researcher met with each service user participant to learn about their preferred communication style (Arksey & Knight, 1999; Hollomotz, 2018). This was particularly useful, and it was apparent that most service user participants welcomed this as they wanted to get to know the interviewer first through an informal 'chat'.

The interviews were conducted in locations convenient to participants - for example, their home or their workplace. A safety protocol was in place for the interviews held at participants' homes, the researcher always had a charged phone, and a colleague always knew when the interview was expected to be finished. Each interview lasted between one to two hours and was audio-recorded. Every participant received an information pack before the interview. This pack included information about the study, confidentiality arrangements and a consent form signed upon agreement to participate (see Appendix 3 for 'Participant Information Sheet').

The interview sessions consisted of two concomitant sections. The first part commenced by asking a set of open-ended questions (see Appendix 2), allowing time and space so that the participant could describe their perceptions and experiences of risk in their own words. The researcher was a skilled social care practitioner working with disabled people for over ten years, which aided in providing a comfortable

environment in which participants own communication preferences could be supported (Hollomotz, 2018). Although all participants could verbally communicate, some support utilising suitable interviewing techniques was required in some cases. The interviewer used social care worker skills such as active listening, sensitivity to non-verbal clues, avoidance of abstract concepts where possible, rephrasing of questions when required, speaking slowly in a calm tone of voice, and using appropriate prompts to enable participants to elaborate on topics for discussion. When interviewees drifted away in their descriptions, the phenomenon of risk was reintroduced either by politely repeating the initial question or by using a suitable probing question. In some cases, when more nuanced responses were needed, supplementary questions were added. Vignettes were introduced in the second section of the interview sessions.

Vignettes served as an immensely effective tool in keeping the participants focused on the phenomenon of risk. They are particularly useful when studying values, perceptions, beliefs or attitudes (R. Hughes & Huby, 2002; Wilks, 2004). Vignettes engaged participants and helped them elaborate meanings, which may not have come to the surface via interviews alone (Barter & Renold, 2000; Bradbury-Jones, Taylor, & Herber, 2014; Kandemir & Budd, 2018; Schoenberg & Ravdal, 2000). It was anticipated that the vignettes would make participants more comfortable and “protect” them “by placing distance between their experience and that of the vignette character” (Bradbury-Jones et al., 2014, p. 427), and this proved to be the case. Furthermore, it has been suggested that abstract concepts, such as risk, can be challenging to discuss in detail “with people who have a more concrete frame of reference” (Hollomotz, 2018, p. 159). When talking about the notion of risk in intangible terms, very few conversation stimuli come to mind. Practical examples that participants

could relate to, however, such as 'smoking in bed' or 'choking hazard', paint a clearer picture and provide a concrete starting point upon which a discussion can take place.

This study used three unique vignette scenarios designed to feature specific risk-related behaviours and the characteristics of a hypothetical service user named Bernie (see Appendix 1). The scenarios were developed by the researcher and two service users using anonymised real-life situations. The vignettes were tested as part of the pilot study interview.

Each vignette presented different challenges or risk related dilemmas common in social care practice. The first vignette featured an incident of Bernie smoking in bed. The second vignette described the risk of fall in a shower, and the third vignette presented Bernie's swallowing issues and a potential risk of choking. The vignettes were presented as a whole in a two-page booklet. The researcher and participants usually read the vignettes together. First, all three vignettes were read aloud either by the researcher or the participants and then each vignette was read and discussed separately. Participants were asked to comment on the risk aspects and perceptions of each vignette and to advise Bernie and the social care workers what they should do. The vignettes were highly effective in prompting participants to reflect on potentially unsafe situations that they encountered in their own lives or their service/practice. The majority of the participants spoke about risk-related concepts only on an abstract level until they read the vignettes, at which point the vignettes evoked stories from real-life experience.

Interestingly, in several cases, participants shifted between discussing risk dilemmas in two dimensions 'what should happen or what is the right thing to say' and 'what would happen in reality'. There were unsurprisingly

some disparities between these two dimensions. For instance, some interviewees stated that all service users ought to choose their activities irrespectively of risk, yet, when provided with concrete examples of risk-taking in the vignettes, they were much more hesitant and wavered around their initial statement. This happened amongst all three groups of interviewees. The emergence of this variation was crucial as it provided insights into how and even why risk is operationalised in practice the way that it is.

In the first parts of the interviews, for example, some social care professionals and managers emphasised that their core ethos, even duty of care in a few cases, was to respect the choices of services users. However, after reading the vignettes, the same participants suggested that some choices are just too risky to support, which pointed to an internal conflict in many cases. On the one hand, social care workers and managers wanted to say the right thing informed by perspectives of social justice and human rights principles. On the other hand, in practice, they were unable to implement these perspectives largely due to concerns around liability. This also indicated that disabled people utilising social care services are often not given full autonomy in making decisions, particularly those that may appear potentially risky, despite the ongoing emphasis on choice and independence in social care (Department of Health (EIRE), 2012, 2018; Department of Justice and Equality (EIRE), 2017; Department of the Taoiseach, 2006; Gadd et al., 2018; Health Service Executive (HSE), 2012; National Disability Authority (NDA), 2010a). This highlights how meanings and interpretations of risk are ambiguous, socially constructed and shape the manner in which services are delivered.

Finally, the vignettes helped to expose participants' "taken-for-granted assumptions" (Jenkins, Bloor, Fischer, Berney, & Neale, 2010, p.

192). For instance, some social care professionals and service users automatically assumed that no service user would ever be allowed to engage in what they perceived as high-risk situations such as those in the vignettes. This can, in part, be linked to a residual medical model culture amongst some participants. Furthermore, some interviewees took it for granted that a manager would always be consulted if a service user wished to proceed with an out of the ordinary activity. Another regular example was how service users' compliance with service recommendations and policies was viewed. Some participants found it difficult even to consider that a service user might disagree with the advice of a professional and therefore challenge it. Finally, the practice of interfering with service users decisions around risk-taking was also considered a norm by several participants in all three groups. These developments further exposed the socially constructed nature and the manner in which risk, choice, and decision-making are operationalised in disability services.

### *Socio-demographics of participants*

All participants were over eighteen years of age at the time of the interview. As there were considerably more females working in the disability agencies that participated in this study, employee participants<sup>14</sup> were predominately female (90%). This is in line with other studies of the social care workforce in Ireland (Meck-Butler & Swift, 2019; Power & D'Arcy, 2018). Employee participants ranged in age from 20 to 59 years of age: 20-29 (20%), 30-39 (50%), 40-49 (20%), 50-59 (10%) and were based predominantly in the West of Ireland. The work status of participants was

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<sup>14</sup> The term 'employee respondents' refers to both managers and social care workers.

mainly full-time permanent (70%), followed by part-time permanent (30%). A total of five separate job titles were indicated by participants, with some working as social care workers (20%), social care managers (30%), social care leaders (20%), community support workers (20%), and support workers (30%). The majority of participants were educated to degree level (level 7 -10%, level 8 - 90%). The area of primary qualification was predominantly social care (80%), but there were two participants with nursing qualifications (20%). All employee participants had a minimum of three years of experience.

Service user participants were comprised of 40% females and 60% males and ranged in age from 30 to 59 years of age: 30-39 (30%), 40-49 (30%), 50-59 (40%). All service user participants lived in the West of Ireland at the time of the interview, although three were born and had lived at least ten years in the UK, while two had lived at least ten years in the USA. All service user participants were labelled by their service as having a physical disability and were registered under social care services for physically disabled people. While four service user participants were disabled from birth, six acquired a disability following an accident or development or progression of an illness in the later stages of their lives. The range of the physical disabilities assigned to service user participants was: hydrocephalus, spina bifida, multiple sclerosis, cerebral palsy, and spinal cord injuries, including Tetraplegia, Paraplegia, and Triplegia. Although there were no official diagnoses, 50% of service user participants were described and labelled by their services as having a mild intellectual disability.



## Data analysis

Data were analysed following Giorgi's scientific articulation of Husserl's descriptive phenomenology (Giorgi, 2006a, 2006b, 2008a, 2008b, 2009, 2012; Giorgi et al., 2017). This thesis uncovered the participants' consciousness constituting experiences and perceptions of risk by the use of a phenomenological scientific method. Giorgi (1994) proposed that "nothing can be accomplished without subjectivity...objectivity itself is an achievement of subjectivity" (p.205). In this sense, corresponding with the constructivist underpinnings of this study, the descriptive method enabled an investigation of risk in disability services through detailed descriptions of the participants' perceptions and experiences.

While phenomenology had been well established as a philosophical movement by the first half of the twentieth century (Giorgi, 2008a)<sup>15</sup>, it only came to be considered a scientific method for research in its second half (Colaizzi, 1978; Giorgi, 1970, 1985b, 1994, 1997, 2000a, 2000b, 2000c; Natanson, 1973; Smith, 2004, 2008, 2017; van Manen, 1997, 2002, 2014). Giorgi provided the required amendments which transformed a philosophical method into a practical scientific research method for social sciences (Giorgi, 1965, 1966, 1970, 1985a, 1985b, 1986, 1992, 1994, 1997, 2000a, 2000b, 2000c, 2002, 2004, 2005, 2006a, 2006b, 2008b, 2009, 2010,

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<sup>15</sup> Different philosophical approaches emerged, including transcendental, descriptive phenomenology founded by Husserl (1858- 1938), existential phenomenology articulated mainly by Merleau Ponty (1908-1961) and heuristic, interpretative phenomenology founded by Heidegger (1889-1976). And although the origins of phenomenology can be traced back to Kant, Hegel, as well as other philosophers concerned with consciousness, Husserl is commonly regarded as the founder of phenomenology. Some other phenomenologists and philosophers who had influenced phenomenological thought include Sartre, Schütz, Scheler, Gadamer, de Beauvoir, Merleau-Ponty, Berger, Luckmann, Ricoeur, Garfinkel, Bourdieu, Derrida, Rocoour, Spiegelberg, Levinas, Foucault, Giddens and Habermas.

2011a, 2011b, 2012, 2013, 2014a, 2014b, 2017; Giorgi et al., 2017; Giorgi & Giorgi, 2003). Utilising in-depth knowledge of phenomenological philosophy, Giorgi developed ways of validating phenomenological scientific research. While acknowledging human subjectivity as critically important, Giorgi disagreed that natural sciences' paradigms alone could offer a suitable model of inquiry for human sciences (Giorgi, 2000b, 2005). Indeed, it can be argued that positivist approaches with their reductionist procedures could be damaging to human and social disciplines and prevent them from further development (Giorgi, 2013).

Traditionally in phenomenology, philosophers based their analyses on their own experiences and reflections. Similarly, Husserl intended phenomenology mainly for describing universal structures of phenomena based on experiences of oneself. In contrast, phenomenological research methods seek to apply phenomenology to study phenomena, most often through the experiences of others (Giorgi, 1997). However, when transitioning phenomenology into the scientific world of human and social sciences, a question has to be posed. Can the experiences of others be analysed phenomenologically?

While phenomenological philosophers often work alone using their self-reflections of phenomena, phenomenological researchers regularly investigate new phenomena that they have no experience with, and thus, must turn to the experiences of others (Giorgi, 2000c; Spiegelberg, 1964, 1975, 1986, 1995). These experiences are communicated through the consciousness of a phenomenological researcher, who follows phenomenological criteria. Although participants who describe phenomena through their experiences may not necessarily understand phenomenology, a researcher conducts the analysis strictly from within a specific stance that is phenomenological. From this perspective, a

researcher makes no reality claims about the given descriptions “but merely restricts the epistemological claim to affirming that the way the subject reported the experience is the way it presented itself to the experiencer” (Giorgi, 2000c, p. 5). The application of this phenomenological stance, which is discussed in detail below, helps to produce phenomenologically rigorous data. Giorgi (2000c) pointed out humorously that it would be unrealistic to train all participants to be phenomenologists, and thus it is up to a researcher to analyse data in a phenomenologically sensitive manner.

Nonetheless, the application of phenomenology in research is not without its critics. Crotty (1996), for instance, argued against Giorgi’s method, or against what Crotty called the ‘new phenomenology’, and suggested that scientific phenomenological methods miss two components: objectivity and critique. He posited that in contrast to the phenomenological research methods, phenomenological philosophy possesses these two elements. Crotty’s main concern with the first element – objectivity, or to be precise with its lack, was that scientific phenomenological methods consider human experiences, which are mostly subjective, and thus can be viewed as compromising objectivity. For this reason, Crotty held the view that phenomenology should take an interest only in the object alone.

However, in light of earlier considerations of the experiences of others, it is apparent that phenomenological research operates in a different way than philosophy, which can also mean that analysing the experiences of subjective participants is not only possible but necessary. In line with Husserl’s thinking, phenomenological descriptive research methods believe that knowledge can be found in experiences and that this knowledge is, indeed, objective (Husserl, 1969). At the same time, these

methods recognise that this objective knowledge is obtainable through sources that can be subjective (Tassone, 2017). Participants often possess the best, or at times the only knowledge, of a phenomenon because they have experienced it first hand, and these experiences cannot be detached from the object of experience as they cannot be treated as two separate things (Giorgi, 2000a). When investigating abstract phenomena that are not physical entities and cannot exist without experience or consciousness, such as 'guilt', 'love', 'hate', and also 'risk', research cannot but examine the experiences and perceptions of these concepts and emotions. These phenomena exist within human consciousness, but also have material consequences. In this sense, it is argued that phenomenological researchers "seek an objective understanding of situations that are subjective" (Giorgi, 2000a, p. 14), which is achieved by following phenomenological research criteria, including the application of 'a phenomenological attitude' and the use of 'free imaginative variation'.

Reflecting on Crotty's second component – the alleged lack of critique in phenomenological scientific methods, Giorgi (2000a) points to the use of 'free imaginative variation' in his method, which means that "critical decisions are constantly being made" (p. 14). Certainly, several philosophical components must be considered when applying Giorgi's method in research.

### *Key considerations when following Giorgi's method*

When applying a scientific research method that is based on Husserl's descriptive thought, certain philosophical criteria must be preserved. In particular, two critical philosophical elements that need to be applied are 'phenomenological attitude' and 'free imaginative variation'

(Giorgi, 2008b, 2009, 2012; Giorgi et al., 2017). At the same time, other scientific criteria are added so that the process is not only phenomenological but also suitable for social research (Giorgi, 2008b). This scientific component means adding “some sense of the discipline being practised” (Giorgi, 2008b, p. 2). As such, within the context of phenomenological attitude, a disciplinary attitude must also be assumed by a researcher when analysing data (Giorgi, 1985a, 2008b).

Phenomenological attitude refers to Husserl's ‘phenomenological reduction’ or ‘epoché’, which is also called ‘bracketing’ (Giorgi, 2008b; Giorgi et al., 2017; Husserl, 1970, 1982). This attitude represents a particular stance or a perspective whereby relevant data becomes apparent in the process of data analysis and through which the results can be then understood (Giorgi, 2008b). Hereafter, both the phenomenological and the disciplinary attitudes will be referred to as perspectives.

In order to achieve the phenomenological perspective, a researcher must abandon prior knowledge and beliefs about the studied phenomena and become open-minded and sensitive to emerging themes that may otherwise be taken for granted or overlooked. In other words, the natural everyday life perspective must be bracketed, which requires suspending or putting aside any judgment or presupposition regarding the external world and its empirical reality (Giorgi, 2008b; Giorgi et al., 2017; Husserl, 1931). In this sense, “the objects that emerge within the description are taken to be phenomena...that present themselves to the consciousness of the experiencer, but the notion that such objects really exist in the way that they present themselves is not acknowledged” (Giorgi et al., 2017, p. 186). This perspective is particularly important “so that full attention can be given to the instance of the phenomenon that is currently appearing to his

or her consciousness” (Giorgi, 2008b, p. 3). It is acknowledged that suspending value judgment is always a challenge in practice because researchers, as all human beings, cannot abandon all their thoughts and emotions (L. Finlay, 2009).

The phenomenological perspective can be accomplished by defining a researcher's assumptions about the phenomena being studied and reflecting on these assumptions and potential predispositions before data analysis begins (Giorgi, 2008b). These reflections may require some time so that in-depth consideration of even deeply embedded assumptions can take place. It has been identified that even this might not guarantee that no biases appear throughout the analysis, and thus it has been suggested that a researcher must continuously reflect on and recognise potential biases surfacing for the full course of analysis (Giorgi, 2008b).

Here, it must be noted that a reflective journal was used throughout this research. While the fact that the researcher is a qualified social care worker practising in services for disabled people brought many benefits to this research, it also presented challenges in terms of potential biases. The reflective journal was used to “map [the] growing and changing understanding of the researcher’s role” (Ortlipp, 2008, p. 703). The first entries that were acknowledged in the journal were the researcher’s values embedded in the social model of disability, such as:

If you are neutral in situations of injustice, you have chosen the side of the oppressor – Desmond Tutu (Extract from the reflective journal, p. 1).

While some values are essential in promoting the voice of disabled people, there are related biases that such values can carry. Thus, as the research evolved, these biases became apparent through the use of the

journal. By continuously reflecting on the entries recorded in the journal, the researcher was able to distinguish between the values essential in representing a social model of disability by linking it to the social model literature and biases that arose from such values. During the analysis process, the journal ensured reflexivity by examining “personal assumptions and goals”, which helped to clarify “individual belief systems and subjectivities” (Russel & Kelly, 2002, p. 2). In this regard, the values and experiences of the researcher were consciously acknowledged, and a timeline of events was noted. This served as a tool for an audit trail (Smith, 1999). Moreover, the journal was used to record the initial thoughts after each interview by using keywords such as the participant was ‘nervous’, ‘hesitant’, ‘anxious’, ‘unsure’, which helped the researcher to revisit the interviews more authentically when analysing.

Thus, before conducting the analysis, the researcher’s preconceptions about the phenomenon of ‘risk in disability services’, such as ‘a risk-averse culture in disability services’ (Extract from the reflective journal, p. 3) or ‘all service users want to be risk-takers’ (Extract from the reflective journal, p. 3) were identified. It was accepted that these biases exist and that, indeed, they are predispositions that must be put aside so that the data can be examined with an open-minded approach. Finally, to fully realise the required phenomenological perspective, any new assumptions that emerged throughout the analysis process (Giorgi, 2008b) were recorded in the reflective journal. In this way, potential arising biases could be pinpointed and bracketed. For example, after analysing some interviews, the researcher had begun to perceive social care managers as ‘risk-taking preventers’ services’ (Extract from the reflective journal, p. 7) and social care workers as ‘risk-taking facilitators’ services’ (Extract from the reflective journal, p. 7). These and other assumptions were recognised

as partiality that had to be put to one side, and ultimately, the findings proved that some of these assumptions were unfounded.

While the phenomenological perspective ensured that the process stayed faithful to Husserl's philosophical underpinning, a disciplinary perspective brought the method within the disciplinary field. In this realm, as well as the phenomenological perspective, the researcher adopted a social care perspective to analyse risk as manifested in a social care context. These combined phenomenological and social care perspectives entailed abandoning any predisposed knowledge or perceptions regarding the phenomenon under study - 'risk in disability services' but preserving the knowledge of the studied field - 'social care disability services'. As such, the researcher retained social care awareness, including social care principles, policies, legislation, and codes of practice, so that the data with rich social care meaning could be found but remained open to different descriptions, understanding, and perceptions of these elements by the participants. It is argued that while a researcher with the knowledge of the social care discipline can distinguish between data that is pertinent to the social care field, a researcher without an appropriate disciplinary background would not have that "sensitivity" (Giorgi, 2008b, p. 2). Finally, the combined phenomenological and social care perspective must also include "special sensitivity to the phenomenon being researched" (Giorgi, 2012, p. 5).

Within this study, it was the understanding of disability social care context that aided the discovery of the key themes, including the manner in which varying interpretations of duty of care determine approaches to risk-taking in practice. It found links between different phenomena, such as duty of care and risk, and determined that at one end are those who define duty of care in terms of protection and therefore strive to minimise



risk and at the other end are those who perceive duty of care as respecting service users' wishes and accordingly approach risk-taking as service users' right. Thus, while the phenomenological perspective ensured that the analysis was open to all possibilities (Husserl, 1973), the disciplinary attitude retained the focus of the analysis on 'risk in disability services' (Giorgi, 2008b). By virtue of the social care perspective, "the findings [are] loaded with the discipline's orientation" (Giorgi, 2008b, p. 5).

Another intrinsic philosophical element - 'free imaginative variation' (Giorgi, 2008b) has been described as "the heart of the method" (Giorgi, 2012, p. 6). It is a phenomenological technique that explicates how phenomena appear to human consciousnesses and experiences (Husserl, 1970). It is a technique developed with the understanding of phenomenology as a descriptive, qualitative science that cannot be:

based upon intuitions of concrete givens...cannot proceed in the same way as formal, exact, eidetic sciences...Nor does the phenomenological procedure involve induction because that would involve generalisation after encountering a certain number of concrete manifestations...For phenomenology, the essential characteristic has to be intuited (seen) and described. This "seeing" is aided by the use of free imaginative variation (Giorgi, 2009, p. 77).

Husserl sought to understand the world through conscious awareness and experiences and believed that phenomena and objects that can be experienced through consciousness are real and thus can be studied via descriptions of these experiences. In this sense, human experiences are sources of knowledge. However, the "concrete experiences" of research participants can be hugely "diversified" and thus challenging to convey to others (Giorgi et al., 2017, p. 278). The process of imaginative variation is

used to see past the concreteness of experiences and uncover the main points – the essences of the studied phenomenon (Eddles-Hirsch, 2015; Giorgi, 2008b, 2009; Giorgi et al., 2017; Wertz, 2010).

The technique of free imaginative variation searches for the key points - the essences of the experience by “systematically vari[ing] key dimensions of the concrete phenomenon in order to see what effect the variation has on how the phenomenon appears” (Giorgi et al., 2017, pp. 278-279). In this sense, some aspects of original descriptions are varied so that the essential meanings of the phenomenon become explicit, and various descriptions can be linked and possibly generalised (Giorgi et al., 2017). For instance, to utilise a simplified example, if a researcher supposes that wings are the essence of an aeroplane, then the researcher should imagine a plane without wings, which will confirm the essentiality of wings. A similar example may be imagining a chair without a seat (Giorgi, 2008a). Moreover, different participants may describe the same plane differently. One participant may say that the plane has wings, is blue, and looks like it is smiling, while another participant may say that the plane is long, light blue, and looks old. By varying these descriptions, the researcher can determine the essentials of the plane. However, straightforward objects such as planes or chairs are phenomena seldom studied in phenomenological research, and as such, the technique has been developed to articulate essences of more complex phenomena. Following is Giorgi’s example of the use of imaginative variation in psychology (Giorgi, 2012, p. 7).

**FIGURE 1 TRANSFORMATIONS OF DESCRIPTIONS USING IMAGINATIVE VARIATION**

The original	The car seemed like a giant boat. I had visions of it going
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description of a participant	out of control or of my crashing into another car. As I went on to the road, and in with traffic, I felt that my car was all over the road—that I took up all four lanes.
Giorgi's first application of imaginative variation	I can say with confidence that the learner experienced the car to be larger than it actually was while at the same time being aware that his perception of it may have been exaggerated. The car seemed to take up more space than it should; it was as though it dominated the road. The learner was also worried about his ability to control the car adequately. He imagined an extreme negative possibility that was correlated with his insecurity about controlling the car as needed.
Giorgi's first application of imaginative variation	In the process of acquiring mastery of driving a car, [the learner] is aware of distorted perceptions of the vehicle and the environment while simultaneously being aware that the distortions are distortions. He is also aware that his control of the vehicle is tenuous as he nevertheless continues to perform adequately.

(Giorgi, 2012, p. 7).

Here, Giorgi explains that it was essential to engage with the data from a phenomenological and a disciplinary, in this case, psychological, perspective (Giorgi, 2012). These perspectives enabled him to employ the process of imaginative variation while being open to new 'essential' learnings relevant to the discipline (Giorgi, 2012).

The effectiveness of the imaginative variation technique rests on the premise that as well as individuality, there is a commonality in how

phenomena are intuited, perceived, and experienced (Wertz, 2010). For instance, a dog can be referred to as 'a dog', because of its essential characteristics – the essences that are shared amongst individuals' intuitive consciousnesses of a dog (Wertz, 2010). Similarly to a dog, other phenomena possess some invariant features - essences, which together form an 'eidos'. The eidos of 'a dog', for example, consists of the essences, including its visual appearance, how it plays, barks, or eats (Husserl, 1973; Wertz, 2010). Because of this eidos, individuals can distinguish between dogs and other animals, or between animals and cars, or between sadness and happiness, or between love and hate. An essence is "without which an object of a particular kind cannot be thought...without which the object cannot be intuitively imagined as such. This general essence is the eidos, the idea in the platonic sense, but apprehended in its purity and free from all metaphysical interpretations" (Husserl, 1999, p. 293). And while "essence is intuitively grasped and immediately seen, its rigorous articulation is neither automatic, instantaneous, or easy" (Wertz, 2010, p. 287). The use of free imaginative variation makes the articulation of essences of new phenomena, which are often more complex than the essences of simple objects or animals, possible.

Husserl acknowledged that some essences are 'formal', such as numbers, and thus can be determined with exactitude through mathematics and logic (Wertz, 2010). In contrast, other 'morphological' essences cannot be mathematised because they are inexact, often vague, and only determinable through descriptions of perceptions and experiences. In order to find these essences and generalise them, free imaginative variation is required (Giorgi, 2008b, 2009, 2017; Giorgi et al., 2017; Husserl, 1973; Wertz, 2010). Although morphological essences can be generalised, they can also change over time (Giorgi, 2009), which can be

seen in the changing concept of 'risk in disability services in Ireland', which was different in the past and can change in future.

Although some empiricists contest the possibility of generalising from non-statistical or small sample studies (Paley, 2017), in phenomenological research, generalisation is achieved through eidetic intuition, which requires rich data and the use of imaginative variation. This method does not require numerical procedures or large samples (Giorgi, 2008a, 2009, 2017). As long as all phenomenological methodological procedures are followed, the findings of a phenomenological study can be generalised (Giorgi, 2008b, 2009, 2017), although the level of generality may not be the same with all phenomena (Wertz, 2010). This, however, is not due to the vagueness of the phenomenological method but due to the vagueness of the phenomena being investigated. Phenomenological research methods tend to study phenomena undeterminable through methods of the natural sciences and empirical enquiries, and thus, produces findings as precise as the phenomenon permits.

### *Giorgi's analytical steps*

This study adhered to the following steps:

1. First, the full transcript is read in order to get "a sense of the whole".
2. While within the phenomenological and the professional; attitude, the transcript is then reread, and the text is marked when "a transition in meaning" is detected. The text is broken down, marked, and bracketed, creating "meaning units".

3. The meaning units are then transformed so that the “value of what the subject said is made explicit for the phenomenon being studied”. The method of free imaginative variation is used to achieve this step.
4. Meaning units are then reviewed and still using the free imaginative variation, “an essential structure of the experience is written”.
5. “The essential structure is then used to help clarify and interpret the raw data of the research”.

(Giorgi, 2012, pp. 5-6).

Thus, following Giorgi’s scientific steps (Giorgi, 2009, 2012; Giorgi et al., 2017), descriptions of the phenomenon ‘risk in disability services’ were obtained via interviews and vignettes. Data were transcribed verbatim and entered into NVivo software. There is no prescribed path through NVivo, and Giorgi’s method guided the full process, and his steps determined how the software was used to code data, for what purposes, and to which structure.

All transcripts were read to get the sense of the whole (Giorgi, 2009, 2012; Giorgi et al., 2017), and the phenomenological scientific and disciplinary perspectives were then assumed (Giorgi, 2008b; Giorgi et al., 2017). Within this perspective, and with a particular sensitivity towards ‘risk in disability services’, the transcripts were reread, and meanings around how risk was perceived and responded to were determined, which led to the separating of the texts into smaller parts called ‘meaning units’ (Giorgi, 2012; Giorgi et al., 2017). While focusing on the phenomenon of risk in disability services, the researcher divided the transcribed texts

where a transition in meaning was detected. As this took place within NVivo, the meaning units were determined by separating the text into 'nodes', while each node represented one meaning unit. To illustrate, these are examples of delineating a meaning unit from an interview:

Honestly, it's all about insurance and covering the organisation's back. So, I don't necessarily think that the risk assessments are always there to protect the person as opposed to protecting the organisations against being sued (Jane, Manager).

Following Giorgi's recommendations, all descriptions in the meaning units were changed into the third-person language (Giorgi, 2009, 2012; Giorgi et al., 2017). This made the distinction between the researcher and the experiencer explicit:

A social care manager, Jane, stated that risk related policies and risk assessments in disability services are all about insurance and covering the organisation's back. Jane noted that she does not think that the risk assessments are always there to protect the person as opposed to protecting the organisations against being sued.

Next, the identified meanings were transformed by applying the process of 'free imaginative variation' (Giorgi et al., 2017; Husserl, 1982) (see Figure 1 and Figure 2). Some meaning units required less transforming than others before the essential value of what was being said by the participant was found, which depended on how clear or vague the essential point of the meaning unit was. Furthermore, some meaning units proved to be irrelevant to the phenomenon during the process of imaginative variation. This step required the most time as the data was

very vibrant and rich in various meanings, which had to be thoroughly understood before proceeding to the next step.



**FIGURE 2 TRANSFORMATIONS OF DESCRIPTIONS USING IMAGINATIVE VARIATION**

<p><b>Meaning unit discriminated from Kaila’s interview</b></p>	<p>It is a difficult one because she is a part of a service, she does have a disability, but there is a fine line between balancing your disability with independent living. And none of us really have an autonomous life, where we are not dependent on the other. And she is dependent on care support staff that have to follow policies and procedures, and one of those would be risk associated</p>
<p><b>Meaning unit changed into the third person language</b></p>	<p>After reading the vignettes, a social care worker, Kaila, stated that Vignette 1 is a difficult one because Bernie has a disability, but, Kaila explained, there is a fine line between balancing disability with independent living. Kaila expressed that she believes that none of us really have an autonomous life, where we are not dependent on the other. Kaila then stated that Bernie is dependent on social care staff that have to follow policies and procedures, and one of those would be risk associated.</p>

<p><b>First transformation using imaginative variation</b></p>	<p>Kaila found Vignette 1 difficult because she felt there is a fine line between balancing disability with independent living. Kaila believed that none of us has an autonomous life, where we are not dependent on the other. Kaila then stated that Bernie is dependent on social care staff that have to follow policies and procedures, and one of those would be risk associated.</p>
<p><b>Second transformation using imaginative variation</b></p>	<p>Kaila felt that it was challenging to balance restrictions related to a disability with independent living. Kaila stated that no one is autonomous and that Bernie is dependent on staff who must follow policies and procedures, including those risk associated.</p>

<p><b>Meaning unit discriminated from Lorna's interview</b></p>	<p>One end is the risk, and one end is the choice, and you are constantly somewhere in the balance. And in every situation, there is no one fit all prescription, you have to decide in each situation on which side you're closer to (Lorna, SCW).</p>
<p><b>Meaning unit changed into the third person language</b></p>	<p>A social care worker Lorna stated that in practice, on the one end is the risk, and on the other end, it is the choice, and she must constantly search for the balance. She stated that in every situation, there is no one fit all prescription, and she must decide in each situation on which side she is.</p>
<p><b>First</b></p>	<p>Lorna felt that she must continuously search for</p>

<b>transformation using imaginative variation</b>	the balance between risk and choice. She stated that there is no prescribed way to approach risk in practice, and every situation must be approached individually, and she must decide in each situation.
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**FIGURE 3 RAISING A MEANING UNIT TO THE GENERALISED/ESSENTIAL STRUCTURE TO CAPTURE THE SOCIAL CARE IMPLICATIONS OF RISK**

Note that this is merely a sample and that considerably more meaning units had been transformed before the essential structure was generalised

<b>The final transformations of the meaning unit using imaginative variation</b> <b>Kaila</b>	Kaila felt that it was challenging to balance restrictions related to a disability with independent living. Kaila stated that no one is autonomous and that Bernie is dependent on staff who must follow policies and procedures, including those risk associated.
<b>The final transformations of the meaning unit using imaginative variation</b> <b>Lorna</b>	Lorna felt that she must continuously search for the balance between risk and choice. She stated that there is no prescribed way to approach risk in practice, and every situation must be approached individually, and she must decide in each situation.
<b>The essential structure derived from the meaning unit raised to a</b>	There is controversy, a lack of clarity and understanding around

<p><b>generalised level capturing the social care implications of risk</b></p>	<p>how to manage competing demands such as duty of care, safety, independence and the right to take risks and make choices.</p>
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Once all meaning units were transformed, and the relationships between different meaning units became readily apparent, they could be synthesised. As such, the meaning units were reduced to capture the essential structure, which could be raised to a generalised level (see Figure 3). In this manner, the essential meanings were synthesised into themes so that the essences surrounding risk in disability services were revealed. This final step found the general structure – the essential characteristics of the phenomenon (Giorgi, 2009). After the second step of the analysis, there were one thousand and six hundred meaning units, which have been analysed and synthesised to four essential structures through this systematic process of analysis. The essential themes of risk in disability services are:

- 1) A perception that disabled people are especially vulnerable and should take fewer risks than non-disabled people, which was most often expressed through the notion that the same activity is riskier if a person is disabled.
- 2) A lack of clarity and understanding around how to manage competing demands such as duty of care, safety, independence and the right to take risks and make choices.
- 3) Fear of potential liability resulting in services becoming preoccupied with the management of risk and risk assessments, which imposes a bureaucratic burden as staff and services seek to cover their backs.

- 4) The subjective nature of risk assessment and the management of risk that was influenced by factors including conflicting views amongst social care workers and managers, competing demands, fear of liability, and by the perception that service users are particularly vulnerable and therefore need more protection.

## Chapter Four: Findings

### Introduction

This chapter details how different perceptions around the manner in which risk should be managed can influence the quality of social care provision. It is divided into five sections and presents findings from interviews with ten service users, five social care workers and five social care managers. The first four sections detail the central findings of this study derived from all twenty interviews, while the fifth section is dedicated to the findings from the interviews with disabled people solely. This approach was included to support the voice of service users. Four main themes identified were:

1. Excessive Vulnerability

A perception that people with disabilities are especially vulnerable and should take fewer risks than non-disabled people, which was most often expressed through the notion that the same activity is riskier if a person is disabled.

2. Balancing Competing Demands

A lack of clarity and understanding around how to manage competing demands such as duty of care, safety, independence and the right to take risks and make choices.

3. Fear of Potential Liability

This fear is resulting in services becoming preoccupied with the management of risk and risk assessments, which imposes a bureaucratic burden as staff and services seek to cover their backs.

4. The subjective nature of risk assessment and the management of risk

This was influenced by factors including conflicting views amongst social care workers and managers, competing demands, fear of liability, and by the perception that service users are particularly vulnerable and therefore need more protection.

*Notes on style and redactions*

All interviewees were allocated pseudonyms, and the names of the organisations were omitted to ensure the anonymity of participants.

SCW is short for a social care worker.

SU is short for a service user.

Staff refers to both social care workers and managers.

LP represents a long pause in an interview.

... indicates that words or phrases have been removed to facilitate the flow of reporting, but without changing the meaning of what was said.

Explanations in [ ] were added to clarify for the reader, e.g. "they [service users]".

## Perceptions of disabled people

If managers and social care workers perceive risk as largely about service users protection and as something that needs to be managed rigidly, then it is unsurprising that service users view it as a natural aspect of their lives. Amongst service users, being able to engage in risky activities symbolises a right to independence, but also, it represents a worry in the sense that it is something unknown. In particular, for individuals that have been using services since the medicalised era, choice is mostly unknown because they did not have the freedom to make choices in the past. In contrast, for people who have acquired disabilities more recently, risk is something of an unknown due to new emerging risks that come with their disabilities.

The general sense from the interviews with service users was that organisations are delivering services that are considerably more empowering than the services operating some decades ago. In saying that, it is also clear that service users still feel the necessity to fight for their right to make choices, especially those involving risk. There was a consensus that service users accept this struggle as a part of their life and as something inherent to engaging with disability services. Rather than viewing the inability to make some risky choices in a negative light, service users overall viewed the improved independence from engaging in services in a positive light.

Of the ten service users interviewed, four have used some form of services all of their lives as they described themselves as born with disabilities, while six acquired their disabilities during their lives. There were significant differences in the confidence levels around risk-taking



between these two groups. The interviewees who had acquired disability presented with considerably more confidence and experience around risk-taking and demonstrated less tolerance towards service intervention in their choices around risk. In contrast, the other group, including Brenda, Celeste, Delia, and Ivan, demonstrated uncertainty and vulnerability in the area<sup>16</sup> and doubted their ability to make decisions around risk. They felt that social care workers, managers, but mainly clinical professionals are more competent in this field. Long-term Service Users outlined that they require help in decisions around risk, although they reported that they have “become a bit more confident” (Celeste, SU).

### *Long-term Service Users’ perceptions of risk*

In general, Long-term Service Users associated risk with their impaired physical movement. For Celeste and Delia, risk meant falling, crossing a road, or sustaining an injury. Correspondingly, Brenda talked about the risk of falls as well as the risk of fire and stated that she would be afraid of being “attacked” or robbed, and although it never happened to her, it is something that she found worrying. Ivan viewed being alone in his house as a risk.

Overall, Brenda, Celeste, and Delia felt positive about the increased independence in decision-making over previous models of care they had experienced and reported that their right to make choices around risk-taking is respected. Although Ivan also confirmed that services have

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<sup>16</sup> In this section, for the practicality of distinguishing between these two groups, service users who have utilised services since their childhood will be referred to as ‘Long-term Service Users’ (Brenda, Celeste, Delia, Ivan), while the other group will be identified as ‘Clients’ (Aaron, Edward, Frank, George, Henry, June). When referring to all ten, the standard term service users will apply.

improved throughout the last few decades, he noted that there are still occasional situations when staff can be too domineering. On the whole, it was clear that Long-term Service Users' perceptions of risk were influenced by their unpleasant experiences from institutional services they had received in the past. Celeste, for instance, referred to "the past" on several occasions when discussing the right to choose and recounted that decisions were made on her behalf and that: "I had to fight for my right to do what I wanted to do" The other Long-term Service Users also mentioned similar recollections when talking about their right to make decisions around risk. It was evident that their positive evaluation of the current state of affairs was affected by comparing to the past, which they described solely in negative terms:

The nuns were very hard. They weren't nice (Brenda, SU).

They were very conservative people. In other words, they, you know; 'you can't do this', whatever the concern might be, and 'you can't do that, it might be dangerous' (Celeste, SU).

Oh my god, the institutions, I've lived in them all my life...and I can tell you I didn't like it (Delia, SU).

I had a rough childhood in regards to places where I stayed, and people were awful mean to me in these services (Ivan, SU).

Thus, while Long-term Service Users described the prospect of participation in activities of their choosing as improved, on several occasions, they illustrated, often implicitly, recent incidents when services restricted their risk-taking. Though Long-term Service Users often emphasised their satisfaction about the right to make independent choices, it was apparent that they considered some level of interference as the standard and that service recommendations come before their choice.

Celeste stated that the staff and other professionals “would know more”, and that is why they would guide her when making decisions around risk. She asserted, however, that: “They can advise me, but it is also my own decision”. Similarly, Delia explained that she is inclined to follow the advice but does not like being “told what to do”. Brenda agreed and declared that she “would do as they say” and highlighted that, in her view, the service would not permit her to engage in anything that involves high risk, although, she did not regard this as a problem and stated that: “they know what they’re talking about, they’ve been trained to know what I should and should not do”.

Celeste explained, for example, that because of “the risk at the moment”, which is getting cellulitis in her skin, she is not able to go out as much as she would like to. Celeste was advised “not to stay up too long in the chair”, and although she finds this challenging as she does not like to spend too much time in her bed, she complies with the service’s recommendations. Delia recounted a similar, but in a way contrasting incident, where staff advised her not to spend too much time in her bed because of Delia’s “high risk of depression”. Delia felt that by advising this, the service was intrusive, but she also complied with the recommendations.

As such, the general sense from the interviews was that the advice or opinion of a professional means something more instructive than just guidance or a recommendation. Long-term Service Users stressed that they feel uneasy when they make decisions that may contradict the advice of the staff, the management or another, mostly clinical professional. Notably, here, Celeste explained why she thought that Bernie should not be supported in her wish to be left alone in the shower (Vignette 2):

Sorry. No. The reason being, no. Because obviously, the occupational therapist's input, those risk assessments they put those recommendations in place for a reason.

### *Social care workers' anxiety, regulatory compliance, and defensive practice*

It is not difficult to appreciate that if managers have a fear of liability, the social care workers will experience uncertainty and anxiety when assisting service users in risk-taking. Social care workers were afraid of supporting a service user with a decision that might be perceived in a negative light, not completing their paperwork satisfactorily when supporting a service user with a choice that involved risk, being held accountable, or even losing their job. Additionally, social care workers feared penalisation by management for making decisions that managers do not approve of or for supporting service users in choices that involve unacceptable risks from the manager's perspective. Social care workers' anxiety was most often articulated in the sense of insecurity around making risk-related decisions, and thus there was frequently avoidance of situations involving risk.

Ashling, for instance, outlined how she would feel about working with Bernie if she decided to have her glass of wine without the thickening powder (Vignette 3):

Oh god, it's like that euthanasia injection, I suppose like, Jesus...like in a way, I wouldn't want to be that staff that does that because if on my watch that happens then.

Similarly, Rose highlighted that she would be afraid of "an inquest" if "something happened". Anna, too spoke about the fear of losing her job

and the strain that she feels when trying to achieve a balance between following guidelines in order to avoid being penalised and respecting the personal wishes of service users.

While all social care workers expressed a significant level of anxiety, even fear, when supporting service users in risk-taking, for Kaila, the concern was present in most of her descriptions throughout the interview. Kaila reported being overly concerned if a service user chose to participate in risk-taking while she was on duty, as she believed that "the law" does not support service users in "having a great time"; it supports them in "being safe". Kaila maintained that: "it is that sort of mentality...no one is going to hurt themselves on my watch". She highlighted that if Bernie chose to have a drink without the thickening powder (Vignette 3), it would be acceptable only if Bernie did not require physical assistance with it. The physical act of "hand[ing] the glass" without the thickening powder was a problem for Kaila, who argued that:

If Bernie is manoeuvring around herself and if she is reaching out for a glass of wine and she doesn't want the thickener in it, then Bernie can do whatever Bernie wants in Bernie's time. If there is a staff member that'd give Bernie a glass of wine (LP) and they don't thicken it, then that's our responsibility.

Kaila explained why she chooses to be, what she described as "overly-cautious" when supporting service users:

It's all about covering your ass. It's all about protecting, protecting, protecting. That's all we do all day long. And that's being facilitated by our legislation and by our laws...Choice is a buzz word, it's a nice word, but when I am working with a service user...if they make a

choice are the repercussions of that choice on me? That's what we are thinking when we are working.

When Kaila was asked how she would respond if Bernie insisted, she replied in an authoritative way, stating that:

Bernie can persist all she likes...If I can't give you a glass of wine, I can't give it to you because I won't have that on my conscience.

There was a strong consensus amongst social care workers that the emphasis on paperwork, predominantly on risk assessments, is disproportionate. Ashling stressed that "it's all about paperwork to the detriment of getting out and living life". She stated that it consumes "seventy-five per cent" of her working time. Being the only social care worker who had the experience of performing risk assessments, she recalled that she "never enjoyed" the task, explaining that:

You'd have to have a very thorough risk assessment done on any kind of a thing that could possibly occur and make sure you had a good management plan in place to negate like any risk happening.

All five social care workers found risk assessments in their workplace impractical. Lorna highlighted that the practicality of a risk assessment is "diminished if it becomes a paperwork exercise", which she maintains is what happens in her service. Anna explained why she thought risk assessments were not useful:

Because it is just on paper, it is something that you would do anyway. You're not just going to take a risk without already having thought it through.

All social care workers pointed out that although policies and procedures around risk-taking are vague and much is left to interpretation; there is a clear emphasis on ensuring that the organisation, or in some

cases the management, does not look bad in the public eye. Lorna observed that:

The service is trying to cover its own ass. So if something does go wrong, they are trying to cover themselves. But does it mean that they are bubble-wrapping the client? Sometimes, yes.

Along these lines, Ashling talked about how organisations and managers approach risk-taking, explaining that:

You don't want negative publicity you don't want anything bad to happen on your watch... It's going to affect your reputation if it's really bad...Where I worked previously like they didn't want any negative publicity, so everything had to be risk-assessed down to the last.

Social care workers reported that as a result of these attempts by organisations to cover every possible angle, managers feel under pressure to implement robust risk preventive measures with a lengthy paper-trail of risk assessments. In turn, social care workers felt that the burden is regularly transferred onto them, as they must manage risks in accordance with the outcomes of risk assessments. Kaila put it bluntly and observed that risk assessments "guide you to what service will cover you to do".

In this culture of anxiety and documentation, to both appear compliant and to eradicate the risk of negative publicity, staff felt that following protocols and risk assessments in a very structured way could protect them if something went wrong. As such, social care workers often followed risk assessments and care plans in a very regimental manner. This frequently extended to documenting conversations about risks with service users so as to fully inform them, but also to have a proper trail to protect themselves. For instance, when discussing Vignette 3, Rose stated:

Maybe we'd have to do up something where she signs it: 'Like look, this is the way I want my wine, and I don't care about the risks.' If she was fully aware of them, I would document that I talked to her...If she didn't want to listen to it at the end of the day, we've looked into it. And that could be shown god forbid if anything did happen.

Similarly, Kaila noted that:

If I have covered all my bases. If I have put everything in place that I could possibly put in place. If I have my documentation done to back me up and support what I'm saying, then I think there should be an element of cover.

Thus, while paperwork provided a certain sense of security, it also added to the ambiguity and anxiety around risk-taking. Both social care workers and managers expressed concerns over the possibility of failing to adequately perform the vast amount of bureaucratic tasks required when supporting service users in activities involving risk.

### *Clients' perceptions of risk in disability services*

Similarly to Long-term Service Users, Clients also associated risk with their physical disadvantages. Edward highlighted that his imbalance represents a risk to him, while George and Henry described pressure sores as high risk. Frank stated that risk is:

The worry of coping, of getting the jobs done, jobs that all able-bodied people take for granted...If you're not fully satisfied or competent with the person that's looking after ya, that would be a risk, would be a worry, it could bring on mental stress.



Overall, Clients were happy with services respecting their independence in risk-taking, although they recounted incidents when they had to be firm to establish an autonomous relationship with the service. Indeed, a point echoed by Frank, George, Henry and June was that their choices around risk are respected as a direct result of their ability to advocate for their independence. Frank affirmed that he “pit[ies] anybody that is not able to speak up for themselves or be able to complain”, which was a point emphasised by several other service users. Edward stressed that one of his priorities is to “hold on to [his] independence”, but noted that the service could interfere with his decisions at times:

I know it’s goodwill. It’s just that, how will I say this, I could be a bit stubborn at times. But I know at the end of the day, they are looking out for me.

Perhaps the most significant difference between Long-term Service Users and Clients was that Clients were able to distinctly identify services’ potential attempts to regulate their choices as a result of risk-averse practice and had the confidence to question these attempts. Aaron recalled situations when he was advised to implement safety measures in the form of medicating as a result of potential health risks, but chose not to follow these recommendations and explained that in general, he would hear out the advice of a social care worker, a manager, or another professional, but it would depend on how it was “delivered”:

I would weigh up the pros and cons of being a nasty person and tell the person to go to hell (Laugh), or I might actually follow up the advice.

Along these lines, Henry also recalled an incident that emerged when he asked a nurse to apply a convener so that he could go out to a pub, but “she

wouldn't do it". The nurse advised him that he should not go out socialising as "it was too risky". Henry explained that he confronted the nurse immediately and stated that "it is my choice what I want to do".

In a similar fashion, Frank pointed out that disability services "try to create the home environment, but you are still bound by the institution's rules", stating that:

They have the carrot in one hand and the stick in the other. The carrot approach and stick approach. So they kinda find balance and act between one or the other, you know.

Frank spoke about his experience of a withdrawal of service when he wanted to implement some of his ideas on how care should be provided to him. He had constructed helping aids, such as a hoisting system, that he wished to use for his transfers in and out of a wheelchair but was told this was not possible as it was too risky. As such, Frank could only use the hoisting system when staff were not present. Equally, a urinal system that Frank constructed was deemed too risky in terms of infection and could not be used when the staff were in his house. Frank explained that because of his lack of compliance with the organisation's risk management policies and his persistent wish to direct his own care, the organisation withdrew the service from him. Frank declared that this had caused him a vast amount of hardship, stating with a despondent tone of voice that:

When you get to a certain degree of disability...I was a ward of the state. They withdrew that responsibility. They're getting state funding to look after me. You can't just abandon a person made stray.

### *Ongoing social oppression*

From the interviews with disabled people it was clear that social oppression continues to be a genuine issue in social care. On several occasions, both service users and clients highlighted incidents of struggle to have their rights heard and respected. While some were more confident and better equipped to fight and at times partially overcome these struggles, others were more passive and 'grateful' for the positive changes in services that had occurred over the past few decades. Not only does this show how deep the roots of social oppression are, but it also shows that many disabled people have accepted that it is an inevitable part of their life. Risk can be seen as yet another mechanism through which control is exerted over disabled people while their rights and choices remain secondary. These issues are unpacked and more fully contextualised in the following four themes.

## Theme one: Excessive Vulnerability

Disabled people are often rightly perceived as vulnerable. However, sometimes their vulnerability can be exaggerated, especially if staff perceptions of disability are linked to their felt obligation to keep service users safe. In part, this is no doubt related to a culture that has still not entirely abandoned some stigmatising aspects of biomedical models, which often linked disability with fragility, incapability, or even illness. This ascribed vulnerability has at times led to the idea that disabled people should take fewer risks than non-disabled people, which is most often rationalised by the notion that the same activity is riskier if a person is disabled. Within this study, there was an evident emphasis on protecting and safeguarding service users. Social care workers and managers felt obligated to guide service users in decisions around risk and viewed a failure to prevent ill consequences of a service user's choices as a malfunction of social care. As such, they perceived the ability to manage risk as a determinant of service quality. By and large, managing risk meant minimising or eradicating risk, and services that did not perform this task competently faced scrutiny from HIQA. However, protecting service users by trying to eliminate all risk appeared very demanding, as it was evident that a large portion of activities was deemed as risky, partly because of the perceived vulnerability of service users.

In many ways, in spite of disjointed perceptions of risk, both managers and social care workers agreed that disabled people are more susceptible to bad outcomes than people that have no disabilities. Although a majority of service users also subscribed to this view to some degree, perhaps the most obvious difference was that service users did not

see this as a valid reason for services to intervene in their decisions. Several managers and social care workers, however, reported that because of service users' vulnerability, some level of service intervention was justified. In addition, while service users defined their vulnerability predominantly in the realm of their physical frailty, such as being more vulnerable to falls as a result of impaired mobility, managers and social care workers often transposed service users' vulnerability across various aspects of service users' lives such as being more vulnerable to financial abuse for instance. In some instances, staff assigned this sense of extended vulnerability to service users' lack of experience and competence to assess risks adequately, which was, staff felt, particularly pronounced in the case of those service users who had lived in institutions long-term.

### *Managers and social care workers' perceptions of service users' vulnerability*

All managers and social care workers expressed to some extent the view that disabled people face a significant amount of risks in their lives due to their disability and thus encounter more risks than non-disabled people. For instance, Lorna (SCW) spoke about some of the most concerning risks for service users:

So obviously, because of their disability, there is like (LP) different equipment that needs to be used while they're transferring and mobilising...some connected to medication...and then psychological risks, say connected to attachments, boundaries, feeling of isolation and loneliness.

A mutual perception amongst social care workers and managers,

shaping the view that disabled people are more vulnerable than others, was that service users' health status must be improved or maintained. In general, social care workers and managers viewed potential ill consequences to the health of service users' resulting from their personal choices as the most dreaded risk. Rose (SCW) and Olivia (Manager), for instance, defined risk as a possibility of "an injury", while Oscar (Manager) noted that:

Something very risky for some of our service users could be going out on a night out and consuming alcohol...because they could have further complications as a result of their varying disabilities, and alcohol may impose or affect their health.

In most cases, managers and social care workers perceived securing good health outcomes and thus avoiding health risks as essential to quality services and service users happiness. They tended to conflate health and happiness and aligned service users clinical needs to their best interest. Although staff spoke about recognising service users' right to make independent choices that may involve health risks when using examples from practice, they consistently described the eradication of risks to health as a key characteristic of good service. Oscar, for example, expressed concerns over the lack of clinical education and training for social care workers. In his view, there is a direct link between the ability to alleviate risks and clinical knowledge. Oscar explained that:

Something that I would consider to be very risky in service users' life is not having adequate clinical support in place for them. And possibly not having adequate clinical training in place for staff who are not medically trained. So say staff like ourselves, who are social care in the background that we would need...relevant information provided to us to ensure that we can...alleviate the risk of, for

example; we have somebody who has autonomic dysreflexia, so we can alleviate the risk.

Nevertheless, Oscar recognised how over-emphasising clinical health in disability services could become problematic in terms of providing social care that is holistic:

We try to ensure somebody's health, safety and wellbeing as opposed to what the person themselves may or may not want.

Another factor contributing to the perceived vulnerability of service users was a one size fits all definition of risk, which was often applied by both social care workers and managers. While Lorna (SCW) described it as "a probability of some adverse event happening", Ashling (SCW) defined it as "any kind of chance they [disabled people] might take as part of their daily lives to participate in activities that are out of the ordinary". It can be incredibly easy to label service users as vulnerable in a climate where everything outside of a routine represents a potential risk.

Another point raised by staff was that service users who cannot assess or understand risk are more vulnerable than others, and they tended to distinguish between two groups of service users: those utilising services all of their lives or long-term, and those receiving social care short-term. Most commonly, people who were seen as 'born with disabilities' versus people who were seen as their disability was acquired later in life. Several managers and social care workers believed that there is a relationship between this and service users' ability to assess risk. Tina (Manager) stressed that "service users who have been institutionalised have never been encouraged to understand what part they had to play in risk up to this point". As such, the majority of staff agreed that service

users who have utilised services all their lives might not understand risks as well as others:

I think people who were, have been brought up in institutions may not understand it [risk] as much because decisions were made for them throughout their lives (Jane, Manager).

There are variant degrees of decision...you make very basic choices every day between your clothes, makeup, getting in and out of your car. I can make those decisions every day. They are very small for me. But for someone else, who may have lived in an institution, they are massive decisions (Kaila, SCW).

People with physical disabilities that have been in residential care all their lives, I wouldn't say, perceive it [risk] the same way because they've always had their risk-managed for them. Whereas somebody that has just recently had an injury and has ended up in a wheelchair would be more aware of risks around them (Anna, SCW).

Thus, in many cases, staff emphasised that the institutionalisation of disabled people had led to service users not taking risks, which prevented them from developing the skills required to now manage day-to-day risks. This shielding of service users from risk shapes practice, partially because staff simply do not trust service users to make safe decisions. In some cases, staff felt that people who have physical disabilities lack the ability to assess the "physical component" of activities, which may lead to physical risks such as the risk of "falls" (Ashling, SCW). Others perceived service users' ability to estimate risks in general as dependent on the type of their disability:



I think it depends on what disability. I don't think every disability is the same; it's kinda broad (Rose, SCW).

It depends if they have like a brain injury or, you know, an impairment in that sense; they might be less likely to analyse the risk (Olivia, Manager).

In examining the perceived vulnerability of service users and their ability to assess risks, there was an association made between service users' ability to evaluate risk and their entitlement to make independent choices. For instance, Rose stated that service users should be involved in risk-related decisions only if they had "the capability of making choices". Out of ten staff, only Jane (Manager) felt that choice should be viewed separately from risk, as it is the person's right to make decisions irrespective of their approach to risk-taking. Participants were, however, often unable to identify how this ability to assess risk should be measured. In many cases, social care workers and managers noted that they would know from their wide-ranging experience based on the type of disability, medical history, or how the service user acted. In general, therefore, the proposed estimations of service users' competence to assess risk were subjective at best. When discussing the vignettes, Kaila (SCW), for example, suggested that she would be able to evaluate Bernie's ability to assess risk based on her experience with Bernie's type of disability:

Spina bifida obviously affects your bones, your joints, everything, and hydrocephalus, then is water on the brain. So not only is her physical-self affected, also her mental capacity is affected because, that's what, very simply put, that's what hydrocephalus is...and knowing, what I know, because we do support a service user with that, it means there is a slight delay in there, as the disability progresses.

A common indicator for many staff of service users' inability to assess risk was a willingness to engage in high-risk situations or lack of cautiousness. The possibility that a service user may have an adventurous or reckless personality and would purposely engage in high-risk activities or simply did not fully care about the consequences was not considered by staff.

### *Capacity*

In discussing service users' vulnerability and their ability to assess risks, capacity arose in seven out of ten interviews with social care workers and managers. While all staff reported that none of their service users lacked capacity, word frequency analysis highlighted that capacity was one of the most regularly used words. Yet, there was a general lack of clarity surrounding capacity and what it meant in disability services. Olivia (Manager) noted capacity is "a very grey area", while Tina (Manager) observed that it is a "vague" topic in disability services, as the guidelines are "very poor" and the proposed supports are still not in place.

Although the term was used regularly, it was apparent that the concept is ambiguous and that social care workers and managers felt equally uneasy about the lack of understanding of capacity and struggled with its application, especially in the management of risk in practice. While the term was left open to interpretation, more often than not the decision was entrusted to the gut feeling of the worker or manager. A manager, Olivia, for instance, described capacity as "being in the right frame of mind to be assessing different risks", and she stressed that when making a choice, service users must "have a level of capacity and a level of understanding of the different risk that's associated with it". Olivia

explained that this is important because a staff member may be viewed as "negligent" if supporting service users who lack capacity in making decisions that involve risks. However, Olivia stated that she could not "judge someone on their capacity" and she was not confident in how she should proceed if capacity became an issue with a service user. After some moments of hesitation, she noted that more than likely, it would be up to the social care worker on duty to assess each situation.

On the whole, social care workers generally felt that the responsibility for judging capacity should be with managers. Rose (SCW) noted, for instance, that management or a clinical professional would determine if a service user had capacity. Kaila (SCW) maintained that social care workers do not "know an awful lot about the legal ramifications" of risk decisions that they are supporting when working with disabled people and felt that this was a problem. She viewed capacity as the "ability to make a decision" and felt that a person's disability determines their capacity. Kaila stated that when deciding about risk, service users must consider several aspects, including their "capacity to be able to make a decision".

### *Service users' perceptions of their vulnerability*

Although a majority of service users reported feeling vulnerable, a sense of being overprotected or not being treated as an adult was emphasised significantly more often. Celeste, for instance, explained that she feels vulnerable "to some extent" but stated that "What happens to me happens to other people; if it happens to me, there is a big thing about it". Brenda also noted that:

Everybody has to take risks, but there are some people that think

that if we are disabled, 'oh, don't let her do that because she will get injured.' That's what they will say.

Similarly, George explained that services could be "very overprotective". While Edward noted that though he appreciates that staff want to protect him, he does not feel that he is being "treated like an adult" and asserted "I am forty years of age. I should know the risk between don't and do". On several occasions, Edward stressed the extent to which he feels overprotected:

They [the staff] could step on my toes any time; you know what I mean...You don't have a full life if you can't live independently, you'd be as well off six feet under.

When discussing their vulnerability, service users were mostly concerned with the risk of falls, the inability to move fast in an emergency, such as a fire, and other restrictions directly contingent on their physical disadvantages. Aaron explained that he feels more vulnerable since he acquired his disability and noted that people who are not disabled perceive risks differently, stating that:

Before my accident, I didn't think of anything being risky. I would do anything at all...See I'm on the wheels, but if I go over a slope, I am always concerned is the wheelchair going to turn over...I have to be careful.

In Edward's view, disabled people encounter more risks than people who do not have disabilities:

A lot more so because they are more vulnerable to falling. That is what I feel myself that I am just safer sitting in the wheelchair rather than standing.

Frank described his view as:

Naturally enough, you feel a lot more vulnerable...you would be more vulnerable now if you're letting people into your home, for example. People that'd be handling money...unless you are fully alert and other people know that there are safeguards in place and checks on your finances.

In contrast, Henry only felt vulnerable in crowds, while for some other service users, their vulnerability was related to their reliance on services. George, for example, felt that:

You would want to make sure you had your own full senses because you would be put lying on one side, and you would be left there (Laugh) if you weren't able to ask or look for what you want. So like you do rely on people...Of course, you would be more vulnerable.

Frank echoed this concern noting that:

In the initial stages when home help was assigned to me...it was a huge shock to the system...I went through an awful lot of people...I wasn't being difficult or anything, but I just found the level of care was deplorable.

Among the service users, only Celeste felt that disabled people lack the ability to assess the physical aspect of risks. This was in marked contrast to the general consensus that the ability to assess risks is in no way reduced due to physical disadvantages or time spent in institutional care. Indeed, Aaron pointed out that "if one has all mental faculties, there is no difference", while Frank and Edward expressed the view that disabled people can evaluate risk even better than many others, stating that:

When you have a physical disability, that when you lose some part in your anatomy or function that other parts of your brain are enhanced (Frank, SU).

They [disabled people] can say what's the limit...More so than someone who doesn't have a disability (Edward, SU).

## Theme two: Balancing competing demands

While most interviewees reported overall satisfaction with the way disability services are delivered, there was a general sense of tension when discussing the management of risk. Although it was evident that all interviewees perform or assist with risk-related decisions routinely, there were significant variations in how individuals viewed their role in this process. This was apparent amongst all three groups of interviewees, though confidence and extent of independence in inputting into risk decisions fluctuated considerably between individuals using services, social care workers and managers, who also differed around assessing and managing risk.

The inconsistencies in service users' confidence around risk-taking can in large part be attributed to a lack of experience with risk-taking and the influence of institutional care, as some had lived in residential settings for many years in the past. While such influences may help to explain the difficulties in managing risk for service users, perhaps the most significant challenge for staff was balancing competing demands such as duty of care, safety, independence, and the right to take risks and make choices. Not only were the demands on staff often in conflict with one another but policies surrounding them were also reported to be unclear, leaving concepts open to interpretation. It was a situation compounded by a lack of clarity in what is expected of social care workers, a lack of recognition of social care workers as professionals, and variation in perceptions of what risk and duty of care represent in disability services.

It was also apparent that managers faced similar dilemmas in fulfilling their obligations. Managers reported feeling under pressure to

implement policies that are in line with the Health Information and Quality Authority (HIQA) regulations while acting in line with service users' rights and also keeping both social care workers and service users safe. They highlighted that they are subject to regular inspections and scrutiny from the HIQA.

### *Duty of care*

While there were variations in how duty of care was described, the manner in which social care workers and managers perceived duty of care often determined how they approached risk. The perceptions of duty of care formed a continuum parallel to the spectrum of risk perceptions, which partially explained the discrepancies in risk approaches. At one end were staff who defined duty of care mostly in terms of protection and therefore strived to minimise risk. At the other end were staff who perceived duty of care as having a vital empowerment component, which includes respecting service users' wishes, and they thus approached risk-taking as a service users' right.

In this fashion, for example, Oscar (Manager), who perceived duty of care as "ensur[ing] that the person is safe", tended to apply a cautious approach to risk. Oscar pointed out that social care workers and managers frequently seek to "influence" service users' decisions around risk because they feel it is their duty of care to protect them. In contrast, Jane (Manager), who viewed duty of care as "supporting the person in their wishes", recognised the service users' right to make choices, and her approach to risk was evidently more liberal.

Amongst social care workers, Kaila and Anna described duty of care in terms of providing services that prevent risk. Anna stated that she could



not respect Bernie's choice in Vignette 2 as it would be against her "duty of care towards Bernie". In contrast, Lorna, who emphasised throughout the interview that it is the service users' right to be autonomous, perceived duty of care as something more complicated than merely preventing risk and defined it broadly as:

...not harming people at minimum, at a minimum...Imposing anything on anybody is harming because you are dehumanising the person.

### *Safety versus independence*

While service users often strived to exercise their right to make independent choices, staff, driven by their perceived duty to prevent risk, endeavoured to steer them to opt for safer alternatives. Here, the vagueness of policies could either facilitate this or lead to confusion, with Lorna (SCW) observing that:

The concept of best interest is sometimes contradicting the concept of self-determination, and policies would benefit by clarifying who is deciding on what's in a client's best interest, that it's the client themselves.

Social care workers and managers face very real challenges when they attempt to protect service users by preventing risks while also respecting their right to make free choices. Indeed, a powerful relationship between risk and choice presented throughout the interviews:

One end is the risk, and one end is the choice, and you are constantly somewhere in the balance. And in every situation, there

is no one fit all prescription, you have to decide in each situation on which side you're closer to (Lorna, SCW).

There is a fine line between balancing your disability with independent living. And none of us really have an autonomous life, where we are not dependent on the other. And she is dependent on care support staff that have to follow policies and procedures, and one of those would be risk associated (Kaila, SCW).

Choice is quite often compromised by risk. While we try to offer people a choice in terms of them living a life...some of us in our thought processes will try to alleviate any risk, so then, therefore, we may limit the choices that we might offer (Oscar, Manager).

In this rivalry between risk and choice, staff reported that safety continues to overrule autonomy, with one manager Jane, highlighting that moving away from "the medical model" in the last few decades "is improving things". Jane asserted, however, that risk-taking is still not supported adequately, and some choices continue to be limited as a result. As such, there was a common perception that service users can have their independence, but only if risk-free. The illogical nature of this governed independence was brought up by Lorna (SCW), Jane (Manager), and Olivia (Manager), who all observed that choices are frequently compromised by risk management policies and that this presented a particular issue. Lorna highlighted this, noting that:

If they [service users] are wrapped around safety, health and safety and risk assessments (LP), then I don't know. Sometimes in the policies, they forget about the choice.

Olivia (Manager) emphasised that "risk takes over in the majority of situations" and that there are things that some service users "would love to do...and just can't". She went on to note that:

We're kind of coming from an era where...there was no such a thing as person-centeredness and all that. So I think that still, and it's kinda sad to be saying that, still it's the risk that is taking priority over the person's choice of doing what they actually want to do.

Oscar held a similar view and explained that his position as a manager is complicated because while he believes that service users' choices should be respected, he has "the overall responsibility for the welfare and safety of the service users" and thus, as a consequence risky choices are limited in the service he manages. Oscar described the drive of services to avoid or prevent risk and explained it as an organisational response to the requirements set by risk management and safeguarding regulations. He acknowledged that there is an incongruence between his personal outlook and what he perceived to be his professional responsibility and stated that "as a person", he feels that the right to make choices around risks comes first, yet, "safety" determines his actions "as a manager".

Along these lines, Tina (Manager) felt that in disability services, some choices are deemed "inappropriate from a service provider's point of view" and that service users have "obligations to the service provider". In this sense, a choice is inappropriate if it involves a risk that cannot be managed within the risk assessment process. Accordingly, services distinguish between choices and risks that are and are not acceptable. Mary (Manager), for instance, felt that while it is ok for a service user to choose the type of beverage they would like to drink, the amount ought to be judged by a professional, most preferably a nurse. Moreover, if a

service user's health care plan outlined that the service user is at risk of dysphagia<sup>17</sup> and the use of a thickening powder was recommended, the service user would not be allowed to opt-out from having the powder in their drink.

Several social care workers also noted that although services have improved over recent decades in offering choices to service users, guidance around risk-taking remains vague, and therefore, risks are largely avoided through restricting choices. For example, Ashling stressed that there are still "very limited choices available" and that:

The service itself might come across as being, you know, very holistic and all the rest of it, but when it comes to like the clients and service users like I would think they are probably more risk-averse.

Rose confirmed that risk-taking is highly regulated and confined at times but with some improvements over the previous era. Lorna noted that a social care worker's ability to support service users in risk-taking could depend on the interaction between management, the family, and organisational policies. She outlined that management and health and safety policies often "overprotect" service users. Indeed, she noted that there are times when she feels that the service expects her to influence service users' choices and intervene in their decisions in the form of risk prevention.

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<sup>17</sup> Some people may develop dysphagia, and as a result, a speech and language therapist may recommend a diet that is modified; modifications can be related to fluids, foods, or both. Dysphagia is "a swallowing disorder characterised by difficulty in oral preparation for the swallow, or in moving material from the mouth to the stomach. This also includes problems in positioning food in the mouth" (The Irish Association of Speech and Language Therapists (IASLT) & Irish Nutrition and Dietetic Institute (INDI), 2009, p. 3).

In general, caution and hesitation around risk-taking were regularly noted amongst both managers and social care workers. While in some cases, they did not see the link between risk prevention and choice limitation, in other cases, they perceived barriers to risk-taking as a natural aspect of disability services. It was abundantly clear that the right to choose did not apply in situations that were perceived as high-risk. Here, services exercised power in determining which risks were acceptable, which was frequently obvious in the disempowering language used when talking about service users' choices around risk were:

...we may limit the choices that we might offer (Oscar, Manager).

...they [service users] will only be allowed to make risky choices if...  
(Ashling, SCW).

### *The right thing to say versus the safe thing to do*

The most obvious situations of uncertainty around how to balance competing demands in disability services emerged when discussing the vignettes. While all managers and social care workers initially stated in the interviews that their services respect the autonomy and independence of their service users when discussing the vignettes, each of them described several limitations surrounding service users' choices around risk. In many cases, interviewees shifted between two dimensions: 'what is the right thing to say' and 'what would happen in reality'.

Although social care workers and managers emphasised that their core ethos is to respect all the choices of services users when approached with discussing the vignettes, they quickly wavered and defaulted to a stance that some choices are just too risky to support. This dominated

considerations, and it was clear that policy emphasis on choice and independence was, in reality, limited to safe choices only.

Indeed, Mary, one of the managers who was initially very confident in describing their service as promoting independence, recounted numerous occasions when, in Mary's words, "bad choices", such as the ones Bernie was making, were not facilitated in her service. Her frustration about these so-called "bad choices" was so pronounced that disapproving non-verbal language was clearly perceptible when she discussed the vignettes. Mary recognised this incongruence, but nonetheless went on to say that:

I better not say what's in my head.

Well, maybe the service isn't able to provide Bernie with the level of support that she needs and that other areas need to be or other services need to be looked at.

When discussing Vignette 2, Mary explained that:

I mean, at the end of the day, it's a massive risk. I think, look at, I think that there would have to be a compromise...It would be very unsafe for Bernie.

Other managers (Tina and Oscar) also suggested that if risks cannot be managed, the service user may need to seek an alternative service. In contrast, managers Jane and Olivia maintained a rights-based approach throughout the interviews and vignettes. Nevertheless, they still felt that they would need to have rigid risk management processes in place and argued for the implementation of some safety measures.

Of the five social care workers, only one - Lorna demonstrated a consistent approach throughout the interview and the vignettes discussion. She maintained that the service users' right to make choices is essential and kept that as a core principle when discussing the vignettes. All four

other social care workers acknowledged the service users' right to independence but were unable to apply this in practice when it came to situations involving risk. For instance, Ashling, who on several occasions voiced dissatisfaction with what she called a "risk-averse" approach in disability services, changed her viewpoint and showed apprehension after reading the vignettes. She thought the risks in the scenarios were unacceptable and felt concerned over possible ill consequences. It was noted that if a service user attempted to engage in an activity deemed too risky, Ashling would also resort to service withdrawal (Vignette 2):

It might just be mandated that staff are either going to be there for the whole shower or...' you are not going to have any staff at all'.

This stance emerged regularly and can best be described as 'my way or the highway' when risks cannot be managed in line with the risk management policies, often because a service user does not wish to comply with the service's recommendations aimed at minimising risk.

In a similar fashion, while empowerment and a rights-based approach were advocated, risk prevention commonly dominated decision-making reality. This left staff feeling trapped between a rock and a hard place when trying to achieve a balance between following guidelines and respecting service users' independence.

### *Service users' conflicting perceptions of Bernie's risk-taking in the vignettes*

Amongst service users, the same divergence of opinion emerged between the interviews and discussion of the vignettes. While June maintained a rights-based approach throughout both, several other service users changed their descriptions when discussing the vignettes. As with

the staff, some service users shifted between 'the right thing to say' and 'the safe thing to do', while others' diverged between 'what should happen if they were in Bernie's situation' and 'what should happen if it were Bernie'. Indeed, some expressed a perception that they are capable of deciding, whereas Bernie was not. As such, while they felt that they should always be able to choose their activities irrespectively of risk, they often felt Bernie should not be given a choice in the matter.

For instance, when discussing Vignette 1, Edward was confident that if he were in Bernie's position, he would not want interference from the service. Yet, paradoxically, he outlined that staff should take the cigarettes away from Bernie even if she did not consent. Edward, who is registered blind and diagnosed with multi sclerosis, felt that the type of disability would determine whether a person can or cannot engage in risk-taking independently. When discussing the vignette, he stated: "We are not all of the same, excuse the language now, mentality, if you know what I mean". Similarly, when discussing Vignette 2, Edward stated that he should be left alone in the bathroom, but for Bernie, it would be too risky. He further explained: "She could slip or anything, fall or anything, she could, if she is not mentally stable upstairs in the head". Edward was unable to explain what "mentally stable" meant or how he would establish whether Bernie is or is not "mentally stable". Edward applied the same rationale when discussing Vignette 3.

Throughout his interview, Henry maintained a persistent rights-based approach and felt that risk-taking is always a service user's choice, but he wavered when discussing Vignette 3. Although he was clear that he would never use the thickening powder, he thought that Bernie ought to as otherwise "it would not be safe". Similarly, George at first did not seem conflicted by the vignettes: "as long as she [knew] about the risk"- it was



Bernie's choice in all cases. However, George hesitated after thinking about Vignette 3 and stated that even though he would not appreciate being told how much he should drink, Bernie should only be allowed to have "a little bit of the wine" (Vignette 3). Additionally, also admitting that he himself would not like it, George felt that the staff should contact Bernie's family (Vignette 1):

I would be awful afraid...If I didn't say it to the family, I'd have to say it to whomever I was working for, were they happy with it like. I'd be happy if they are happy with it. I wouldn't want the responsibility of her setting fire to her bed like.

Overall, though Aaron and Frank also aspired to respect Bernie's right to choose, after reading the vignettes they struggled to appreciate that she may be engaging in something they would never want to engage in: being left alone having a shower (Vignette 2). While Aaron questioned privacy as a sufficient enough reason behind the wish, Frank maintained that Bernie should never be left alone in a shower as it would be dangerous and unthinkable for both Bernie and him. When discussing Vignette 1, Frank explained that he was in a similar situation to Bernie's where his staff would hide his cigarettes before they left at night to alleviate the risk of fire. Frank did not seem too concerned and explained "it was a habit of theirs", but it is now resolved.

When discussing Vignette 1, June admitted that she had dropped her cigarette in bed twice. She talked explicitly about switching her perceptions between her "health and safety brain" and "the smoking service user's brain" and stated that "there is a risk of the house going on fire...but it is her personal choice". June further maintained that:

They (social care workers) are being paid to come in and care for her and if they feel there is a risk they have every right to go to their manager and the manager should have a risk assessor to come out to the house.

At the same time, June also reiterated her view of "Leave the girl some independence (Vignette 2)...the girl has to have choices (Vignette 3)".

Brenda, Celeste, Delia, and Ivan were somewhat alarmed by the potential risks they identified in the vignettes and appeared uneasy about the possibility that they might be involved in similar situations to those described in the vignettes. Although throughout their interviews, they all spoke about their awareness of their right to make choices, their response to the vignettes was to be risk-averse, and they disregarded Bernie's right to choose. For instance, in discussing Vignette 1, Delia argued that: "I know it's her own house, but she shouldn't be allowed do it like for her own sake". In discussing Vignette 2, Brenda's response was: "I wouldn't leave her alone at all". Similarly, in Vignette 3, Delia applied a rigid risk-preventive approach: "Even if she doesn't want it, she should use the thickener all the time in her drinks". Neither Brenda, Celeste, nor Delia would allow Bernie to choose freely in any of the vignettes, while Ivan remained unsettled and mostly indecisive when it came to discussing the vignettes.

### Theme three: Fear of potential liability

If the duty of care and the right to make choices around risk were subject to a variety of interpretations, this stood in marked contrast to a shared feeling of apprehension toward accountability amongst the managers and social care professionals. Throughout the interviews, there was a clear concern around potential liability for a failure to protect service users by preventing risks, which was expressed at least once by each manager and social care worker. It was apparent that both services and staff have become preoccupied with what they see as covering their backs via risk assessments and other administrative mechanisms, which at the same time, many perceived as a bureaucratic burden.

#### *Managers' anxiety, regulatory compliance, and defensive practice*

Amongst the managers, their fear of accountability was mostly connected to a potential failure to complete the required paperwork adequately or supporting service users in decisions that may look bad in the public eye, with the possible consequences being losing their job or being sued. This apprehension was also apparent in relation to national and organisational level policy-making. There was a sense that policies were developed to cover organisations, often by implementing tick-box exercises designed to pass audits that concentrated on compliance documentation. As a consequence, managers felt that a failure to complete a thorough risk assessment and a paper-trail for every activity would leave them open to both scrutiny and criticism. Although more than half of the managers felt that the emphasis on risk prevention and the related administrative burden are inappropriate, in order to avoid potential penalisation, they nevertheless enforced it rigidly in their service. As such,

paperwork, including risk assessments, represented an element of cover for some managers, while others viewed it as a time-consuming burden.

For instance, Tina and Mary reported that they would worry most if required paperwork was not completed in proper order, while Oscar revealed that he does not feel "protected" by risk assessments when supporting service users in risky choices. Oscar also reported being afraid of "[his] career ending" or "being in the media", which was compounded mainly by negative media coverage of services that were accused of failing to prevent risk.

Olivia expressed a worry that she may be "held responsible...if something went wrong". Olivia's main concern was related to both managers' and social care workers' fear of liability which, she explained, can have "a massive influence" on service users' choices around risk. Olivia emphasised that often staff might discourage service users from doing "what they actually want to do" because they are afraid of being viewed as "negligent". Olivia argued that:

It's just such a grey area, and it's such a blurry, blurred blind in who is responsible if something does happen...Until they do something about it until they look into it properly, there will always be that fear.

Notably, Mary confirmed that she would hold staff personally accountable if they did not follow risk assessments and care plans strictly, and she went on to outline that she would be intensely dissatisfied with the performance of a social care worker who following the wishes of a service user disobeyed her instructions or the instructions of a clinical professional.

Mary was unequivocal:

Staff are directed as to what's in the care plan and what measures are in place, and the risk assessment, and that's what they have to

follow.

Mary, who is also a registered nurse, explained why she feels she needs to be firm when implementing risk-preventive measures: "I could get fired...taken off the register and bye bye...door closed forever".

If views reflected the fear amongst managers, these views were shaped extensively by concerns over liability at the organisational level. Oscar noted that as a response to their fear of accountability, organisations developed strict risk management policies and that concerns were:

very insurance-driven. It is very much what can we do to prevent things from happening, as opposed to going and trying things and seeing how they go...It is very much about protecting the staff team, protecting the organisation.

Jane (Manager) also echoed this concern and stressed that "organisations think of insurance companies all the time...so policies are put there to prevent being sued". Jane also noted that regulations place strong emphasis on risk management, and organisations, therefore, enforce rigid paperwork processes. She highlighted that health and safety policies in her workplace require "risk assessments and control measures" implemented in all situations, and rather than being constructive risk assessments, they are there to "cover the organisation's back", not "to protect the person". Jane stressed, however, that they are only "a tick box exercise...so when people come and do internal audits, or HIQA [Health Information and Quality Authority] comes, you hand them a lovely folder, and they are happy".

This preoccupation with ticking boxes and ensuring that the paperwork is compliant often took precedence and dominated managers' day-to-day workload, which compromised time spent with staff and service

users. Jane bemoaned that "documentation comes first with everything" and Oscar reported that filling out risk assessment forms takes up "forty per cent of [his] day-to-day work". Olivia also lamented that she "could spend hours doing different risk assessments", outlining that:

There is an awful lot of paperwork...Everything that you go to do from dyeing somebody's hair to getting I don't know a dog, or a car, or anything, there is a risk assessment that has to be completed...I think it's a bit too much. Rather than on the choice, it's you can do this, but we have to do X Y and Z before we do this.

### *Service users' perceptions of the defensive practice amongst staff*

As these were the issues experienced by managers and social care workers, there may be a little surprise that the anxiety amongst staff was also intuited by service users. For service users, this anxiety was manifested mostly through social care workers' and managers' desire to avoid the kind of situations that represented potential risks for service users. The consequence, as service users viewed it, was an inappropriately exaggerated focus on risk assessments and other paperwork. Celeste, for example, noted that:

It's just a lot of those things like risk assessments and all this...that, you wonder why, you know. Do they think that it's going to reflect badly on them if I do something?

Similarly, Frank spoke about why staff avoid risk:

They are more or less liable for your wellbeing. So if an accident occurred...would there be a claim made against them?...they might say to you 'don't do this or don't do that', but if they are engaged in

there on their time, then they are leaving themselves exposed if anything went wrong. What happens when they're not here is totally different altogether.

Celeste explained that staff and management prioritise safety because they are concerned over service users' "physical wellbeing" as "they feel responsible". Ivan also felt this way and asserted that "they are always on about this health and fucking safety". Along these lines, Celeste reported an incident that she encountered when social care workers failed to follow a risk assessment adequately. Celeste is a stoma<sup>18</sup> appliance user and requires assistance from staff with this task. She explained that on one occasion, the staff omitted some aspects of the steps outlined in the colostomy care plan, and she became at a high risk of an infection as a result. The manager decided to penalise staff and implement disciplinary measures. However, Celeste expressed frustration with this unnecessary escalation, noting that:

I told her to do this as diplomatic as she could, but she went around, and she asked eight people... She's asked them to write a letter stating what happened...I asked her to be discreet about it, and I had no other request but for her to be discreet about it.

Celeste further explained that the manager also encouraged her to write a formal complaint about the incident, stating that: "I thought it was finished, and she wants a complaint, which I am not going to give her". Celeste outlined that this is not the first time the manager has asked her to write a formal complaint about the staff and emphasised that she feels

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<sup>18</sup> Stoma is "a surgically created opening of the bowel onto the abdominal wall, allowing waste (faeces or urine) to drain in to an appliance or stoma pouch" (Irish Stoma Care and Colorectal Nurses Association Ireland (ISCCNA), 2016).

that she is caught in the middle and that she cannot now "bring up anything because she [the manager] will make a big hoo-ha about it".



#### Theme four: The subjective nature of risk assessments and the management of risk

If these latter points reflect ways in which staff and services seek to protect themselves from liability, then risk assessment tools were portrayed as the most pivotal element of cover. Although described as impractical, risk assessments were identified as one of the most accentuated components of health and safety policies in disability services. While all social care workers and managers spoke about their significance in their service, only the managers and two social care workers had experience in taking part in a risk assessment. In contrast, the majority of service users were unaware of them. In practice, risk assessments were the domain of managers, and more often than not, clinical professionals such as nurses, general practitioners or/and speech and language therapists, though this varied from service to service. While the outcomes of risk assessment were implemented by social care workers, their professional input in their development was absent. More importantly, perhaps, in none of the twenty interviews was a service user mentioned as being included in the generation of a risk assessment.

In employing the mechanism of professionally performed and structured risk assessments, services often justified the management of risk to such an extent that compromising service users' independence became a routine part of the process. Once managers and clinical professionals identified and measured risks via risk assessments, they incorporated the outcomes and recommendations of the assessments into care plans, and social care workers then managed risks in accordance with these.

If this organisational structure values the judgment of clinical professionals above to the exclusion of the social care workers' and service users' judgement, the separation of the assessment of risk from its management also makes very little practical sense. While risk assessments are developed by largely clinically based professionals, the day-to-day management of risk and also the responsibility for those decisions are left to social care workers. Indeed, the vast majority of interviewees noted, both explicitly and implicitly, that while their input is not formally recognised, social care workers are responsible for evaluating and managing daily risks:

I suppose it's trial and error, and if it goes to the stage then that it's getting too risky, it's up to the staff member to risk-assess it there and then (Olivia, Manager).

Staff are there to safeguard and to help with the decisions and choices, especially if it is a high risk (Rose, SCW).

They [service users] are thinking about it: this is my life, and I can't get off the kerb. But, I am thinking when I am looking at the kerb, they can't get down of that. So, I need to be thinking in terms of probability and percentages. What's the probability that x is gonna fall off the kerb if they go down there? Well, it's pretty high...But I am thinking almost on behalf of them (Kaila, SCW).

A lack of objectivity was also identified in risk assessment tools used to measure risk in practice. These tools attempt to quantify risk by multiplying the estimated probability of an adverse event with the approximated severity of the probable adverse event (see Figure 4). This formula means that even if the likelihood is low, the risk can still be rated high if the severity appears significant. Ultimately, this method only gives

the illusion of objectivity in risk-assessing, as individuals incorporate personal meanings, subjective values, and fears when they establish the seriousness or the likelihood of a risk. This was demonstrated clearly in the interviews. All interviewees were asked to rate the vignettes in terms of risk, and although each participant had the same scenario at hand and was probed to employ the same standard tool used to assess risk in disability services (see Figure 4), the differences in the risk-rating of individual interviewees were substantial (see Figure 5).

While the average rating for each vignette showed no clear variation between the three stakeholder groups, the differences in individual risk ratings pointed to risk assessments being affected by personal bias. For instance, while one manager, Olivia, thought that the risk she identified in Vignette 1 was low, another manager, Oscar, felt it was high. Similarly, a social care worker, Anna, rated the risk in Vignette 3 as low, while another social care worker, Rose, rated it high. Finally, service users also risk-assessed the vignettes differently; George stated there was no risk in Vignette 2, while Frank felt that the risk was high. As such, since it is apparent that the outcomes of risk assessments are often used to determine service users' risk-taking, it is clear that subjective meanings can impact service users' ability to engage in situations involving risk.

**FIGURE 4 RISK RATING TOOL USED TO RATE RISKS IN THE VIGNETTES** <sup>19</sup>

(see the vignettes in Appendix 1.)

<b>RISK RATING</b>					
<b>Severity/ Likelihood</b>	<b>Insignificant</b>	<b>Minor</b>	<b>Moderate</b>	<b>Severe</b>	<b>Catastrophic</b>
<b>Almost Certain</b>	Low	Low	Moderate	High	High
<b>Likely</b>	Low	Low	Moderate	High	High
<b>Possible</b>	V.Low	Low	Moderate	High	High
<b>Unlikely</b>	V.Low	V.Low	Low	Moderate	High
<b>Rare</b>	V.Low	V.Low	Low	Moderate	High

<sup>19</sup> This table was provided by Oscar (Manager), who explained that this is a risk assessment tool used by his organisation. All other managers and social care workers confirmed that either the same or a similar risk assessment tool is used in their organisation.

**FIGURE 5 PARTICIPANTS' RISK-RATING OF THE VIGNETTES**

	Vignette 1 Risk Rating		Vignette 2 Risk Rating		Vignette 3 Risk Rating		
Aaron (SU)	Very Low	1	Moderate	3	Low	2	6
Brenda (SU)	High	4	Low	2	Low	2	8
Celeste (SU)	High	4	High	4	High	4	12
Delia (SU)	High	4	High	4	High	4	12
Edward (SU)	High	4	High	4	High	4	12
Frank (SU)	Moderate	3	High	4	High	4	11
George (SU)	High	4	No Risk	0	Low	2	6
Henry (SU)	High	4	Moderate	3	High	4	11
Ivan (SU)	High	4	Moderate	3	I do not know		7
June (SU)	High	4	Low/Moderate	2.5	Low/Moderate	2.5	9
Jane (Manager)	High	4	Very Low	1	High	4	9
Mary (Manager)	High	4	Moderate	3	High	4	11
Olivia (Manager)	Low	2	Moderate	3	High	4	9
Oscar (Manager)	High	4	Moderate	3	Moderate	3	10
Tina (Manager)	High	4	Low	2	Moderate	3	9
Anita (SCW)	High	4	Moderate	3	Moderate	3	10
Anna (SCW)	Moderate	3	Moderate	3	Low	2	8

<i>Kaila (SCW)</i>	<i>High</i>	<i>4</i>	<i>Low</i>	<i>2</i>	<i>High</i>	<i>4</i>	<i>10</i>
<i>Lorna (SCW)</i>	<i>High</i>	<i>4</i>	<i>Moderate</i>	<i>3</i>	<i>Moderate</i>	<i>3</i>	<i>10</i>
<i>Rose (SCW)</i>	<i>Moderate</i>	<i>3</i>	<i>High</i>	<i>4</i>	<i>High</i>	<i>4</i>	<i>11</i>

The issues concerning the subjective nature and lack of service user involvement raise questions around the suitability of the manner in which risk-related decisions are established in disability services. It was evident that individuals attach subjective meanings to risk, which can be partially attributed to the perceived vulnerability of service users, which is also being influenced by different models of care, as well as the fear of accountability. These factors contribute to varying approaches to risk between individual participants, as well as between different stakeholder groups.

### *Managers' approach to risk-assessing and the management of risk*

Repeatedly, managers spoke about a collaborative approach to risk assessments or what they called a multidisciplinary approach. When faced with the dilemmatic situations in the vignettes, managers almost instinctively referred to an approach that would distribute the responsibility for risk-assessing amongst different professionals. A multidisciplinary approach often meant that a manager would ask a nurse, a general practitioner, or other, mostly clinical professionals, for their opinion to aid them in establishing control measures or determining whether or not a service user could be supported in the activity. The input of social care workers was almost entirely absent in this process. This can

be seen as a further demonstration of the medical model' legacy in disability services.

It was apparent that while managers expect social care workers to oversee the day-to-day operation of risks, they rarely involve them in the formal decision-making process. In part, this can be attributed to hierarchical structures in which social care workers are poor relations of the professionals with a clinical background. For instance, Oscar noted for Vignette 1 that: "You could go as far as looking at Bernie's GP advising her...or the clinical person would be maybe a nurse". Similarly, Jane outlined that in her work, "coordinators, managers, [and] nurses" complete risk assessments, which she felt is inappropriate as it involves "everybody, except the person that should be involved - the service user". Jane felt that this absence of both service users and social care workers could be ascribed to the long-standing dominance and legacy of the medical model in disability services.

In general, managers view risk assessments as a means for implementing risk-prevention control measures through which risk-taking might not be restricted entirely, but "compromises" (Mary, Manager) would need to be made so that the unacceptable risks are alleviated. The need for risk assessments was often identified as in accordance with the views of managers and other professionals who attached subjective meanings to service users' choices based on their perceptions of risk:

...if ever there is a bad choice made...then we would have to look at it and look at the risks of that (Mary, Manager).

Olivia (Manager) acknowledged that her perceptions of what is risky could be different from the views of other staff, which she highlighted can influence the outcomes of service delivery significantly. The extent to

which managers subjective views could impact risk-assessing, and thus, service delivery, was also apparent in the inconsistency in approaches to identical situations, for instance, in Vignette 3:

So the likelihood of aspiration or reoccurring chest infections from not using thickened fluid would be high (LP). I would speak to her to give her an informed choice, but it would still be her choice whether she wants to take the drink or not. And how would I support staff around that? I'd talk to them through the risk assessments and the discussion that we've had and make staff aware that if something does happen that...it has been her decision (Jane, Manager).

The staff member will need to explain that, you know, these are the guidelines from speech and language. You can't swallow properly, you know, it's not advisable without the thickener in it (Mary, Manager).

Jane and Mary, at perhaps the most opposite extremes of how services should be delivered, exhibited how managers subjective views impact the manner in which risk is assessed and subsequently managed. While both believed that social care workers must follow the directive of a manager, their directives were contradictory. At the one end, Jane explained that she would instruct social care workers to support service users in all chosen activities, even if potential risks were high:

As a line manager, I would hope that the staff take the directive from me. And they can work under protest as well....She [Bernie] isn't smoking when her staff are there, so they shouldn't have an issue with that (Vignette 1).



At the other end, Mary maintained that she would not facilitate Bernie's choice, as it "could be potentially deadly" and explained that she would not appreciate it if a social care worker decided to follow Bernie's wishes:

Well, they [the staff] are not following the directions of the speech and language. I mean, there is a reason for her having a speech and language assessment, it's to, for the safety wellbeing of the service user (Vignette 3).

In a similar fashion, Jane stressed how social care workers approach service users risk-taking can be influenced by their educational background. Jane felt that staff who have a social care level 7 degree or above in social care approach risk in a less interventionist way than others. She maintained that staff with lower qualifications are not as confident in managing risk and often seek guidance from clinical professionals even in non-clinical situations. Jane assigned this to historic hierarchical structures, in which clinical staff, mostly nurses, dominated disability services. While all social care workers interviewed were educated to above level 7 degree, Jane explained that some social care workers working in her service are below the level 7 threshold and viewed this as problematic in working against transitioning from a medical to a social model, particularly as:

Some people that work here have FETAC<sup>20</sup> courses, and I have no disrespect to them, but I don't think they have knowledge around choice and (LP)...I think they'd look to a nurse for advice

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<sup>20</sup> The Further Education and Training Awards Council (FETAC) is a former statutory awarding body for further education in Ireland. Some people continue to use the term FETAC to name current level 5 courses such as the QQI Health Service Skills, QQI Community Health Services, QQI Healthcare Support awards. Quality and Qualifications Ireland (QQI) was established on 6 November 2012 under the Qualifications and Quality Assurance (Education and Training) Act 2012 (Citizens

Noteworthy, Jane also pointed out that like some social care workers, many service users perceive the opinion of a clinical professional as instructions:

From my experience, people that have been brought up in institutions are of the mindset that you do what you are told; by the doctor, by the nurse, by whomever it is that is looking after them. People that you see coming into services now that are acquiring disabilities, I think they have more life experience to have the confidence to make their own decisions around risk.

### *Social care workers' approach to risk-assessing and the management of risk*

#### Risk assessments

Among social care workers, risk assessments meant risk-preventive instructions prescribed by management and other professionals. While Lorna defined risk assessments as "trying to foresee the possible risks", Ashling described them as "a systematic process put in place to address risks and negate them, where possible". Anna highlighted that in her experience, risk assessments often label activities as "too risky". Of the five social care workers interviewed, four described risk assessments as something distant, which they knew about on a theoretical level, but which they did not participate in.

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Information Board, 2019). QQI is an amalgamation of the following four bodies: the Further Education and Training Awards Council (FETAC), the National Qualifications Authority of Ireland (NQAI), the Higher Education and Training Awards Council (HETAC), the Irish Universities Quality Board (IUQB) (Citizens Information Board, 2019).

Social care workers did not seem concerned about their lack of involvement. Kaila, for instance, felt that risk assessments should be performed by “a trained risk-assessor” or “the nurse” if it involved clinical considerations. Rose noted that risk assessments ought to be completed by “the management” and by “a person who is qualified in doing risk assessments”, while Ashling thought there should be “a team approach”.

Although it was clear that social care workers are responsible for a substantial portion of the day to day management of risks, their role as active agents and professionals was generally not recognised within services. There may be a little surprise, therefore, that there was often apathy and a lack of confidence in managing risk amongst social care workers. This manifested in avoidance of risky activities where possible or, at the very least, of those activities that were not pre-risk-assessed by management or other professionals. Indeed, Ashling stressed that social care workers feel confident supporting service users only with risk-assessed activities. As a consequence, service users spontaneous choices are extremely limited, as everything has to be pre-planned:

They [service users] are gonna go surfing, for example, you can't just go and do that like. You have to sit down and go through what the risks actually are...They [service users] will only be allowed to make risky choices and follow through on whatever that activity is if there are risk assessments done (Ashling).

Thus, social care workers avoid or encourage service users to steer away from activities that are not risk-assessed, or they postpone the proposed activity so that the decision can be diverted to management for approval. It was clear that there was a strong tendency toward notifying a manager or clinical professional where a service user wanted to engage in a new activity that may involve risk or when a service user did not want to

follow the recommendations of a risk assessment that was in place. The extent of this practice was noted by Anna when discussing Vignette 3: “I'd tell her: well I'll give it to you, but I'm going to have to run this by my manager or the nurse first”.

In light of such examples, it is evident that a general disregard for the expertise of social care workers is often internalised. As with managers, some social care workers felt that other professionals, such as nurses or general practitioners, are more qualified in assessing risk because of their clinical background. This sense of inferiority was more pronounced where staff were not educated to degree level, which is common in disability services<sup>21</sup>. Rose emphasised that she was “shocked” when she started her employment after finishing her degree when one of her colleagues “who doesn't even have a degree asked [her]: Did you do one of those Mickey-Mouse courses?” Therefore, there may be a little surprise that individuals with such views would view clinical professionals as more suitable to make decisions around risk. Rose stated that: “You don't know whether to laugh or cry, these people will ask for permission from a nurse if a service user wants to have as much as a glass of wine”. She noted in a despondent way: “Even if I suggest that I am competent in making a decision, they [other colleagues who do not have a degree in social care] completely dismiss me”.

It is not difficult, therefore, to appreciate social care workers experiences of powerlessness to respect service users' choices when they

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<sup>21</sup> Currently, in disability services there is no requirement to employ staff that are qualified social care workers and “the level of training or qualification required is at the discretion of the employer” (Health Information and Quality Authority (HIQA), 2017a, p. 14). Many employers expect a Major Award at Level 5 in QQI (Quality and Qualifications Ireland) Health Service Skills, QQI Community Health Services, or QQI Healthcare Support, for instance (Frontline Training Services, 2017).

feel their hands are tied by control measures set out by other professionals and when their knowledge and skillset is not respected by colleagues. In all cases, social care workers spoke openly about their view, risks are often managed in a way that negatively influences service users' ability to make independent choices. Anna put it bluntly, observing that some risk assessments provide instructions about what service users "can't do".

Lorna noted that:

Sometimes people would like to...self-transfer, for example, from a chair to a wheelchair. And our risk assessment and our policies forbid this. And I feel like, we are made to stop them or try to, you know what I mean, limit them in this.

Here, Rose similarly used speech and language therapist's guidelines as an example of something that dictates how the often limited extent to which social care workers can support a service user in the preparation of their meal:

Someone could have the capacity to choose what meal they wanted, but then...because of their SALT [speech and language therapy] guidelines, they may not have the capacity to choose how you prepare the meal for them.

Similarly, Anna, when discussing Vignette 1, was adamant that Bernie must wear protective clothing when smoking, whether she is agreeable to it or not:

She might not want them, but because she's under the service, she is required by policy and procedures to wear it for her own safety...So there has to be a compromise there.

It was evident that some social care workers, as well as managers, viewed the requirement to compromising as the norm in disability services:

You have a disability. Decisions are made because you are in receipt of service. The world is not ideal, you know, it's more like a mother making a decision for her child (Kaila, SCW).

I don't think it's right, but I think it's life (Tina, Manager).

### Managing day-to-day risks outside of the risk assessments

While it is evident that risk assessments are often performed in advance for varying potential activities, it is also clear that some events simply cannot be predetermined. Social care workers can find themselves in situations that are not risk-assessed, as well as situations where a service user decides to ignore the recommendations of a risk assessment. More often than not, such situations happen in the absence of management personnel, and thus the onus falls to the social care worker to manage the situation. Here, personal values and principles often then come to determine how social care workers respond. While some social care workers endeavour to respect service users' right to choose, others reinforce a limiting culture and err on the side of caution and discourage service users from engaging in anything that is outside of the risk assessments or care plans. Moreover, some social care workers feel anxious even in situations that have been risk-assessed if they feel that some elements are too risky, and thus they try to avoid them. Kaila, for instance, outlined that when it comes to service users' liberty in risk-taking, it depends on whether the staff would "give [them] the freedom to make the decision", which "comes down to how cautious" the staff are. Similarly, Ashling and Lorna noted that staff frequently prescribe the amount of risk-taking that can take place. Ashling emphasised that staff are very cautious, stating that:

I think disabled people who are in services are very guided by the staff they work with, and they just live in that bubble, and I don't know it depends like on the staff.

The subjectivity in social care workers' approaches to risk in practice was also demonstrated in discussions around the vignettes. While Lorna maintained a more liberal approach and recognised Bernie's right to make choices, other social care workers endorsed risk preventative measures, even if it meant restricting some portion of Bernie's independence:

She could choke, but then again, I could choke...Would I allow her to have her wine without thickener? (Laugh) Absolutely I would (Lorna, SCW).

So if it's Bernie that's going bungee jumping (LP)...she has spina bifida, she has hydrocephalus, she is fifty, whatever...I don't necessarily know that there is a risk involved there...But now, Bernie wants to go to the pub, and she is on twelve glasses of wine, and none of them is thickened. I can't really stand behind going facilitating that (Kaila, SCW).

As seen with managers, a lack of impartiality in risk approaches was demonstrated by social care workers assigning subjective meanings to service users' choices frequently based on the personal or moral judgment of potential risks:

I think they could make their choice, but I think they'd need to be advised...so that they weren't taken advantage of or they weren't making invalid choices (Rose, SCW).

...but we know that, unfortunately, some of the service users we support do make bad choices (Kaila, SCW).

...when someone is making a decision that you know is a bad decision (Kaila, SCW).

If personal values shape how staff manage risk in day-to-day practice, there may be a little surprise that their perceptions of what represents an acceptable risk for service users varied considerably. While Kaila saw bungee jumping as safe, she viewed binge drinking as too risky. Kaila was open about enforcing these subjective views in practice and stated that if a service user chose to participate in what she thought was too risky, she would not “facilitate” it. Another social care worker, Rose, felt that service users management of money was high risk and felt that for this reason, social care workers should be involved. At the same time, Anna felt that service users going out without a staff member represented a high risk and also disclosed that she would be mindful of what she thinks is unsafe when risk-assessing activities.

A further confounding variable that influences the way risk is perceived and approached by social care workers was their background. Rose noted that some staff that have “worked a long time and are used to the medical model” are more risk averse than others. At the same time, Kaila pointed out that staff can become “complaisant” and “institutionalised”, which can affect the way they approach risk-taking.

#### *Service users’ perceptions of risk-assessing and the management of risk*

In the context of person-centred care, it can be challenging to grasp that the ten service users had never participated in a risk assessment concerning their safety<sup>22</sup>. Furthermore, while a majority of service users knew what risk assessments were, they were unaware of risk assessments

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<sup>22</sup> June has performed risk assessments in the past as part of her employment.



in their service. In addition, Brenda, Delia, Ivan, and George did not know what a risk assessment was.

There was a strong sense that service users who were aware of risk assessments viewed the absence of their involvement as a problem. For instance, Celeste, who clarified that she had never been involved in a risk assessment, stated that there was "plenty of them being done" in her service. Frank viewed this as an issue, particularly because risk is a subjective concept and "what might be a risk for you might be a bonus to me". Aaron described risk assessment as "calculating all the pros and cons of doing any particular activity and...putting systems in place to minimise the possibility of an accident happening", though he initially stated that there were no risk assessments in place concerning his safety. Upon checking with the staff, however, he clarified that his assumption was incorrect as there were several risk assessments in place regarding Aaron's safety. Subsequently, Aaron stated that it is appropriate that management is in charge of risk assessments, but he felt he should be involved if they are in any way connected to him.

June, who defined risk assessment as "the probability of an event happening that could cause an injury", identified several issues with the manner in which risk assessments are performed in disability services. June stated that currently, risk assessments are executed by unqualified "half-baked persons". She strongly emphasised that "it is absolutely essential" that only a qualified risk assessor performed a risk assessment and highlighted a case when management in the service she utilises "allegedly" completed a risk assessment concerning her care. While she did not wish to disclose exact details, she explained that she disputed the validity of the document, as it was performed "behind [her] back", was not completed by a qualified risk assessor, and was not completed in her house

where the supposed risk was situated. In June's view, "a risk assessment has to be done in situ", not "in theory at a distance". June, who had worked as a health and safety officer, stated she was "shocked by what the service could call a risk assessment" and stressed that neither the social care workers nor the managers are qualified to perform them.

Certainly, it was clear from the interviews with service users that they feel that risk assessments are subjective and can most often restrict and overprotect them. In the majority of cases, service users reported at least some incidents when staff interfered with their decision due to recommendations in a risk assessment. For some service users, mostly those who have utilised services all their lives, this was considered the norm, while for others, it represented a significant impediment to their independence. Edward, for instance, explained that the service he utilises developed a money management plan for him due to a risk assessment that suggested he was at a high risk of financial abuse. Edward was not involved in the process of risk-assessing and strongly disagreed with its outcome, which suggested that social care workers manage his finances. Edward explained that the dispute is ongoing and that, at times, he feels overwhelmed by how coercive staff can be when implementing risk assessments.

When discussing overprotection, several service users mentioned risk assessments that mandate staff supervision; supervised walking because of the risk of falls, for instance. Such recommendations become especially problematic in instances of staff shortages. Ivan found this incredibly frustrating and noted that: "a person with authority can say; no you are not doing this today because we haven't the time". In a similar fashion, some service users reported that they often feel that before proceeding with an activity that was assessed as risky, they would need to ask for permission

which was off-putting. Edward explained: "because I know there would be people asking me did you say this, do that and the other".

A common concern amongst all service users was the significance of a social care worker's outlook and approach. Several service users stressed that when it comes to freedom to make decisions and live an independent life, it depends on the staff working with them more often than not. Frank observed that "you are dealing with a very subjective thing, you are dealing with human relations" and noted that in disability services, there is "a mixture of personalities...attitudes, likes, dislikes", and these shape how services are delivered. Frank explained that different staff often have near opposite views of risk, which is reflected in how they engage with service users, and he noted that:

You got extreme situations where one doesn't want you to smoke at all, and the other one will give it to you because she thinks she is making you feel better.

By and large, varying personalities, different backgrounds, and disjointed training pathways determine the quality of the front line staff according to service users. Frank, for example, noted that:

There is a lot of people in the job that shouldn't be in it, do you know. Some are, it's their vocation like. And others, they're just doing it for the whatever, for the money or whatever....you get good and bad...there was some of the staff that were genuinely good and...some that you know shouldn't be working there.

While Ivan described some staff as "too bossy", Henry called them "patronising". June similarly suggested that "some staff just don't have it in them" and she assigned this to an insufficient educational background for some staff:

At first, I didn't know. I couldn't put my finger on it. I was asked which staff I preferred to be on my team, and I picked the ones I thought were good. Only after a very long time, I realised that the people I picked were the only ones in the service that went to college. They were qualified. They were what you call social care workers. The rest of them, no offence, but they would come up with very intrusive shit. I mean one of them once told me that I shouldn't smoke, that it kills people. I mean she was twice my size, I am sure that kills people too.

Henry stressed that disability services should have higher entry criteria for staff, stating that "they should be vetted more".

## Conclusion

This chapter examined how risk is perceived and experienced in practice by service users, social care workers, and managers. Firstly, it examined the perceived vulnerability of disabled people and identified that there is lacking clarity in how social care workers and managers should balance competing demands between following guidelines and respecting service users' independence. It identified that attempts to achieve harmony between principles of independence and the right to choose with the principle of duty of care and safeguarding cause real challenges for staff. Secondly, it looked at anxiety over accountability that was present amongst staff when supporting service users that engage in risk-taking or make choices with potentially ill consequences. It also identified a general lack of recognition of social care work as a profession, both internally and by other professionals in disability services. This chapter also explored the subjective nature of risk assessment and, subsequently, the often biased approach to the management of risk in disability services. Lastly, it looked closely at the perceptions and concerns of service users so that their voice could come across directly.

## Chapter Five: Discussion and Conclusion

Risk is an inevitable aspect of daily life, and while often it has been associated with negativity, danger, or fear (Douglas, 1992; Furedi, 1997; Stanford, 2010), risk can also represent exciting and valuable opportunities (Morgan, 2004; Robertson & Collinson, 2011; Veselinova, 2014; Waterson, 1999). It has been recognised that in order to achieve personal growth and be independent, people need to have the freedom to make choices around risk (Veselinova, 2014). Thus, with an increasing focus on independence, scholarship on risk in social care has been moving toward affirmation that risk be viewed in a more positive light (Methven, 2009; Morgan et al., 2016; Neill et al., 2009; Robertson & Collinson, 2011; Seale, Nind, & Simmons, 2013; Veselinova, 2014), not least because positive risk-taking can enhance service users autonomy and improve the quality of their lives (Ramon, 2004; Robertson & Collinson, 2011).

Traditional models of care have long been contested for imposing attitudes that were considered controlling or even oppressive and for their tendency to underscore the need to shelter disabled people from risks (Morris, 1993; Oliver, 1990; Silvers, 1995). It is now acknowledged, however, that in order to provide person-centred care in an environment that respects disabled people's rights and choices, services and social care professionals need to embrace positive risk-taking and challenge approaches to care that seek to avoid or minimise all risk (Carr, 2011; Department of Health (EIRE), 2018; Health Information and Quality Authority (HIQA), 2019b; Methven, 2009; W. Mitchell & Glendinning, 2008; Veselinova, 2014). At the same time, it is recognised that social care

workers play a significant role in the lives of disabled people and thus have the capacity to influence their health behaviours and empower them to prevent or self-manage health issues and to make healthier choices (Brown, 2017; Leser et al., 2018; McDermott et al., 2012). This outlook reflects the shift in policy in recent decades from “managing” service users to “enabling” service users (Morgan et al., 2016) and, consequently, a change in how risk is approached in social care is necessary (Carr, 2011; Morgan et al., 2016; Neill et al., 2009). Put simply, risk can “no longer” be seen as “an excuse to limit people’s freedom” (Veselinova, 2014, p. 529).

### Perceptions, challenges, and demands that shape approaches to risk in practice

Although promoting choice and enabling risk are central features of person-centred and rights-based care (Carr, 2011), the emphasis on increased risk-taking brings complex challenges for social care workers and managers (W. Mitchell et al., 2012; W. Mitchell & Glendinning, 2008; Morgan et al., 2016; Stalker, 2003; B. Taylor, 2006b; N. S. D. Taylor, 2008; Whitelock, 2009). In practice, when it comes to risk-taking, practitioners “may be anxious about transferring responsibility to, or sharing responsibility with, the individual if they do not feel confident to do so” (Carr, 2011, p. 130). This lack of confidence can in part be attributed to the difficulties faced by professionals when attempting to consider both the service user's right to take risks and what the practitioner perceives to be their professional duty of care (Robinson et al., 2007). Practitioners feel bound by their health promotion duties, including their responsibility to promote a healthy lifestyle and facilitate interventions that minimise the adverse effects of disability on an individual's health (Dines & Cribb, 1993).

It has been suggested that social care workers should implement a health promotion model of social care in practice, in particular, to support making healthy choices easier for service users (Naidoo & Wills, 2009). Indeed, it has been claimed that practitioners “key health promotion role [is] to improve fitness and nutrition and thereby minimise illness and dependence” (Naidoo & Wills, 2009, p. 134). Within the health promotion model of social care, disability services must respond by increasing the focus on interrelated interventions that include “health education targeted at [service users], re-orienting services to improve the quality of service provision, advocacy to improve service provision and safeguarding the health and well-being of service users” (Hubley & Copeman, 2008, p. 293).

Understandably, efforts to work in line with such obligations can result in ethical dilemmas when considered against the backdrop of positive-risk taking (Bergström & Wihlman, 2011). While some practitioners feel unable to promote positive risks-taking as they feel this could compromise their ability to promote health effectively, others feel that promoting health is a challenge “due to a general fear over doing anything that could be perceived as violating rights” (Doody, 2016, p. 45). As those such as R. Ellis, Hogard, and Sines (2013) have observed, “there is thus a tension between risk management as a feature of care and fostering individual freedom to take risks as an element in personalisation” (p. 253).

Managers and practitioners feel obliged to safeguard those disabled people to whom they provide services. At the same time, they strive to acknowledge and promote the need for service users’ rights to be respected and their choices to be heard and actioned. It is not difficult to appreciate that meeting both aims can represent genuine challenges, particularly as “good practice” is often defined by the ability to achieve a balance between the principles of empowering and protecting (Carr, 2011).



Nonetheless, it is also recognised that these principles are somewhat contradictory and may come into direct conflict (Hawkins, Redley, & Holland, 2011). In practice, therefore, finding a correct balance can be an incredibly complex task, even more so against a backdrop of increasing oversight, regulation, inspection, and monitoring of disability services and the social care profession (Byrne, 2016; Health Information and Quality Authority (HIQA), 2017a, 2017b, 2019c; Law Reform Commission, 2019). No doubt there are very real fears amongst staff. Given the subjective and unpredictable nature of risk, there are understandable concerns that decisions could be seen as failing in their duty of care, which they feel can be “interpreted as negligence”, particularly if there are adverse outcomes (N. S. D. Taylor, 2008, p. 51).

Roberston and Collinson (2011), for example, found that perceptions and experiences of positive risk-taking vary amongst different stakeholders in disability organisations. They identified that practitioners often find themselves “negotiat[ing] a balance of control over risk-taking with the service user” while being acutely aware “that misjudging this balance could ultimately result in service responses shaped by rare, adverse incidents rather than by the everyday risks faced by most service users” (Robertson & Collinson, 2011, p. 147). This is especially the case where organisational guidelines around risk-taking are inconsistent, and as a result, practitioners can feel they are “gambling” when promoting positive risk-taking (Robertson & Collinson, 2011).

Within this study, it was abundantly clear that social care workers feel compelled both to protect service users, while promoting their health and facilitating positive risk-taking. Health, as well as risk, can be perceived and defined in various ways:

for some people: Being healthy simply means being happy – for others, there is an inherent expectation of living for a long time... For others, health is a definition of exclusion, the avoidance of medication and specific illness. For others, again, it is a question of how one relates to daily work... For some people, health is very particularly oriented around factors in lifestyle (Kelleher, 1991, p. 116).

Indeed, attempts to harmonise service users' choices with staff responsibilities represent daily challenges for both social care workers and managers (R. Ellis et al., 2013; Hawkins et al., 2011; Morgan et al., 2016; Robertson & Collinson, 2011; Robinson et al., 2007). Interviewees frequently described positive risk-taking more in terms of 'fancy terminology' than routine practice. In practice, empowerment and a rights-based approach are often advocated; however, risk prevention commonly dominates decision-making in reality, and although practitioners clearly endeavour to empower and enable service users to take certain risks, in complex situations or where the risk seems too great, they err on the side of caution (Davidson & Campbell, 2007). This reflects findings from the UK, where some practitioners choose to "prevent or avoid" a situation when they feel that the risk is high or the outcome uncertain (Robertson & Collinson, 2011, p. 161). In Ireland, such uncertainties are only likely to increase with the shift from institutional to community-based independent care, as the community environment is less easily controlled, and this shift will introduce new opportunities and, thus, new risks (A. Power, 2013a).

Interestingly, while managers' perspectives of risk in disability services appear somewhat overlooked in the literature, this study has highlighted that managers face similar dilemmas. Managers' anxiety can

be directly linked with the concerns of services around potentially undesirable outcomes of service user choices that may involve risks and the reputational damage this might incur (Robertson & Collinson, 2011). Many services in Ireland rely on public funding and donations, and reputational damage could have dire consequences for both<sup>23</sup>. Managers have the unenviable task of trying to manage and minimise adverse events, ensuring that the service users' rights are recognised within their services, and at the same time must keep both social care workers and service users safe. Meanwhile, they are also cognizant that they are subject to regular inspections and scrutiny from the HIQA (Health Information and Quality Authority (HIQA), 2013, 2017a, 2019c). As such, while service users may value their autonomy and freedom to be respected above all else, managers' and practitioners' default response is to prioritise safety first (Independent Living Movement Ireland, n.d.; Independent Living Movement Ireland (ILMI) & O'Duffy, 2018; Leece & Leece, 2011; Robertson & Collinson, 2011; Robinson et al., 2007; Wallcraft, 2012) especially against the backdrop of an "increasingly litigious society" (Robinson et al., 2007, p. 389; B. Taylor, 2005, p. 1424).

Perhaps unsurprisingly, therefore, practitioners are often preoccupied with ensuring adherence to very rigid and uniform risk management procedures (Hawkins et al., 2011). Risk management in disability services, as in many other domains, has become a heavily prescribed process, in which risks are to be approached as objective, quantifiable entities (Robinson et al., 2007), and commonly "involve

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<sup>23</sup> Several organisations for disabled people experienced reputational damage during the austerity period as a result of national scandals around inappropriate pay scales of higher management that impacted substantially on the organisation's public image and resulted in reduced donations (Kenny & Power, 2018; McLnerney & Finn, 2015).

measures which are often used as if they can clearly predict risk” (Robertson & Collinson, 2011, p. 148). In an increasingly regulated environment (Byrne, 2016; Health Information and Quality Authority (HIQA), 2017a, 2017b, 2019c; Law Reform Commission, 2019), risk assessments act as a means through which organisations, managers, and practitioners can protect themselves. As such, risk assessments are often used to justify control or intervention (Stein, Asenova, McCann, & Marshall, 2010), based on what is frequently presented as a scientific recommendation within a risk assessment. Thus, although the discourse around supporting positive risk-taking has grown, the emphasis remains firmly on managing risk, most often in a defensive manner and this stands in the way of service users becoming truly independent (Murphy & Bantry-White, 2020; Seale et al., 2013).

While the above considerations point to the growing regulation and formalisation of risk assessment and risk management in social care (Broadhurst et al., 2010), from this study, it is clear that subjective values and personal judgment play a substantial role in how risks are perceived, assessed, and managed in practice (Hawkins et al., 2011). Even though actuarial risk assessment tools commonly used in social care practice follow predominantly positivist methods to measure risk, assessing and managing risk in daily practice is open to personal, social, organisational, and cultural biases. Individuals do not comprehend risk from a purely analytical, rational stance, as they cannot simply abandon their intuitive awareness guided by experiences and emotions (Slovic et al., 2004). Put simply, risk is not an abstract concept that can be separated from the cultural and social values individuals attach to it (Candlin & Candlin, 2002; Douglas, 1992; Giddens, 1991), and it is crucial to acknowledge that professionals evaluate risk subjectively (Kemshall, 2010; Munro, 1999;

Wood & Kemshall, 2008). This is clearly evident in the variances between how different individuals and stakeholder groups respond to risk (W. Mitchell & Glendinning, 2008). Within this study, it was increasingly obvious that how individual practitioners, managers, and service users interpret a risk assessment varies considerably, as it is influenced by their differing experiences, views, desires and understandings of risk (Candlin & Candlin, 2002). Indeed, personal biases, including anxieties and concerns over certain risks, as well as organisational beliefs, play a significant role in how professionals and service users react to and engage with risk in practice (Broadhurst et al., 2010; Kemshall, 2003, 2010; W. Mitchell & Glendinning, 2008; B. Taylor & McKeown, 2013). Moreover, practitioners' gut feelings and tacit knowledge also frequently determine their actions in practice when it comes to risk (Robertson & Collinson, 2011). Understanding and appreciating the importance of this is a critical step on the path toward supporting service users' independence and a rights-based and person-centred approach to social care practice.

Practitioners and managers play a significant part in service users' lives and affect service users' ability to achieve independence and participate in risk-taking (Kilroy, Egan, Walsh, McManus, & Sarma, 2015; Murphy & Bantry-White, 2020; Robertson & Collinson, 2011). Certainly, a recent Irish study has highlighted that "the culture, values and expectations" and what practitioners consider to be "the best" for service users often determines approaches to care in practice (Kelly, McConkey, & Craig, 2019, p. 765). Although some literature has noted improvements in services facilitating more positive-risk taking and, hence, control for service users (Glendinning et al., 2008; Heath & Phair, 2009; Kettle et al., 2011), a recent review of international research around service users' perspectives has stressed that many service users do not feel entirely in control of their

lives (Gjermestad, Luteberget, Midjo, & Witsø, 2017). It is a feeling similarly highlighted by a very recent study in Ireland, where the authors concluded that service users lack choice and are often “disempowered, controlled, and monitored” (Murphy & Bantry-White, 2020, p. 14). The findings of this study do not suggest that service users do not have control over their lives, although some aspects of disempowerment were nonetheless present, especially when it came to risk-taking. Rather these disempowering elements were most often subtle and manifested in practitioners monitoring and influencing service user choices around risk. Indeed, Some practitioners, both explicitly and implicitly, imposed authority when it came to service users decisions and behaviours, sometimes even around simple everyday tasks (Altermark, 2018).

It has been acknowledged that risk-taking within services is much more complicated than risk-taking in life outside of services. Nonetheless, scant attention has been paid to why it is complicated or what part different stakeholders play in service users risk-taking (Robertson & Collinson, 2011). In everyday life, people often take risks with no input from others in services; however, it is clear that practitioners, managers, and organisational policies and culture impact service user choices. In general, how risk is perceived and managed “frequently reflect[s] wider professional ethos and priorities” (W. Mitchell & Glendinning, 2008, p. 304). Although it may be appealing, not least for reasons of simplicity, to generalise around each stakeholder group in terms of how they approach service users’ risk-taking, it is evident that not only do service users, practitioners, and managers perceive risk differently but also that there are clear variations between individuals within these groups.

If this further underlines the subjective nature of risk, it is also clear that practitioners perceive and understand service user risk-taking as

something that needs to be managed, while service users think of choices around taking a risk more as their right (Robertson & Collinson, 2011). If this reflects a view of services users as vulnerable, it can also lead service users to disagree with how professionals perceive, assess, or manage risk (Langan & Lindow, 2004). Often, disabled people strive to be empowered, as opposed to being cared for in a traditional sense and view risk-taking as their choice and an essential part of empowerment (Abbott & McConkey, 2006; Duggan & Linehan, 2013; Garcia Iriarte et al., 2014; W. Mitchell & Glendinning, 2008). In contrast, many social care workers predominantly see themselves as caregivers (McConkey & Collins, 2010). While managers view the ability to manage risk as a determinant of service quality, and it is not uncommon for the quality of service delivery to be linked with the service's ability to minimise risks (Stein et al., 2010). Nonetheless, not many studies have focused specifically on the perceptions of managers in relation to managing service user risk-taking, although one Swedish study did find some managers expressed the view that service users should not be overprotected and should make even those choices that may seem "bad" (Bergström & Wihlman, 2011, p. 173). This was to some extent confirmed by this study, as views varied between individual managers.

In terms of differences between individuals within different stakeholder groups, it is clear that while confidence and independence in inputting into risk decisions fluctuated considerably between service users, individual social care workers and managers tended to differ around assessing, managing, and approaching risk in general. It was found that professionals' views of how risks should be managed vary to such an extent that some practitioners do not agree with the manner in which other professionals manage risks. In particular, it is evident that more liberal practitioners do not subscribe to what they perceive to be the conservative

and overly-cautious approaches to risk applied by some of their colleagues (European Union Agency for Fundamental Rights, 2014; Robertson & Collinson, 2011). Though the literature is far from extensive in this area, a distinction between practitioners who employ empowering and supportive approaches to service delivery and those who apply approaches that are more in line with traditional protective models of care have been noted (Duggan & Linehan, 2013; Garcia Iriarte et al., 2016). This was similarly observed in this study in relation to managers as well as practitioners. Some managers feel that the health, safety and safeguarding of service users are paramount, while others think that promoting risk-taking in a positive manner is essential in person-centred social care. As such, the situation is perhaps best described as one shaped by a continuum of risk perceptions.

At the over-protective or cautious end are social care workers and managers with a firmly risk-averse approach influenced by factors such as a fear of reputational damage for themselves and for the organisation, being held accountable, losing their job, or by an inclination to follow more traditional biomedical models of care. In part, this can be attributed to a perceived culture of blame, which has been known to cause anxieties for practitioners (Douglas, 1992; Furedi, 1997; Kemshall, 2009; Morgan et al., 2016; Robertson & Collinson, 2011).

In addition, the legacy of previous care models can influence how risk is managed, particularly amongst professionals who had worked in institutions long-term and who carry the legacy of institutional attitudes and are consequently risk-averse (Mansell et al., 2007). At this end are also service users who lack confidence in risk-taking, often because of previous experiences in long-term institutional care. While it is increasingly emphasised that service users should be encouraged to take greater



control over their lives (W. Mitchell & Glendinning, 2008), much support is needed if this control is to be assumed by disabled people who were institutionalised and for many years and thus were unable to exercise their right to make choices and take risks. Some service users simply lack the confidence, experience, and skills around risk-taking, which the current study identifies as a considerable barrier to service users' independence.

At the other end of this continuum of risk perceptions are social care workers and managers with a more liberal approach to risk-taking, who are often well educated about the rights-based and social model of care, and those service users who acquired their disability later in life and, as such, have more life experience and are better able to make decisions around risk. While managers and practitioners that occupy this end of the risk continuum often disagree with the more traditional and prudent approaches of their colleagues, they are in the minority, which reflects the slow pace of change and the large volume of work still to be done. It would appear that while risk management strategies in social care can range from controlling to empowering ones (Stalker, 2003), the former commonly prevail (S. Donnelly et al., 2019; Stalker, 2003; Whitelock, 2009). In short, it generally makes more sense to adopt a rule of thumb of overestimating risk, as in this way, practitioners make sure that risk is not underestimated, as the latter can have far more potential negative consequences (Tuddenham, 2000; Whittaker & Havard, 2016).

If such considerations remain as yet unknown, the points highlighted from this study contribute to understandings of the challenges faced by managers, practitioners, and service users around positive risk-taking and help to explain why safety can often overrule autonomy when it comes to service user risk-taking (Barry, 2007; L. Brown, 2010; Carr, 2011; M. Donnelly, 2019; S. Donnelly et al., 2019; Killick & Taylor, 2020; Munro,

2010; Robertson & Collinson, 2011; Scottish Executive, 2006; Stalker, 2003; Stanford, 2010; B. Taylor, 2005; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whittaker & Havard, 2016). Certainly, there is the potential for the tensions between risks and rights to hinder the delivery of person-centred services (Robertson & Collinson, 2011; Robinson et al., 2007), particularly where there are approaches or practices that start to be more and more restrictive to the point where they could be viewed as even coercive (Robertson & Collinson, 2011).

An important finding from the present study that helps to account for these significant differences in risk approaches between individual managers and practitioners is the variation in how duty of care is perceived, understood, and operationalised. When professionals consider a services user's risk-taking, they also consider their professional duty of care (B. Taylor, 2005; B. Taylor & McKeown, 2013; N. S. D. Taylor, 2008). While many managers and social care workers understand duty of care as a mixture of protection and empowerment (Hawkins et al., 2011), this study found that the former more often wins out. Managers and practitioners who define duty of care primarily in terms of protection tend to strive to minimise risk. In contrast, are managers and practitioners who perceive duty of care as having a strong empowerment component and as the duty to recognise autonomy (Hawkins et al., 2011), who tend to respect and promote service users wishes and choices around risk. It is clear that if services are to advance toward increased person-centeredness, then perceptions of duty of care that continue to nurture risk averse approaches must be abandoned, as they can construct potential barriers to the implementation of individualised social care (Carr & Robinson, 2009)

Another factor that helps explain subjectivity and variances in risk management strategies in practice is the observed differences in

professionals' attitudes and views of risk in connection to service user vulnerability. Staff perceptions of service user competence, or its lack, which are often latent, influence how risk is managed, and a stereotypical view of services users as vulnerable can affect service users risk-taking prospects, as well as their involvement in risk decision-making (W. Mitchell & Glendinning, 2008). Moreover, perceptions of vulnerability play a significant role in assessing which risks are acceptable or which risks are too great (Carr, 2011; Carr & Robinson, 2009; Ray et al., 2008). Here, the findings of this study revealed a culture of distinguishing between acceptable and unacceptable choices for service users, informed by moral undertones around lifestyle choices. For instance, smoking or consuming alcohol were often viewed as unacceptable risks for service users and, as such, service users were frequently discouraged from making such choices. This discouragement was often justified by a desire to keep service users healthy. While this was caused predominantly by the general desire of staff to apply a 'better safe than sorry' approach, it was compounded greatly by often exaggerated perceptions of service user vulnerability amongst staff and by the felt moral obligation to shield service users from risks that are viewed as 'unhealthy' or 'wrong'. There was a near-standard view amongst managers and practitioners that disabled people are more vulnerable than non-disabled people, and although this can be justified in some respects, such generalisation pose problems, in particular where lifestyle choices are involved.

This may be reflective of a broader view connected to biomedical models, which placed disability in a medical context that regarded it as something that requires treatment (Goering, 2015). In many ways, clinical professionals are concerned with "identifying groups who are vulnerable to specific types of illness, and...seek to make vulnerable groups aware of

their heightened risk and encourage them to take action to minimise this risk” (Alaszewski, 2013, p. 382). Thus, some managers and practitioners can feel that it is their primary responsibility to judge which lifestyle choices are morally right and wrong and identify any potential risks to service user health and minimise such risks. Overemphasising service users health status, however, can place service users more akin to the position of a patient and social care professionals in the corresponding position of a clinical professional.

Tensions experienced by social care professionals and managers must also be explored against the backdrop of their health-promotion responsibilities. Risk discourse has been linked to health and lifestyle choices (S. Brown et al., 2013; Lupton, 2005; Robinson et al., 2007). In disability services, safeguarding and promoting service users’ health frequently guide how social care is delivered to the extent that a failure to prevent ill-health consequences of service users lifestyle choices can be perceived as a malfunction of care. Indeed, some managers and practitioners have been overly preoccupied with service users clinical needs to such an extent that they felt that they could justify making decisions on behalf of service users if it is for ‘the good of their health’. Risk assessments were often then used to justify these interventions (Stein et al., 2010). These overly-cautious approaches to service users health can contribute further to labels of vulnerability. Exaggerated labels and perceptions, in turn, can lead to service users being discouraged from risk-taking, resulting in a near self-fulfilling prophecy (Neill et al., 2009; Parley, 2011; Veselinova, 2014). This can further contribute to paternalistic approaches to practice with over-protective or even restrictive elements (Barry, 2007; L. Brown, 2010; Carr, 2011; S. Donnelly et al., 2019; Killick & Taylor, 2020; Munro, 2010; Scottish Executive, 2006; Stanford, 2010; B.

Taylor, 2005; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whittaker & Havard, 2016). Nonetheless, if services are to move to more personalised and person-centred delivery, then this cycle of perceived excessive vulnerability will need to be broken.

It would be hard to challenge the notion that promoting health falls within the vast remit of a social care practitioner and that the true wellbeing of a service user can be achieved only through an approach that is holistic, multi-sectoral, and multi-strategic (Rootman, 2001). Indeed, a partnership across health and social care systems can provide holistic services with a more pronounced emphasis on health promotion replacing excessive medicalisation and curative approaches in the health and social care sectors (Naidoo & Wills, 2009, 2010; Health Services Executive (HSE), 2011a; World Health Organisation (WHO), 2009). It is proposed that:

A mandate of reorienting the health services should support the needs of individuals and communities for a healthier life, and open channels between the health sector and broader social, political, economic and physical environmental components (WHO, 2009, p. 4).

When considering the health and wellbeing of disabled people holistically, a multidimensional perspective must be applied, taking into account the social determinants of health (Frier et al., 2018). Obstacles linked to the label of disability are known to be directly interconnected a range of social determinants of health for disabled people, including insufficient housing supports, inadequate employment and income, poor access to transport, and lack of social and personal relationships (Frier et al., 2018; Kavanagh et al., 2015). In addition, disabled people do not have adequate access to health and social care services (Groce & Tranj; 2009). These unfavourable conditions and inherent societal inequalities ultimately result in reduced

quality of life, shortened life span, and heightened risk of ill-health (Wilkinson & Marmot, 2006; Wolbring, 2011). Consequently, disabled people are often considered to be vulnerable and susceptible to ill-health (Groce & Trani; 2009; World Health Organization (WHO), 2015).

The interviews highlighted the genuine concerns of practitioners and managers who linked their views of service users vulnerability to their perceptions that service users experiences around risk-taking are limited. In discussing this connection between service users vulnerability and their ability to assess risks, capacity arose in a majority of interviews with both social care workers and managers. Although capacity tends to be associated mainly with people with the label of intellectual disability or people with mental health difficulties, it has been acknowledged that its application is wide-ranging, from the ageing population to people with acquired brain injuries, developmental or psycho-social disabilities, or people with fluctuating capacity (Davies et al., 2019; M. Donnelly, 2019; James & Watts, 2014; Ni She et al., 2020; Simmons & Gooding, 2017; Wade & Kitzinger, 2019).

It is evident that there is a general lack of clarity surrounding capacity and what it means in adult disability services. Although managers and practitioners describe capacity as an essential aspect of service users decision-making around risk, what this means in practice is not entirely clear, and social care workers and managers often feel uneasy about this lack of clarity. Indeed, this dearth of understanding of the term has been noted internationally (Davies et al., 2019), which is hardly surprising considering that the manner in which capacity has been defined has changed radically throughout the world in recent years. In Ireland, the outdated 'Ward of Court' system (Lunacy Act of 1871) will be replaced by The Assisted Decision-Making (Capacity) Act. Nonetheless, along with

legislative reforms, this framework will necessitate a cultural change in how capacity is understood and how positive risk-taking is approached (Morgan et al., 2016). Certainly, this “will require a shift in practice”, and managers and practitioners will need to accept that even those decisions that they deem to be “unwise” belong to service users (Ni She et al., 2020). Capacity will only be linked to a particular issue, time, and context, while no one will be deemed incompetent to make decisions in general terms (Ni She et al., 2020). This is a crucial point in changing the mindset around risk, as, within this new capacity framework, no one will be deemed to be unfit to be in control of their own life, even if extensive support is required to facilitate this control. Moreover, this lends further weight to the argument that risk is becoming a matter of individual responsibility and that service users are becoming increasingly responsible for the management of risk.

Undoubtedly, the assisted decision-making framework seems particularly relevant to changing the ethos of social care practice, as it is designed to initiate new ways of providing care by ensuring less risk-averse and more person-centred services (S. Donnelly et al., 2019; Ni She et al., 2020). However, it also fits within a responsabilisation agenda and broader neoliberal reforms that seek to encourage disabled people to become more fully responsible for their choices and risks. Nevertheless, the implementation of the capacity framework is still in its early days, and thus neither managers nor practitioners are entirely sure how this framework will inform decision-making around risk. Capacity is an essential component in risk decision-making, and once implemented, this framework has the potential to further emancipate disabled people by changing how risk is approached and by placing the service user “at the centre of decision making” (Ni She et al., 2020, p. 2). However, careful consideration and adequate supports, training, and resources are required if this framework

is to empower service users in a meaningful way as opposed to merely transferring responsibilities to service users (Roulstone & Morgan, 2009). For example, if service users make unhealthy choices, such as drinking, smoking or eating unbalanced diets, will this become the mechanism through which to engage in service withdrawal or reduction on the grounds that it was their choice? Similarly, without training and support services could, for instance, spend unwisely, and what might this mean if bills couldn't be paid? Indeed, without these considerations, service users can find themselves in a very vulnerable position, which could hardly be described as empowering.

While the Assisted Decision-Making (Capacity) Act was enacted in 2015 and will be instigated in 2021, there is currently no active legislation to govern instances when the capacity of a service user to make a particular decision is absent. In such cases, it is expected that health and social care professionals will act in the best interest of the service user (National Consent Advisory Group, 2013). Understandably, this can mean more uncertainty for social care professionals, and this uncertainty came across very strongly in the interviews, not least because what is seen as best interest is often subjective. Certainly, the implementation of capacity legislation in practice will require a multidimensional approach focusing not only on policy but also on education and practice (Davies et al., 2019; M. Donnelly, 2019). Given the novelty of this legislation, there has been little time for the literature to examine how supported decision-making will be implemented (Arstein-Kerslake et al., 2017; Davies et al., 2019; Ni She et al., 2020), and thus its connection to risk is yet to be both realised fully or investigated.

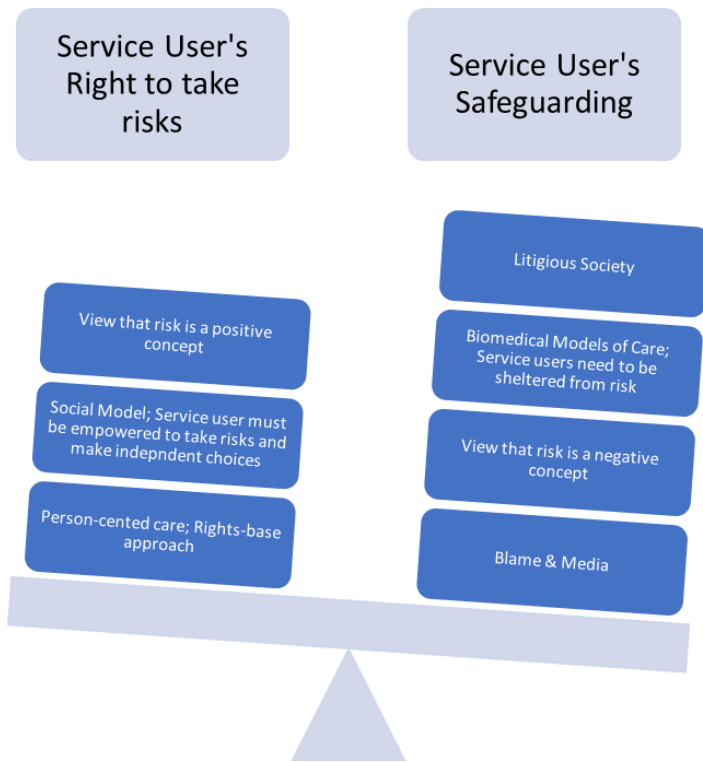
If the above demonstrate how risk management is mediated by often exaggerated perceptions of service users vulnerability, incomplete



understanding of capacity, by practitioners and managers varying interpretations of risk assessments and duty of care, as well as by their concerns and worries, it also helps to identify how paternalistic approaches to risk can impose limitations on service user independence. While service users can feel vulnerable in some aspects of life, predominantly in the realm of physical frailty, such as being more vulnerable to falls as a result of impaired mobility, above all else, service users “value rights, independence, choice and support” (Wallcraft, 2012, p. 142).

The above considerations point to the subjectivity of managing risk and the tensions experienced by managers and practitioners in balancing service users' rights with their autonomy (see Figure 6). These considerations help to draw attention to how managers and practitioners anxieties and views can influence service user risk-taking and that the challenges they experience have the potential to hinder service user opportunities to take risks. This study is largely in keeping with Irish studies, which found that while practitioners “place considerable emphasis on the rights of individuals”, they are “reluctant to take risks” (National Disability Authority (NDA), 2010b, part 6) and that concerns over risk and safety can suppress the empowerment of service users in practice (A. Power, 2013b).

**FIGURE 6** BALANCING RISKS & RIGHTS



## Defensive practice and regulatory compliance

The calls for independence in social care have occurred in an increasingly marketised environment leading to a cross over between economic and social policies. Moreover, recent reforms of adult social care have evolved against the backdrop of austerity cuts that have often targeted welfare services and disabled people (A. Power, 2013a; Taylor-Gooby, 2012). In Ireland, it has been argued that vulnerable people have been “sacrificed” at the altar of the neoliberal reforms of the welfare system (Van Aswegen, 2019, p. 438). While the move from institutional to rights-based independent care has been promoted on the grounds of equalising rights and enhancing social inclusion, it has also decreased state intervention and intensified the focus on service users and social care practitioners responsibilities (W. Mitchell & Glendinning, 2008; Van Aswegen, 2019). Indeed, “under the guise of ‘choice’ and ‘freedom’, self-regulation operates subtle workings of power that rely upon individual responsibility” (Burch, 2017, p. 97). This rearrangement of responsibilities between the state and individuals can be felt in both the individualisation of adult social care (Scourfield, 2007) and the regulation of the social care profession (Byrne, 2016; Graham, 2015). Recent reforms in social care happened in tandem with a neoliberal agenda that is concerned primarily with expenditure cuts and the transfer of liabilities to the private market (Burch, 2017; Ferguson, 2007; Fyson, 2009; Leece, 2004; Pearson, 2000; Stainton, 2002; N. S. D. Taylor, 2008).

In this climate, the security and protection once afforded through the state, human solidarity and altruism, has been substituted by financial compensation and private insurance (Rose & Miller, 2010). Following a

neoliberal agenda that strives to roll back areas of state provision to make them ripe for market provision, the state is seeking to attempt to create conditions in social care where market provision can emerge and flourish. This suits the state in many ways keen to shift to the market the costs associated with permanent jobs, pensions, and other entitlements, to produce a leaner state. This can be seen, for instance, in increasing agency staffing, which has become common in disability services (Cantwell & Power, 2016). Although disability services in Ireland are provided mainly by state-funded voluntary organisations, services for children and older people have been largely privatised (Kenny & Power, 2018). Nevertheless, these trends can also be anticipated in disability services (Kenny & Power, 2018; M. Power, 2017). Certainly, the disability sector represents a significant and as yet untapped market for private providers.

In Ireland, as in many other capitalist countries, these considerations have had significant ramifications for disability services. The responsibilities of service users are increasingly emphasised in disability policy, which advocates for disabled people to “autonomously take control”, make “informed choices”, and take responsibility for their risks (Graham, 2015, p. 600). However, it is rather challenging to foster an increase in service users’ choice and social inclusion against the backdrop of decreasing resources (Fleming, McGilloway, & Barry, 2016; Kenny & Power, 2018). Disability services have experienced significant funding cuts in recent years (Disability Federation of Ireland (DFI), 2019), and thus, perhaps unsurprisingly, there is a clear divide between policy and practice. The policy seeks greater 'freedom' and 'choice' for services users, while at the same time, there is little investment in the resourcing of the supports needed to facilitate such approaches (Lymbery, 2012). This was echoed in the interviews. While the policy places a strong emphasis on service users

taking control, becoming responsible, and making informed choices, in reality, service users' choices remain limited due to lack of resources and overprotective or even restrictive approaches that are often used in practice.

A similar disconnect has been identified by a recent study around social inclusion in Ireland, which found that policy aims are not always reflected in the lived experience and that there are continuous limitations to service users' choice and social inclusion (Kenny & Power, 2018). This has been assigned to policy moving too fast, with limited supports being put in place (Fleming, McGilloway, & Barry, 2017), as well as services fear and the consequent that encourages defensive practice (Kenny & Power, 2018). Thus, it would seem that while there is a rhetoric of choice and independence in disability services, service users are still very much limited by what is available, and service user choices are "shaped by the focus on risk assessments, regulatory compliance and responsibility" (Kenny & Power, 2018, p. 12).

Thus, notions of independence are intertwined with responsibility and choice, and while it is increasingly emphasised that service users should be able to purchase the services they wish to receive, this does not always mean increased independence (Antaki et al., 2009; W. M. L. Finlay et al., 2008; Fullana et al., 2019; Jingree et al., 2006) not least because it is often Hobson's choice, as what services have to offer is the only real choice available. Moreover, service users who are less able to exercise choice will, therefore, have increasingly limited options. For example, a service user may wish to access a community service as an individual but is restricted by the available staff and transport, which often results in group activities "it's like everyone get on the bus, you might as [sic] well have our colours" (Kenny & Power, 2018, p. 9). Thus, it is not that service users can take

control and choose when they go to a coffee shop or a gym, rather the circumstances are determined for them based on available resources or, more precisely, by their lack, particularly when funding is under pressure (Kenny & Power, 2018). Another noteworthy example is individualised supports and funding, through which disabled people may have the option to live independently from their family, but their options to choose whether or whom to share their home with are commonly minimal (Fisher et al., 2021). Certainly, this was supported by the interviews, where both social care practitioners and services users provided several examples of service user choices and independence being limited by a lack of resources. For instance, in the vignettes, many interviewees described situations in which a service user would only be able to smoke a cigarette, have a shower, or choose the consistency of their food or drink if there was a staff member available to supervise them. Nonetheless, it was clear that staffing levels are often an issue and as such, service users' choices were limited to certain days and times.

A recent study that undertook a critical discourse analysis of the Comprehensive Employment Strategy for Disabled people 2015–2024 describes it as “trapped between the dominant discourses of ableism and neoliberalism” (Van Aswegen, 2019, p. 454) and highlights that the strategy is replete with normalisation terms, such as ‘being employed’ and ‘independent’ (Van Aswegen, 2019). Within this study, it is clear that while it is advocated that service users should take responsibility for risk and become less dependent, not much attention, training, or resources has been allocated to support service users in achieving this goal in a meaningful way. While it is apparent that different groups of service users require different supports around risk-taking, there is no evidence that would suggest that these supports are being tailored to meet these varying

needs. Moreover, social inclusion policies rather assume that communities understand differences and are accommodating and welcoming (Kenny & Power, 2018; National Disability Authority (NDA), 2017; A. Power & Bartlett, 2018). Thus, it can be argued that rather than becoming independent and autonomous in the real sense of the word, service users have no real option other than to become responsible and at the same time 'less dependent' on the state.

Here, it is crucial to recognise the neoliberal discourse that uses risk to normalise acceptable behaviour and to define concepts and actions that are undesirable (Burch, 2017). Economic policies and responses to risk have led to the creation of the notion of responsible citizens, in which people are considered to be independent, rational, and prudential actors (Kemshall, 2010). Meanwhile, these seemingly liberated individuals are stimulated to make choices deemed as acceptable and rational (Burch, 2017; Rose & Miller, 2010; Scourfield, 2007), which was also located in the findings of this study, where there was a strong consensus amongst managers and practitioners that service users should be encouraged toward certain choices and risks and discouraged from others. It is argued that risk is used to "reinforce a neoliberal agenda" (S. Brown et al., 2013, p. 333). In addition, risk assessments are "informed by a fear of being held accountable" (Kenny & Power, 2018, p. 12) as well as practitioners' moral judgment and used to establish and justify boundaries around how much risk-taking is acceptable and which risks should be avoided. For instance, it is perceived as desirable for a service user to engage in risk-taking that may result in less dependency, such as going into a shop alone or seeking employment. At the same time, service users should be discouraged from partaking in undesirable risk-taking such as alcohol consumption. Indeed, it is evident that in many instances, service user risk-taking is guided by the

needs of the service as oppose to the wishes of the service user (Kenny & Power, 2018; Morgan et al., 2016). In this environment, there is very little room for spontaneity, which is a key element of independence, as everything has to be risk assessed and documented, especially if there are any potential health concerns (Kenny & Power, 2018; Morgan et al., 2016).

In light of such considerations, especially against the increasingly litigious backdrop in Ireland (Cusack, 2000; Kenny & Power, 2018), where an investigation follows almost every instance when something does not go to plan, practitioners and services fears around accountability can hardly surprise. Indeed, in the near future, practitioners' anxiety may be heightened with the introduction of registration with CORU. Certainly, the establishment of a register now creates the possibility of being removed from that register, effectively ending the person's career. While previously, the worst-case scenario might have been perceived as being dismissed from an organisation, removal from the register raises the stakes considerably. Though the risk of such a situation may be very small, the extent of the potential consequences may add to the concerns of practitioners. There have been concerns expressed that risk is an instrument used to assign blame to professionals in adverse situations (Douglas, 1992; Waterson, 1999). This, compounded by the avoidance of the costs of negligence (McDonald, 2010; B. Taylor, 2005; B. Taylor & McKeown, 2013), as well as unfavourable media coverage, has led to practice increasingly being conducted in a defensive manner (Barry, 2007; L. Brown, 2010; Carr, 2011; S. Donnelly et al., 2019; Killick & Taylor, 2020; Munro, 2010; Scottish Executive, 2006; Stanford, 2010; B. Taylor, 2005; B. Taylor & Whittaker, 2017, 2018; Warin, 2010; Whittaker & Havard, 2016). The interviews demonstrated consistently that social care professionals feel anxious about the potential negative consequences of supporting



service users in taking a risk, which has been demonstrated by continuous worries and uncertainty around who is responsible if something goes wrong (Glendinning, 2008; Hasler, 2003).

Notions of defensive practice were reflected in the findings of this study via two phenomena. Firstly, social care workers and managers sought to share or shift responsibility to either service users or other colleagues. Secondly, managers and practitioners used risk assessments and other administrative mechanisms as an element of cover. Indeed, while they also viewed them as an unpractical bureaucratic burden, managers and practitioners felt under pressure to risk-assess “everything” (Kenny & Power, 2018, p. 12) and to implement robust risk preventive measures with a lengthy paper-trail of risk assessments to protect themselves. This sharing out of accountability for risk decisions and strict following of formalised procedures further reflect the broader shaping forces of neoliberalism and have been observed previously in child protection practice and amongst nurses (Whittaker, 2011; Whittaker & Havard, 2016). Similar patterns have been noted in the UK, where practitioners seek to “reduc[e] the weight of responsibility” often through “ritual task performance”, continuous “checks and counterchecks”, by involving others in decision-making, and by shifting responsibility to managers (Whittaker, 2011, p. 486). This sharing to reduce responsibility also manifested in practitioners seeking to involve other practitioners in decisions that carried a significant amount of responsibility (Whittaker & Havard, 2016). Although this study reflects the findings of Whittaker’s and Havard’s (2016) work, it also found that managers more commonly use these patterns. While practitioners clearly engage in “upward delegation to managers” (Whittaker, 2011, p. 486), it is evident from this study that managers likewise engage in a downward delegation of responsibilities and

that while some level of downward delegation is to be expected, the present study has linked this delegation of responsibilities mostly to the management of risk in situations that are spontaneous and thus not pre-risk-assessed by managers. At the same time, where there are concerns around potential liability managers tend to opt for a multidisciplinary approach where responsibility can be shared between other professionals.

Another important theme that emerged in this study and further confirmed the influence of the neoliberal project in disability services was that this shifting of responsibility is not limited to practitioners and managers, and responsibility is also being shifted to service users. This was demonstrated through a discourse around informed choices. In disability services, it is common to use terminology such as ‘an informed choice’ or ‘informing about risks’ (Health Information and Quality Authority (HIQA), 2019a, 2019b, 2019c; National Consent Advisory Group, 2013; Rowlett, 2009). In an environment where risks and responsibilities are increasingly individualised (Graham, 2015), it appears logical that as long as a service user understands the risks associated with their choices, the liability for the repercussions of these choices rests with that service user. Nonetheless, it was evident from the findings here that this ‘informing’ is often more about setting up cover rather than making service users fully aware or more prepared to take risks. Practitioners themselves often do not feel informed about risks, and a lot of the time, they work “with significant amounts of unknown information when making judgements as to the wisdom of risk-taking by service users and deciding on what actions to take” (Robertson & Collinson, 2011, p. 161). The appearance of giving a choice and documenting informing can be seen as shifting responsibility onto the service user while also appearing compliant with regulations. Put simply, social care workers often find themselves in the invidious position

of needing to be seen to provide choice while remaining acutely aware of being vilified if they do should the consequences turn out to be negative.

Thus, as Whittaker (2011) has pointed out, the practitioners' default position is one informed by a view that “following rules and being compliant can appear less risky than carrying the personal responsibility for exercising judgment” (Munro, 2010, p. 6). This preoccupation with ensuring that the paperwork is compliant often takes precedence and dominates day-to-day workloads, which can compromise the relationship and the time spent with service users (Robertson & Collinson, 2011; Whittaker, 2011). Indeed, it has been suggested that this can mean that service users “deprivation and needs will not be addressed because more time will be spent talking about them, meeting about them, writing about them and reporting on them than caring for them” (Howard, 2012, p. 40). Moreover, it reduces the opportunities to develop relationships that support practitioners understandings around service users values, orientation and goals, and what a service user might view as acceptable or necessary risks in pursuit of an aim of importance or value to them.

While it is no doubt the default position that it is safer to follow the rules and administrative tasks to the letter, abandoning creativity and replacing human interactions with paperwork can only undermine the very nature and ethos of social care practice (Howard, 2012; Howard & Lyons, 2014; Macdonald & Macdonald, 2010; Munro, 2010; Parton, 1998; Trevithick, 2014). Moreover, if risk assessments continue to be considered more valuable than professional judgment (Barry, 2007; Broadhurst et al., 2010; Manthorpe, 2007; W. Mitchell et al., 2012; Parton, 1998), social care workers are likely to lose their professional confidence as their skills are underutilised (Barry, 2007; Scottish Executive, 2006). In this study, although risk assessments provide a certain sense of security, they also add

to anxiety around risk-taking, not only for managers and practitioners but also for service users. Social care workers and managers were concerned over the possibility of failing to adequately perform the vast number of tasks required when supporting service users in activities involving risk. At the same time, service users feel that there is little room for spontaneity, as everything must be pre-planned and pre-assessed in terms of risks.

Although there is a substantial commentary on practitioner perceptions and experiences around risk, there are also considerable gaps in knowledge around the involvement, perceptions, and experiences of service users in risk assessments and risk-related decision-making. In addition, few studies have considered the day-to-day “realities of defensive practice” (Whittaker & Havard, 2016) and even less so from the perspective of service users. This study sought to contribute to addressing these gaps. It found that service users are concerned over the amount of paperwork that is required with every activity and notes that social care workers and managers frequently seek to avoid the kinds of situations that represent potential risks partly because of this. Service users also feel that the focus on risk assessments is exaggerated and inappropriate. At the same time, service users feel bound by the outcomes of risk assessments and obliged to follow recommendations on which activities they should avoid. It is noteworthy that some service users behave differently in the presence of staff and only feel free to revert to their daily routine, which often involves taking risks only when staff are gone. As such, the general sense is that the outcomes of risk assessments or the advice or opinion of a professional mean something more instructive than just guidance or a recommendation. Indeed, from the interviews with all three groups of stakeholders, it is clear that if a service user does not comply with organisational risk management policies or the recommendations of a risk

assessment, there can and has been a withdrawal of service.

Understandably, this causes severe significant concern and anxiety for service users, which can result in some service users becoming very passive and obedient.

This resembles the insurance trade, which does not provide insurance cover to those who are not prepared to comply with a specific set of rules, avoid certain risks, and act responsibly (Rose & Miller, 2010). For instance, those that do not secure their vehicle sufficiently by locking it or storing it in a suitable location are not covered against theft, as they are seen as willingly taking the risk of their vehicle being stolen and thus responsible. Similarly, those service users who are knowingly engaging in what may be perceived as reckless or risky behaviour may lose their service. As such, for the service, these service users are viewed as a risk. Certainly, within this study, service users constantly felt under the threat of losing their service if they did not comply with the services' guidelines and recommendations of risk assessments. Moreover, from the interviews with managers, it was clear that service users' fear of losing their service was not ungrounded. Managers confirmed that if service users did not comply with risk assessment guidelines, there was a possibility of the service being withdrawn. This is very much a reflection of the neo-liberal backdrop, which uses an adversarial litigious framework to apportion blame and allocate compensation. Where there is a market for legal services and insurance cover to protect against risk, which reflects the risk society (Beck, 1999, 2006, 2009a, 2009b, 2012; Lash, 2000; Webb, 2006b), insurance companies strive to pass the consequences on to the person, if they can be blamed for making the 'bad decision'. Through this responsabilisation process, insurance companies avoid liability.

Under social democratic forms of state organisation, there was a recognition of the inherent riskiness of life, and the idea was collective responses through redistribution of risk of ill-health, for instance. However, with the growth of neoliberalism, responsible citizens are expected to manage risks and “take the necessary precautions...through private insurance” (Kemshall, 2002, p. 43). The relationship of the state and its citizens has been reconstructed from a political/legal to an economic/legal one, in which producer and consumer play a central part (G. Taylor & Power, 2011). Consumers are increasingly stipulated to become thus responsible for the management of risk.

Against the backdrop of a growing focus on avoiding insurance costs, it will come with a little surprise that one of the key findings of this study was the lack of involvement of service users in risk decision-making (Wallcraft, 2012). It was found that even when services include service users in discussions around risk (B. Taylor & McKeown, 2013), their participation in decisions around risk is still uncommon (Fullana et al., 2019). Although it is crucial for service users to be actively involved in the management and the assessment of risk (Barry, 2007; Killick & Taylor, 2020; Mantell, 2010; Ottmann et al., 2017; Stalker, 2003; B. Taylor & McKeown, 2013; Whitelock, 2009), as their input is invaluable (Stalker, 2003), this study found that service users are not included in risk assessments, even where they directly refer to their care plan or wellbeing. Yet, it has been argued that in line with the participatory principle of health promotion, it is crucial that “all health promotion initiatives...involve those concerned in all stages of planning, implementation and evaluation” (Canavan, 2013, p. 19). Participatory approaches in both health promotion and social care lay the foundations for empowerment (Canavan, 2013; World Health Organisation (WHO), 2006). The involvement of service users

in discussions around risk is not part of standard procedure and is something that is very much dependant on practitioner initiative and discretion (Robertson & Collinson, 2011). As such, the level of involvement, if any, can depend on the relationship between the practitioner and the service user (Robertson & Collinson, 2011). Thus, not only are risk assessments that play a significant role in service users' day to day lives are often performed in their absence (Carr, 2011; Robertson & Collinson, 2011), but also the time that could be spent developing relationships is frequently spent documenting assessments, informing, and engaging in risk management processes. Not least because, in many ways, the provision of service represents a risk to the organisation.

Service users lack of involvement in risk assessment is concerning, particularly given that risk assessments have a significant impact and power over service users lives (Langan & Lindow, 2004; Robertson & Collinson, 2011). Moreover, service users often disagree with the recommendations of risk assessment, and along similar lines, practitioners disagree with how their colleagues respond to risk (Robertson & Collinson, 2011), and as this study has shown, this also applies to managers. With varying degrees of disagreement around risk, it would appear especially relevant and vital to involve service users (Langan & Lindow, 2004; Robertson & Collinson, 2011). Service users should be equally involved in the management of risks (Langan & Lindow, 2004; Robertson & Collinson, 2011). However, it is clear that standardised approaches to risk management "where decisions regarding risk are made at the level of the organisation and applied to all service users" (Hawkins et al., 2011) do not respond to individual needs and preferences of service users. This is because while the neo-liberal view is that services will respond to choices by service users to meet customer demand, the reality is that this does not

happen in the same way as consumers do not really control what is being offered by the market. Instead, the market controls what is being offered to the consumer. In a similar fashion to where a home becomes uninsurable after it has been flooded, where a service user engages in something considered too risky the service is withdrawn.

Not only do the above considerations point to an alarming lack of empowerment of disabled people in social care services, but they also point to an abundantly clear gap in the promotion of self-advocacy amongst service users. Advocacy, one of the most powerful strategies of health promotion (WHO, 2006), can be described as “a combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or programme” (WHO, 1992, p.2). It is a social care professionals duty to advocate for the rights and needs of service users and speak on their behalf when it is required (Goodbody, 2004). This is embedded in the Code of Conduct and Ethics for social care workers, which states social care workers “must respect, and where appropriate, advocate on behalf of service users” (CORU, 2019, 1c, p. 8). Thus, advocacy goes hand in hand with empowerment, especially when supporting self-advocacy in service users. Indeed, advocacy is “a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf” (Citizens Information Board, 2007, p.7). Despite the indisputable need for advocacy in disability services and emphasis on this in social care education (Canavan, 2013), the interviews suggest it is often overlooked in practice.

Furthermore, the findings of this study have shown that while risks are managed in accordance with risk assessments, which are the domain of managers, and more often than not, clinical professionals social care



workers are often completely “disconnected from higher-level decisions” (Robertson & Collinson, 2011, p. 159). This, of course, is because if social care practitioners act and make decisions, they might make a ‘bad one’, and that is a risk to the service. In such cases, the responsibility could not be transferred to the service user. It is argued that not only do uniform approaches to risk management ‘from a distance’ fail to take into account the individuality and views of each service user, but they also disregard their strengths, weaknesses, and autonomy (Hawkins et al., 2011). Moreover, in an environment where practitioners are “unable to tailor standardised risk management approaches to the goals and wishes of the service users,” it is highly unlikely that they can support their independence and risk-taking in a meaningful way (Hawkins et al., 2011). This is a further reflection of the shaping context in which managing the risk to the service outweighs managing the risk to the service user. If these considerations point to increasingly formalised ways of managing risk in social care, it is apparent that practitioners’ judgment and knowledge around risk are often not considered in formalised risk assessments (Hawkins et al., 2011; Robinson et al., 2007). This study confirms that practitioners, but also service users, find risk assessments developed from a distance by managers and clinical professionals impractical and, they also feel that their function is less to benefit service users and more to protect the organisation and manager.

Furthermore, this study suggests that this lack of appreciation for the expertise of social care workers has also been internalised. As well as managers, some social care workers deemed other professionals, such as nurses or general practitioners, as more qualified in assessing risk. This sense of inferiority was assumed, in particular by practitioners who do not have a social care degree. Currently, in disability services, there is no

requirement to employ staff that are qualified social care workers and “the level of training or qualification required is at the discretion of the employer” (Health Information and Quality Authority (HIQA), 2017a, p. 14). Many employers expect a Major Award at Level 5 in QQI (Quality and Qualifications Ireland) Health Service Skills, QQI Community Health Services, or QQI Healthcare Support, for instance (Frontline Training Services, 2017). It was reported that practitioners without the level 7 qualification in social care are mostly dismissive of social care as a profession and feel that clinical professionals are more suitable to make decisions around risk. Qualified social care workers noted general negativity toward having a degree and described a divide between social care qualified and unqualified staff, which was also noted by others (M. Power & D’Arcy, 2018). In this climate, it is not difficult to appreciate social care workers’ experiences of feelings of powerlessness to enact their professional values.

This feeling of powerlessness, a lack of recognition, and a “sense of disempowerment” have been reported in a recent study of statutory registration awareness amongst social care workers in Ireland (M. Power & D’Arcy, 2018, p. 30). This study has found that “social care is often viewed as the ‘poor relation’ both within services and by other professions” (M. Power & D’Arcy, 2018, p. 16). It pointed to organisational structures in which clinical professionals, such as nurses, continue to dominate managerial positions in social care, especially in disability services (M. Power & D’Arcy, 2018). It also observed that some social care workers feel that there is very little difference in terms of reward and recognition between ‘qualified’ and ‘unqualified’ staff and that social care workers feel disheartened as a result (M. Power & D’Arcy, 2018).

This study has found that social care workers approach to service

user risk-taking can be influenced by their educational background. It was reported in the interviews that staff with a degree level 7 or above in social care approach risk in a less interventionist way than others and that social care workers without this qualification are not as confident in managing risk and hence tend to seek guidance from clinical professionals even in non-clinical situations. Some managers and social care workers have ascribed this to the previous dominance and legacy of the medical model in which clinical staff, such as nurses, dominated disability services. Remarkably, a similar point was raised by two service users who noted that social care professionals with a degree are more empowering and approach risk in a less controlling way than other staff. It has been identified that practitioners without formal education in social care require training around human rights and person-centred care (Windley & Chapman, 2010). Indeed, “having a skilled and knowledgeable workforce is an imperative” (Rycroft-Malone et al., 2016, p. V).

## Conclusion, implications, and recommendations for social care

This study has shown that risk in disability services is a complex and subjective concept that is perceived in various ways. It has demonstrated that social care practitioners, managers, and services users perceive risk from varying perspectives and thus approach risk differently.

Understanding these perspectives matters a great deal because how risk is approached in practice can influence service users autonomy and independence.

This study has identified how adults using disability services experience and perceive risk and how they approach risk in day-to-day life. There is a clear connection between service users' ability to live an autonomous life and social care practitioners' competence to support them in achieving this goal. Nonetheless, while disabled people want to engage in positive risk-taking and make choices around risks, the findings here show that service user risk-taking remains limited, and their involvement in decision-making around risk is almost always lacking. There is a clear indication that risk-aversion remains to the fore within social care and that managers and practitioners find the balancing act between ensuring safety and supporting empowerment to be a real challenge.

In particular, it is clear that a dominant political paradigm in which risk and disability are becoming a matter of individual responsibility is reflected in the current climate in disability services. While disability services are being individualised, the role of the state in protecting the welfare of disabled people is gradually fading. At the same time, in an increasingly litigious society and against a backdrop of moral panic and

blame, health and social care professionals are often perceived as a potential liability to the state, and thus many such professions are becoming rigidly regulated, frequently in a heavily documented manner.

Given such constraining forces, social care professionals find it hard to step back from their protecting role when it comes to service user rights to take risks, and thus service users can feel that choices are limited to what services deem safe options. This study has identified how social care workers and managers in disability services experience and perceive risk. It found that often social care professionals and managers face similar dilemmas when approaching risk in day-to-day practice. Practitioners are compelled to comply with ever-expanding sets of rules, which manifests most obviously in adhering to the recommendations of risk assessments strictly and documenting all service user activities in detail. Moreover, risk assessments tools used in practice are subjective, and assessments are often performed by other professionals, with the input of social care workers and service users overlooked or ignored completely. In large part, this is because of hierarchical structures and cultures in disability services that value the input of other, mostly clinical, professionals more so than the input of social care workers and service users. At the same time, it is evident that social care workers skills and expertise in facilitating positive risk-taking are invaluable, and thus it would seem that while social care professionals do 'the heavy lifting', this often goes unrecognised. If this lack of recognition of social care professionals is to be addressed, it would require commitment from the HSE and the voluntary sector in accepting and promoting social care professionals as experts in disability services.

This situation is further compounded by ideas and perceptions of service users' vulnerability that are often exaggerated, which in many ways is related to the frequently deeply felt obligation of social care workers and

services to keep disabled people 'safe'. This is shaped substantially by an intensive focus on risk management and a fear of litigation in services, which was powerfully demonstrated throughout the findings, and while empowerment and choice are advocated, risk prevention commonly dominates decision-making. As such, any attempts to harmonise service users' choices with staff responsibilities represent ongoing challenges for both managers and social care workers.

It is evident not only that the stakeholder groups perceive risk differently, but there are also obvious differences between individuals within each of the three groups; as such, there are both 'intra' and 'inter' group differences. This spectrum of interpretations of risk is extensive, and the management of risk is thus challenging, inconsistent, and at times incoherent. At one end are professionals and managers with a firmly risk-averse approach influenced by factors such as a fear of reputational damage, being held accountable, losing their job, or by an inclination to follow more traditional biomedical models of care. At this same end are those disabled people who had been institutionalised and thus have never had the opportunity to build confidence in risk-taking. In contrast, At the other end are professionals and managers with a more liberal approach to risk who are frequently informed by a rights-based social model of care and those disabled people who had not been institutionalised.

It is further clear from this study that people born with disabilities and those who acquired disabilities later in life perceive, experience, and approach risk differently. Standardised risk assessments are a blunt instrument, as they do not respond to different levels of need of individual service users. While it is evident that this is shaped mainly by the previous experience of institutionalisation, how this variation impacts service users ability to participate in positive risk-taken needs to be further investigated.

This could inform future training around positive risk-taking and form part of social care education that could potentially guide practitioners in how to support different groups of service users in risk-taking appropriately.

Interestingly, the findings also highlighted a gap between what managers and practitioners say that they do and what they actually do in practice. Choice and empowerment are widely discussed principles but not implemented consistently. Indeed, it was found that although managers and practitioners openly discuss a rights-based approach, service user rights are often subordinated by concerns over issues relating to risk. There is scope for participatory action research to explore this gap between positive risk-taking theory and practice.

These findings are concerning, and any efforts to address these issues and the tensions faced by social care professionals and managers in balancing the safeguarding and empowering aspects of care in an increasingly rigidly regulated environment will require more than one approach. Nonetheless, it is clear that the involvement of service users in risk-related decisions should be a priority going forward. Moreover, further research, specific training and education should be sought to guide services and practitioners in how positive risk-taking can be implemented and how a health promotion model of social care can be successfully introduced in practice. Furthermore, proper consideration needs to be given to how supported the decision-making framework will be in practice. This study underscores the need for social care providers and policy-makers to prioritise addressing the gaps in knowledge and experience of capacity identified in this study in order to clarify the role capacity will play in service user decision-making and the management of risk in disability services. Furthermore, research into how service users can be included in the assessment and the management of risk is especially necessary

(Ottmann et al., 2017; Wallcraft, 2012). Understanding how best to involve service users in decisions around risk would become a valuable tool in developing more coherent policies in disability services.



## Limitations

While every effort was made to recruit a diverse sample for each of the three participant groups, the sample was relatively small and geographically limited to the West of Ireland. This, therefore, limits generalisability. In addition, it can be anticipated that those participants recruited via the snowball method may have presented with a higher level of agreement as they were likely to share the views of their colleagues who had suggested them. In addition, given that the participants knew the interviews were about risk, the most risk-averse people were unlikely to have volunteered. Finally, the disabled participants had predominantly been labelled as having physical rather than intellectual or other disabilities, and thus the findings may not be as applicable to services and service users in different types of services.

It is also important to acknowledge the potential influences of the changing regulatory context of social care work and the impending capacity framework. Registration for social care workers was on the near horizon at the time of the interviews<sup>24</sup> and had been a topic of discussion, debate, rumours and misinformation for some time. As there has been no registration requirement for social care workers previously, this introduction of registration has undoubtedly brought risk and regulation issues into sharp focus. The changing capacity framework no doubt further compounded this focus on risk. Traditional outcome or status-based

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<sup>24</sup> “The Social Care Workers Registration Board has decided that the opening of the Social Care Workers Register, which it had hoped to open in 2022, will now open in 2023” (CORU, 2020, para. 1).

capacity assessments strongly emphasised risk in determining whether a person can or cannot make decisions. While there is no place for such assessments in the new capacity framework, which suggests functional approaches to determining capacity, this means significant changes in the rhetoric around risk. Thus, participants were likely to be cognitively more attuned to topics such as risk, regulation, and especially the role and input of social care workers. Finally, all participants held a degree qualification and the vast majority (90%) had a level 8 degree qualification. This would not generally be reflective of disability services.

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## Appendices

### **Appendix 1: Vignettes**

**Please, read the following scenarios carefully and rate the severity of the risk using the risk assessment tool provided below.**

Bernie is a fifty-two-year-old female who has been diagnosed with spinal bifida and hydrocephalus as a child. She is a wheelchair user and lives in a two-bedroom apartment, which is fully adapted and equipped for her physical needs. She lives alone and utilises care support services provided by a local organisation for disabled people.

#### **Vignette 1**

Although Bernie is a smoker, she is very respectful of all staff supporting her, and she never smokes while they are present in her apartment. Bernie goes to bed around five in the evening and stays in bed until eleven in the morning. Although it may seem like a long time spent in bed, it is Bernie's requirement mainly due to her poor skin condition but also due to staffing levels and shift times. While in bed, Bernie likes to have her cigarettes, a lighter and her ashtray available on her bedside table, as she likes to be able to have a cigarette should she wish so throughout the night.

#### **Vignette 2**

Bernie requests to have her shower when she gets up in the morning. She is very weak on her feet. Her physiotherapist and her occupational therapist have recommended that two members of staff would support Bernie while in a shower. The manual handling assessment for Bernie's

shower calls for the use of a hoist with the support of two care support practitioners. Bernie is aware of the recommended safety procedures, which should be followed, but she likes her privacy and alone time. Occasionally, Bernie asks her support staff to leave her alone while in the shower. When this happens, staff will wait until Bernie calls them back, which could often take as long as forty minutes.

### **Vignette 3**

A couple of years ago, Bernie began to experience some swallowing problems when drinking and eating. She would also cough extensively and would get chest infections frequently. When someone has swallowing difficulties or dysphagia, there are risks associated with food and drinks being swallowed incorrectly or in an unsafe manner. A common way to manage swallowing difficulties is to thicken food and drinks to a consistency considered safe and appropriate for the person by a Speech & Language Therapist (SALT). Bernie was referred to the therapist, who completed the SALT assessment. The assessment recommended that Bernie should be on a modified diet (grade 2 fluids, texture B food). A thickening powder should be used to achieve the desired consistency. This could help Bernie in preventing reoccurring chest infections and swallowing difficulties. It could also decrease the risk of choking significantly. Bernie follows these recommendations generally. However, at times Bernie would have a fizzy drink or a glass of wine when she would decline the use of the thickener, as she enjoys these types of drinks in their natural consistency. In these instances, Bernie will not use the thickening powder and chooses to take risks associated with her decision.

<b>RISK RATING tool</b>					
<b>Severity/ Likelihood</b>	<b>Insignificant</b>	<b>Minor</b>	<b>Moderate</b>	<b>Severe</b>	<b>Catastrophic</b>
<b>Almost Certain</b>	Low	Low	Moderate	High	High
<b>Likely</b>	Low	Low	Moderate	High	High
<b>Possible</b>	V.Low	Low	Moderate	High	High
<b>Unlikely</b>	V.Low	V.Low	Low	Moderate	High
<b>Rare</b>	V.Low	V.Low	Low	Moderate	High

## **Appendix 2: Interview Schedule/Guide**

### **Interview Schedule/Guide**

Interview Schedule – ‘**Risk in Adult Social Care: Perceptions and experiences of risk in disability services in Ireland**’

#### **Service Users**

Before we begin, I would like to reiterate that the contents of this interview will be treated in the strictest confidence. All data from this and other interviews, which may be contained in any subsequent reports or publications, will be reported globally so that no individual can be identified. I would also like to take this opportunity to remind you that you are free to withdraw at any point and that no reason for withdrawal need be offered. Finally, please confirm that you are comfortable with this interview being recorded.

- Male \_\_\_ Female \_\_\_
- Age range: 18--30 \_\_\_ 31--40 \_\_\_ 41--50 \_\_\_ 51--60 \_\_\_ older than 60\_\_
- Can you tell me a little bit about yourself and how long have you been living independently?
- How long, if ever, have you lived in an institutionalised setting?
- How would you define risk and risk assessment?
- Can you give me an example of something you would consider very risky and something you would consider mildly risky?

- What risks do you encounter in your life?
- Do you feel more vulnerable? Do you feel more vulnerable than other people that may not have physical disabilities?
- Do you need help in making choices around risk?
- Do you think that non-disabled people perceive risks differently from you? If yes, why?
- How do you understand the relationship between risk and choice?
- Do you engage in risk-taking?
- When you decide to do something risky tomorrow would you just go ahead and do it?
- Can disabled people evaluate risk and risky activities the same as non-disabled people?
- Do you feel that disabled people need to understand risks when making decisions/choices?

### **Social Care Workers and Managers**

Before we begin, I would like to reiterate that the contents of this interview will be treated in the strictest confidence. Data from this and other interviews, which may be contained in any subsequent reports or publications, will be reported globally so that no individual can be identified. I would also like to take this opportunity to remind you that you are free to withdraw at any point and that no reason for withdrawal need be offered. Finally, please confirm that you are comfortable with this interview being recorded.

- Male \_\_\_ Female \_\_\_
- Age range: 18--30 \_\_\_ 31--40 \_\_\_ 41--50 \_\_\_ 51--60 \_\_\_ more than 60\_\_
- What is your qualification and what year did you qualify in?
- How long have you been working with disabled people?
- How would you define risk?
- What are risk assessment and risk management? And who should be in charge of them? Who should take part in the process? Do you participate in risk assessments?
- Can you give me an example of something you would consider very risky and something you would consider mildly risky in your life?
- Can you give me an example of something you would consider very risky and something you would consider mildly risky in a service user's life?
- What risks do you think disabled people encounter in their lives? Do they encounter more risks than you?



- Do you think that disabled people perceive risks differently from you (the same risk, the same activity)? Can disabled people evaluate risk and risky activities the same as you?
- Do you feel that disabled people need to understand risks when making decisions/choices?
- How do you understand the relationship between risk and choice in your profession? What is the current relationship between risk and choice in your workplace?
- Do you feel that organisational policies, particularly those around health or safety, influence service users' opportunities of doing what they like? How? Why?
- Do you think that disabled people are supported around making risky choices?
- Are disabled people who utilise services free to make any choices they wish to make?
- Do you support service users when they decide to make risky choices?

## **Appendix 3: Participants Information Sheet**



Jarka Velartova

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### **Participant Information Sheet**

#### **'Risk in Adult Social Care: Perceptions and experiences of risk in disability services in Ireland'**

Dear Sir/Madam,

You are being invited to take part in a research study that is exploring perceptions of risk in disability services. Before you decide to take part, it is important for you to understand the purpose of this study. This Participant Information Sheet will tell you about the aim, risks and benefits of this research study. If you agree to take part, you will be asked to sign a Consent Form. If there is anything that you are not clear about, I will be happy to explain it to you. Please take as much time as you need to read the information provided. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision.

Thank you for reading this.

#### **Purpose of this study**

This research will explore understandings that surround the manner in which risk is experienced and perceived by individuals with physical disabilities, social care workers and social care managers.

### **Taking Part**

You have been asked to take part in this study because of your first-hand experience with disability services. It is entirely up to you to decide whether you would like to participate. If you decide to participate, you will keep this information sheet and will be asked to sign a consent form. Even if you decide to participate, you can choose to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect you or your rights in any way. You can change your mind anytime without any consequences.

### **If you decide to take part...**

You will be asked to participate in a one-to-one interview which should take approximately one hour. In the interview, you will be asked to talk about your experiences and views of concepts such as risk, choice, autonomy, health, safety and independence in disability services. With your permission, the interview will be audio-recorded. The recording will be used for transcription purposes only. Please, feel free to stop the interview any time.

### **Confidentiality**

Any information provided by you will be treated in strict confidence. Throughout the study, identifier numbers rather than names will be used on files, and pseudo-names/nicknames will be used in written works. The results of this study will be submitted within a thesis as part of my PhD work, and reports or publications may also be produced. In any of these works, no individual or organisation will be identified, and only the

pseudo-names/nicknames will be used. Any information surrounding individuals, such as age or gender, will only be presented in a global form, for example, '6 of the participants were male and age between 21 and 30 years of age'.

**What are the possible benefits of taking part?**

Taking part in this research will contribute to knowledge and understanding of risk in social care practice. In particular, it will help researchers to understand how risk is perceived by service users, social care workers and service providers.

**What are the possible disadvantages of taking part?**

There are no foreseeable risks attached to taking part in this research study.

**What happens at the end of the study?**

The results of this research will be submitted as part of the work for my PhD, and the results may be published. No individual will be identifiable in any publication that results from this study. Should you have any questions during or after participating in this study, please feel free to contact me at - J.VELARTOVA1@nuigalway.ie

**Researcher signature:**

*If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie.*

