The risk of good intentions: How professional systems shape risk, respect, and outcomes for people with disability

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Statement of originality

This is to certify that the content of this thesis is my own work. This thesis has not been submitted for any degree or purposes. I certify that the intellectual content of this thesis is the product of my own work, and that all the assistance received in preparing this thesis and all sources have been acknowledged.

Joanne Ragen

Supervisor's certificate

This is to certify that the thesis entitled: The risk of good intentions: How professional systems shape risk, respect, and outcomes for people with disability, submitted by Joanne Ragen in fulfilment of the requirements for the degree Doctor of Philosophy is in a form ready for submission.

Professor Anita Bundy

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Dedication

To all who have stood to protect the rights of disabled people—past, present, and still fighting. This work stands because you did.

Abstract

Disabled people frequently navigate systems that frame risk as something to be avoided or controlled. While often grounded in good intentions, these systems—through policy design, professional practices, and cultural assumptions, can restrict autonomy, stifle participation, and disrupt opportunities for ordinary flourishing.

In this qualitative study, I draw on Critical Disability Theory, Human Rights Approaches, and Hope Theory to explore how disabled people experienced and resisted risk-averse systems to live the lives they wanted. In-depth interviews with 24 people with physical disability aged 12-56 years, and 4 parents of adolescents with disability were included in the analysis.

The findings are presented through three interconnected results chapters. Chapter 4 reveals how policy enacted through the everyday decisions of professionals created barriers that limited choice, undermined autonomy, and disrupted opportunities for ordinary flourishing. Chapter 5 identifies four interrelated strategies—becoming proud, understanding rights, reframing risk, and building wise networks—used to reclaim agency and forge pathways in risk-averse environments. Chapter 6 distinguishes operational respect from genuine respect. In the final chapter, I conclude with a fresh theoretical model of risk and respect in disability practice and call for structural reform grounded in rights, recognition, and lived expertise.

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CHAPTER 1

Introduction

Throughout my life and work, I have encountered what I call the risk of good intentions—well-meaning actions which, despite their positive intent, often lead to unintended consequences. This concept is deeply personal, shaped by my own experiences of growing up with disability, where I often had to prioritise other people's comfort, particularly around risk, over my own needs and aspirations. Under the guise of protection, I was often reassured that "they mean well", even when these good intentions limited my autonomy and participation.

The risk of good intentions surfaced again in my professional roles across aged care, youth services and in disability service contexts, where I saw firsthand how protective measures, framed as support, could create barriers. In these environments, decisions were often made about disabled people rather than with them, reinforcing paternalistic structures that undermined autonomy. I recall one instance where an adult client with disability was forced to wear a jumper during a summer storm—not because she was cold, but because support staff did not want to "deal with her having a cold".

As an intersectional researcher and educator, I have critically engaged with this concept through multidisciplinary collaborations, including the Sydney Playground Project (Bundy et al., 2011; Bundy et al., 2015), which explored risky play for children with and without disability. Here the risk of good intentions became particularly visible in well-meaning interventions designed to minimise harm but which, in practice, restricted opportunities for growth, autonomy and self-determination. Over-cautious approaches, intended to protect, often stifled the very experiences essential for learning, resilience and agency.

Risk and uncertainty are fundamental to daily life (Tulloch & Lupton, 2003) and essential for personal growth and flourishing (Seligman, 2011b). However, disabled people frequently face additional barriers when navigating these everyday experiences. Stigma, discrimination and overprotective interventions not only create structural disadvantages (Wilkinson-Meyers et al., 2015) but also place the burden on disabled people to actively assert their right to risk—a right inherent in an ordinary life.

The risk of good intentions has become a central theme in my research, shaping my exploration of everyday risks and the right to take them as part of an ordinary flourishing life. Therefore, this research begins with the question: How do disabled people and their families navigate professional advice and services in the context of everyday life, particularly in relation to risk?

In this chapter, I introduce this concept as a foundation for the thesis and explain the motivations behind this research. I also examine the role of professionals in shaping disabled peoples' experiences of risk and decision making, grounding the research in Critical Disability Theory (CDT) (Goodley et al., 2017; Pothier & Devlin, 2005; Shakespeare, 2006), and Human Rights Approaches (HRA) (Kanter, 2007; Kayess & French, 2008; United Nations, 2006). Finally, I outline the structure of the thesis, framing how these discussions will unfold in the chapters ahead.

Navigating language in disability research

Because language is a powerful tool in shaping perceptions of disability and advocacy (Campbell, 2009; Goodley, 2014; World Health Organisation, 2011), it is important to clarify my approach to terminology in this thesis. The terms I choose—whether "disabled people", "people with disability", or collective pronouns like "us" and "we"—are intentional and serve different purposes depending on context.

In disability advocacy and critical disability studies, I use the term “disabled people” to acknowledge disability as an integral part of identity. This choice aligns with a rights-based perspective, challenging the stigma that positions disability as something to be ‘overcome’ (Goffman, 1963; Healey & Titchkosky, 2022; Jacobsen & Smith, 2022). It asserts that disability is a valid and central aspect of who we are, inseparable from our lived experiences.

In educational and professional practice settings, I often shift to person-first language, such as “people with disabilities”. This is a strategic choice that serves as a gentle reminder to audiences who may be less familiar with the complexities of disability identity that disabled people are people first, with inherent dignity and rights. Here, language becomes a teaching tool, encouraging reflection and understanding.

At times, I use collective terms like “us” and “we” to foster solidarity within the disability community. These terms emphasise the shared experiences, struggles and collective advocacy of disabled people, highlighting the importance of community-driven narratives.

I also recognise and respect that language is deeply personal. Many individuals claim terminology that best reflects their own identity, whether using terms like Deaf person, reclaiming words like crip, or rejecting identity-first language altogether. These choices reflect the diversity and richness of disability identity, reinforcing that language is not fixed but dynamic, evolving alongside social and political contexts. As my friend, the late Stella Young (2014, 2018), powerfully asserted, language can also be a source of pride and protest. Her reclaiming of the word crip was a political act, grounded in defiance, ownership and a refusal to be reduced to euphemism or pity.

Throughout this thesis, readers will encounter these variations in language. My choices are deliberate, shaped by audience, purpose and the aim of fostering nuanced discussions around disability, risk and autonomy. By intentionally shifting between identity-first and person-first language, I aim to challenge assumptions, create teachable moments and emphasise the complexities of disability while advocating for respect, dignity and the right to risk.

Personal narrative: An ordinary life

Let me begin by introducing myself.

I move through the world with both hands—ambidextrous in more ways than one. I create with ink, with colour, with flavour, sketching moments, preparing meals and expressing ideas through art. I live with an intense and irrational fear of cockroaches, but am deeply fascinated by geckos, turtles and frogs. In my personal life, I am the organiser, the planner, the problem-solver. I carry the maps, the lists and the unspoken weight of holding things together. Professionally and politically, I am a calculated risk taker, a community builder and an educator. I am a researcher committed to social justice, an advocate for systemic change and someone who continues to believe in the possibility of better. I am also a disabled person—whole, complex, not here to inspire you.

You may wonder why I begin with this kind of introduction. The reason is simple: despite increasing discourse about disability, many people still struggle to see disabled people as individuals living full, ordinary and flourishing lives. My introduction is a quiet refusal. A reminder. A challenge to that perception.

Despite my rich and complex identity, there remains an ongoing tension between how I understand myself and how others perceive me as a disabled person. These moments of misalignment are often the most difficult—not because of my impairment, but because of the socially constructed rules and interventions that intrude in the name of inclusion. These intrusions can be overt or subtle, fleeting or lifelong, but their ripple effects are hard to escape.

They show up in loud, patronising tones and unsolicited intrusions. It is the extra planning, negotiations and effort needed for routine healthcare, education or employment, and it is in every inaccessible space that serves as a reminder that I am not considered in the same way as those without disabilities.

Navigating these everyday spaces demands energy, wisdom and confidence every single day, and the risks of not addressing these barriers can be significant. The Australian Institute for Health and Welfare (2022b) highlighted just how widespread these challenges remain. People with disability are twice as likely to experience discrimination as those without disability. Among those people with disability who experienced discrimination in the previous year, 82% avoided situations, 74% had lower income levels and 70% reported high or very high psychological distress.

As Konrad (2021) described, the process of repeatedly negotiating these everyday spaces leads to what she calls "access fatigue"—the cumulative exhaustion that comes from continually justifying one's right to participate. The energy required to push back against barriers is not infinite and, over time, the weight of repeated negotiations takes a toll, reinforcing the very exclusion that policies claim to prevent.

These experiences, while deeply individual, are not isolated. They reflect broader systemic and historical patterns that continue to shape the lives of disabled people. Understanding these patterns requires a look at how global shifts in disability policy and rights—particularly through the Convention on the Rights of Persons with Disabilities (CRPD)—have aimed to transform these realities.

The promise of the Convention on the Rights of Persons with Disabilities (CRPD)

Disability in Australia, as in many parts of the world, has been shaped by evolving societal attitudes and policies. Historically, disabled people were institutionalised, and disability was framed as a medical problem to be solved by professionals (Barnes et al., 1999; Shakespeare, 2006). This medical model locates disability within the individual, viewing impairments as deficits to be fixed or managed. This perspective marginalised disabled people, excluding many from education, employment and social life (Goggin & Newell, 2005). In contrast, the Union of the Physically Impaired Against Segregation (UPIAS) argued that disability results not from impairment itself, but from the social and structural barriers imposed by an inaccessible and exclusionary society. Later formalised by Mike Oliver (1990, 1983), the social model of disability shifted attention from personal impairments to external disabling conditions, including architecture, social attitudes, institutional policy and systemic discrimination (Barnes et al., 1999; Shakespeare, 2006). The social model laid the groundwork and became a key driver for the global disability rights movement, exemplified by the rallying cry, Nothing About Us Without Us (Charlton, 1998), demanding legal reform, anti-discrimination laws and international frameworks grounded in dignity and equal participation.

As these ideas evolved, the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) marked a step toward a more integrated understanding. The ICF introduced a biopsychosocial model that aimed to bridge the gap between medical and social models. It recognised that disability arises through the interaction between individual impairments and environmental and contextual factors, offering a more rights-aligned, holistic view of participation and health.

As understandings of disability continued to evolve through the social and the global disability rights movement, the Human Rights Approaches reframed disability not only as a social or political issue, but as a matter of justice, dignity and legal obligation (United Nations, 2006; Kayess & French 2008)). While the social model of disability challenged exclusion by identifying physical, attitudinal and systemic barriers, human rights approaches took this further by asserting that states and institutions have legal and ethical responsibilities to remove those barriers and ensure the equal participation of disabled people. Where the social model centred exclusion, human rights approaches centre accountability.

The most significant formalisation of this shift came with the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006. The CRPD was the first international human rights treaty to be developed by and with disabled people, and it provided a comprehensive legal framework for upholding dignity, autonomy, participation and non-discrimination. As Kayess and French (2008) noted, the CRPD moved disability from a matter of welfare to one of rights, grounding the experience of exclusion in a legally recognised framework of injustice.

Global leaders publicly acknowledged this shift. On the day the CRPD was adopted, the then United Nations Secretary-General Kofi Annan, (2011), declared a new era for disabled people, free from discrimination. High Commissioner for Human Rights, Louise Arbour, also emphasised that the CRPD filled a long-standing gap in international law, ending what she described as a "protection vacuum" that had, in practice, left disabled people behind.

Ratification of the CRPD undoubtedly raised expectations for governments, policy makers and healthcare and disability service professionals at all levels to ensure all people enjoy their rights and freedoms as equal citizens. While disability policies now often emphasise autonomy, dignity and equal opportunity to meaningful participation, the gap between rhetoric and practice remains (Emerson et al., 2018; Smyth et al., 2024).

These historical shifts provide a backdrop for understanding how past legacies and ongoing challenges shape the lives of disabled people today. In this context, the role of professionals—as individuals whose influence can either uphold or undermine the rights the CRPD seeks to protect—becomes central.

What role do professionals play?

The healthcare sector has long played a defining role in shaping understandings of disability, influencing not only medical definitions but also the social, cultural and structural conditions that affect the lives and opportunities of disabled people. In my experience, professionals across education, employment and social services become a common presence in the lives of many disabled people. These professionals provide support, offer guidance, and frequently occupy positions of power in shaping access to support, resources and participation.

Many professionals position themselves as allies, working within policy frameworks and best practices guidelines to promote access and support participation. When professionals genuinely embrace their role as allies, they contribute to a rights-based approach that upholds autonomy, self-determination and meaningful participation. Nonetheless, the influence that professionals wield is significant. How professionals act can either advance or undermine the rights the CRPD aims to protect (Fisher et al., 2021).

Understanding this dynamic is critical to addressing systemic barriers. It also requires reflection. My own lived experience and professional background intersect with the systems I critique—offering both insight and responsibility.

Researcher positionality and professional background

This brings me to my own position in this work not only as a researcher but as someone whose life has been shaped by these systems and relationships. My journey into this research is deeply rooted in both my personal experiences and professional roles. As a person with physical disability, I have lived through the everyday challenges and opportunities that disability brings. These experiences have shaped my worldview (Mills & Sanchez, 2023) and fuelled my passion for disability advocacy and research.

Service and leadership

Over the years, I have taken on various direct service, advisory and leadership roles in youth, community and disability advocacy projects, collaborating directly with individuals and groups to foster rights and self-determination. My contributions to clinical governance, project design and leadership, and advisory roles have had a direct impact on service delivery, policy review and formation, professional development and training.

Teaching and research

In parallel, I have also worked in academic settings. Alongside my PhD studies, I have held teaching and supervisory roles in allied health, guiding emerging and experienced professionals in fields such as occupational therapy, physiotherapy and exercise and sports sciences. These roles have not only strengthened my expertise in disability, education and professional practice but have also reinforced the importance of interdisciplinary collaboration.

As part of a multidisciplinary research team, I contribute to studies on risky play for children, both with and without disabilities (Bundy, 2024; Bundy et al., 2008; Bundy et al., 2009; Bundy et al., 2011; Bundy et al., 2015). This work, along with research on reframing risk perceptions for parents and teachers (Grady-Dominguez et al., 2021; Niehues et al., 2013; Spencer et al., 2016), highlights the critical role of everyday risk in fostering skill development and autonomy, which is essential for all individuals, regardless of disability status.

While my work in service, leadership, teaching and research is deeply meaningful, my strongest passion lies in community development. These are the spaces where I feel most at home—where knowledge and action meet. One example of how these values materialised outside formal structures is Wishbone Day, a grassroots initiative that emerged during this research.

Wishbone Day

I founded Wishbone Day in response to a growing need within my community for a space where people could navigate life with disability on their own terms. Unlike a formal organisation or association, Wishbone Day operates without paid staff, sponsorship, or external funding. Instead, it exists as a social movement driven by the collective voices of individuals with osteogenesis imperfecta (i.e., OI, or brittle bones), who share their experiences and perspectives in ways that are most meaningful to them.

The purpose of Wishbone Day was to raise awareness of the diverse lives of people with OI, highlighting both the challenges we face and the solutions we create in pursuit of full and meaningful lives. Although not formally part of my research proposal, Wishbone Day became a valuable learning tool. The model it fostered and the communities that formed around it offered firsthand insight into the power of collective storytelling and self-representation, and the ways in which disabled people create spaces for advocacy and support on their own terms.

This experience, alongside many others, deepened my understanding of how disabled people shape their own lives and futures, often outside formal systems. It also reinforced the importance of lived experience, community knowledge and self-determined approaches to change.

These experiences—my personal journey with disability, my professional roles in education and advocacy, and my research collaborations—have all converged to shape my approach to this study. Through my research, I aim to contribute to ongoing discussions about disability, risk and autonomy, advocating for the recognition of everyday risks as essential to the full realisation of human rights for disabled people.

This thesis research has been both professionally and personally significant. I conducted all interviews myself, beginning each by sharing my own story—openly disclosing my physical disability, community involvement and professional background. This transparency helped foster a sense of trust and mutual respect, creating a space for participants to share their experiences with honesty, insight and confidence. Their narratives form the foundation of this research.

Theoretical framework

In this thesis, I draw on three interconnected frameworks: Critical Disability Theory (CDT) (Garland-Thomson, 2018; Goodley et al., 2017; Pothier & Devlin, 2005; Shakespeare, 2006), Human Rights Approaches (HRA) (Kayess & French, 2008; United Nations, 2006), and Hope Theory (Snyder, 2000, 2002). I did not begin this research with a rigid theoretical framework; instead, these perspectives became meaningful as the study evolved—through engagement with participant narratives, reflection on my own positionality and the incorporation of constructive feedback from supervisors and examiners.

Each framework contributed something distinct. CDT (Goodley et al., 2017; Pothier & Devlin, 2005; Shakespeare, 2006) and the HRA (Kayess & French, 2008; United Nations, 2006) helped me examine the systemic and structural barriers that shape disabled people's access to autonomy, dignity and participation. Hope Theory (Snyder, 2000, 2002) added a cognitive and relational dimension, helping me understand how people sustain motivation and navigate toward self-determined futures, even when systems make that difficult. Together, these frameworks offer a way to hold systems to account while recognising the resourcefulness and agency of disabled people, whose lives are often defined by negotiation, adaptation and resistance.

Critical Disability Theory

Critical Disability Theory provides the foundation for this research. It highlights how systems—rather than impairments—create exclusion (Garland-Thomson, 2018; Goodley, 2014; Goodley et al., 2017; Meekosha & Shuttleworth, 2009; Shakespeare, 2006). CDT encourages a critical examination of the policies, professional practices and cultural assumptions that sustain exclusion.

What resonates most with me in CDT is its commitment to lived experience as expertise. It recognises disabled people as experts in their own lives and calls for meaningful involvement in designing the systems that affect us. This is not abstract for me—my own experience gives me insight into how these dynamics play out, and a sense of responsibility in how I hold systems to account.

Human Rights Approaches

Alongside CDT, I use Human Rights Approaches (HRA) to foreground the ethical and legal dimensions of disability rights. Rooted in the Convention on the Rights of Persons with Disabilities (CRPD, 2006), the HRA frames autonomy, dignity and participation not as optional or exceptional, but as entitlements that must be actively upheld (Kayess & French, 2008).

This approach rests on four key principles: dignity, autonomy, participation and accountability. It helps me stay focused on the obligations of institutions and professionals—not just to do better, but to dismantle the structures that maintain exclusion. What I value about the HRA is that it does not rely on good intentions. It insists that meaningful participation is a right, not a favour—and that systems must change to reflect that.

Hope theory: Agency and pathways

While CDT and HRA helped me frame structural and ethical issues, I turned to Hope Theory (Snyder, 2002; Snyder et al., 2002) during data analysis to better understand how people keep going, despite the barriers they face. Hope Theory defines hope as a cognitive process with two key components: agency (the motivation to pursue goals) and pathways (the ability to identify routes to those goals) (Snyder, 2002).

I introduced Hope Theory to frame how participants described navigating barriers and reclaiming autonomy in everyday life. It helped me see these responses not as isolated acts of determination, but as reasoned, hopeful actions in response to systemic failure. It also allowed me to explore how people reimagine possibility in constrained conditions, and what that reveals about the systems we must navigate.

Complementarity of frameworks

These three frameworks together shaped my approached to this thesis:

- Critical Disability Theory helps me name and interrogate systemic inequities, professional power and the practices that reinforce exclusion.
- Human Rights Approaches anchors the work in legal and ethical obligations, reminding us that dignity and autonomy are not negotiable.
- Hope Theory offers a way to understand how people hold onto possibility, and why that matters in systems that often limit it.

I draw on these frameworks throughout the thesis. They inform my examination of systemic and professional barriers (Chapter 4); the strategies people develop to navigate them (Chapter 5); how respect influences autonomy, risk and participation (Chapter 6); and the final conclusions (Chapter 7).

This approach reflects both my professional understanding and my lived experience. It has helped me stay grounded in the real-world consequences of the systems I write about, and to hold space for the futures disabled people imagine for themselves. In doing so, this research adds to a growing body of work calling for structural reform, community-led approaches and deeper respect for disabled people’s knowledge, lives and leadership.

Research aims and objectives

In this research, I sought to understand how people with physical disability and their families navigated professional advice and everyday risks, with a focus on achieving the life they want.

Research Objectives

- Examine the impact of professional advice on autonomy, dignity and participation.
- Identify strategies used by disabled people to navigate risks and barriers.
- Investigate factors that help or hinder disabled people in achieving fulfilling lives.

Structure of the thesis

In this chapter, I introduced the risk of good intentions as a foundation for this thesis and explained the motivations behind this research. I also positioned the role of professionals in shaping disabled peoples' experiences of risk, autonomy, and participation, grounding this study in Critical Disability Theory and a Human-Rights approach.

The chapters that follow explore these ideas in depth:

Chapter 2: Literature Review situates this research within existing scholarship on disability, risk, autonomy and flourishing.

Chapter 3: Methodology outlines the research design, participant selection, ethical considerations and analysis approach.

Chapters 4-6: Findings and Analysis present and interpret key findings, drawing on participants' experiences to illustrate how risk, autonomy and professional interventions shape disabled people's lives.

Chapter 7: Discussion & Conclusion synthesises the key insights, connecting them to broader theoretical and policy frameworks; reflects on the implications of the research; and proposes directions for future work in policy, practice and advocacy.

By weaving together lived experience, professional insights and participant voices, this thesis advocates for a shift in how risk is understood in relation to disability—not as something to be avoided or controlled, but as a fundamental aspect of self-determination, learning and an ordinary, flourishing life.

CHAPTER 2

Literature review

Consistent with qualitative research principles, I adopted an iterative and reflexive approach to reviewing the literature (Ezzy, 2002). This approach emphasises adaptability in keeping with the study's exploratory nature and the complex, context-driven factors involved (Charmaz, 1990; Varpio et al., 2017). Rather than conducting a one-time, static review, I engaged with the literature dynamically (Ezzy, 2002), with a two-way interplay between the literature and the insights and themes emerging from the data. As new themes were identified, I revisited and refined the literature review, deepening engagement with established and newly relevant literature.

Table 2.1 summarises the literature review process, including databases, search terms, inclusion and exclusion criteria, screening methods, thematic analysis and conceptual frameworks. This process was adopted to ensure that the review comprehensively addressed the corpus of interdisciplinary research relevant to the study's aims. In this review, I synthesise and critique literature related to two central questions: "What risk?" and "Whose risk is it?" These questions are key to understanding how risk is conceptualised and experienced by disabled people in their everyday lives, and the role professionals play in shaping these experiences.

Table 0.1 Structured overview of literature review strategy and key components

Component	**Details**
Databases and Sources	PubMed: Healthcare-related research, focusing on professional practices in disability. Scopus: Interdisciplinary research in social sciences, health, and policy research. PsycINFO: Insights into autonomy, agency, and risk-taking in psychology. Google Scholar: Access to grey literature & policy documents. Web of Science: Professional behaviour, ethics, and respect in disability

Keywords and Search Terms	Core Disability and Risk Terms: Disability /Disabled people / People with disabilities / Physical disability / impairment / Risk / Risk-taking / Dignity of risk / everyday risk / positive risk / therapeutic risk. Professional Practice and Interventions: Professional practice / Professional Behaviour / Professional Roles / Professional Responsibility Risk Management / Risk Assessment / Risk Frameworks Theoretical and Conceptual Frameworks: Critical Disability Theory / Human Rights Approach/ Social model of disability / Medical model of disability / Dignity of Risk / Respect/ Human Flourishing
Inclusion Criteria	Peer-reviewed studies from 2000 onwards, to reflect contemporary discussions. Research focusing on physical disabilities and professional practices within healthcare, education, and social services. Literature discussing Critical Disability Theory (CDT) and Human Rights Approaches (HRA). Studies examining everyday risk, risk management, autonomy, and respect within professional settings, particularly from the perspectives of disabled people. Policy documents and global frameworks, such as the UNCRPD, relevant to autonomy, dignity of risk, and participation.
Exclusion Criteria	Studies limited to medical risk or specific medical treatments, rather than exploring everyday risk. Literature addressing risk in contexts outside healthcare, education or social services (e.g., criminal justice, domestic violence, sexual abuse). Articles not available in English or without accessible full-text availability. Preference was given to electronically accessible sources due to physical access limitations, thereby excluding literature sources that required in-person access to physical libraries or archives.
Screening and Selection Process	Title and Abstract Review: Titles and abstracts were reviewed to assess the relevance based on keywords and alignment with the core themes of risk, autonomy, respect, and professional practices. Full-Text Review: Articles that met the initial criteria underwent a full-text review to confirm their eligibility. Each study's methodology, theoretical framework, and relevance to the primary themes of risk, autonomy, and professional practices were assessed, with eligible studies included in the synthesis.
Thematic Analysis and Synthesis	Evolving Definitions of Risk: Analysis of how risk has been defined within disability contexts, from medicalised approaches to dignity of risk and rights-based discourses. Professional Risk Management and Autonomy: Exploration of how professional practices, often driven by paternalism and protectionism, may inadvertently restrict disabled people's autonomy and life choices. Respect for Inherent Dignity and Autonomy: Examination of how respect serves as a foundational principle shaping autonomy, dignity and everyday opportunities. Language, Power and Professional Control: Analysis of discourse, particularly how terms like "allow" and "empower" reinforce professional dominance and influence perceptions of autonomy and risk.

Conceptual Framework	Critical Disability Theory (CDT): framework for critiquing social, cultural, and structural factors limiting disabled people's autonomy. Human Rights Approaches (HRA): emphasises dignity, autonomy and rights, positioning disabled people as agents of their own lives

The question of "What risk?" examines literature exploring the different types of risks identified by both professionals and disabled people, focusing on how these risks are defined and managed. In contrast, "Whose risk?" addresses the question of who holds the authority to make decisions regarding these everyday risks, highlighting tensions between professional responsibility and disabled people's autonomy. The literature reveals two contrasting approaches to risk: one that emphasises safety and harm reduction, which is typical of professional practices and disability services; and another that advocates for disabled people's right to autonomy, including the right to take risks as part of ordinary life. I critically examined these perspectives to understand how risk is framed within the literature as either something to mitigate or as an essential opportunity for autonomy and personal growth.

Although respect was not initially part of my research focus, it was identified as a significant theme during my data collection, revealing itself as deeply intertwined with how risk was framed and navigated. This unexpected but consistent emphasis on respect made it essential to anchor respect alongside risk in this review, as the presence or absence of respect shapes autonomy, agency and the broader experiences of risk for disabled people. In this context, respect supports autonomy within professional relationships, honouring disabled people's right to make meaningful choices about their lives. Recognising respect as central to understanding risk shifts the focus towards valuing disabled voices and ensuring agency is upheld. Mutual respect, therefore, involves both recognising intrinsic worth and fostering reciprocal exchanges in which both individuals' and professionals' decisions are respected and valued. This aligns with the CRPD, which affirms respect for dignity and self-determination as foundational human rights. Consequently, mutual respect serves as an anchor for examining “What risk?” and “Whose risk is it?” within a rights-based approach.

What risk? Risk as opportunity, autonomy and personal growth

Risk, defined as the potential for exposure to harm or uncertainty, is commonly associated with danger, hazard or threat within the ‘risk society’ (Beck, 1992; Giddens, 1990). However, risk can also be framed positively. Emerging research highlights that risk is not only inevitable but also necessary for human development and wellbeing (Bundy et al., 2009; Bundy et al., 2011; Niehues et al., 2013), positioning risk as a natural and integral part of ordinary life (Mackay, 2013; Seligman, 2011b; Tulloch & Lupton, 2003).

Everyday risk involves the routine decisions people make in their daily lives, which inherently carry some levels of uncertainty. Lupton and Tulloch (2002) argued that within the context of personal, everyday life, individuals’ circumstances—such as social positioning, resources, and experiences, as well as factors such as race, gender, class and cultural background—influence how individuals perceive, understand and navigate risk and uncertainty. Far from being merely a danger to avoid, risk-taking in daily life is linked to the pursuit of goals, exploration and self-fulfilment. These everyday risks enable people to step outside their comfort zones, challenge their capabilities and achieve new levels of success (Tulloch & Lupton, 2003). Contemporary understandings of risk as articulated by Mackay, Seligman and Ungar emphasise the role of risk-taking in fostering resilience, personal growth and human flourishing.

Hugh Mackay, a social researcher with a focus on human values and happiness, emphasised that unpredictability, including risk, enriches human experiences. In *The Good Life* (2013) and *What Makes Us Tick* (2010), Mackay argued that accepting risk as an inherent part of life fosters meaning. Drawing from his background in social psychology, Mackay viewed the willingness to take risks as a pathway to creating connections and achieving self-understanding. Without this willingness, he argued, human experiences become stagnant, and the potential for richness and growth diminishes.

Similarly, Martin Seligman, renowned for his work in positive psychology, initially studied learned helplessness (Seligman, 1972) before moving on to explorations of resilience (Seligman, 2011a), optimism (Seligman, 2006), and happiness and flourishing (Seligman, 2011b). His PERMA model (Positive Emotions, Engagement, Relationships, Meaning, and Accomplishment), developed in *Authentic Happiness* (2002) and *Flourish* (2011b), emphasised risk-taking as integral to psychological resilience and autonomy. He argued that people can thrive when they face challenges, which helps to build the psychological resources necessary for happiness and flourishing. This engagement with risk fosters autonomy and fulfilment, enabling people to approach future uncertainties with optimism and confidence.

Michael Ungar (2011) conceptualised resilience as a dynamic process that is shaped by environmental interactions, which include facing and managing risks and uncertainties. Through fieldwork and cross-cultural studies, Ungar showed that resilience building requires engagement with risk. When individuals engage with risk and successfully navigate uncertainty, they gain confidence in their ability to cope with future challenges. Ungar's (2011) social-ecological model proposes that risk-taking fosters personal growth and capacity, highlighting the importance of risk as a core component of well-being.

In other words, the work of these authors demonstrates that risk is not merely a threat to be avoided but an essential driver of autonomy, personal growth and well-being in everyday life, and risk-taking plays a crucial role in shaping human flourishing. From this perspective, everyday risk-taking is not only an opportunity for self-fulfilment but also a vital part of resilience-building and the achievement of happiness.

Despite these positive aspects, a significant gap exists in empirical studies that explore how disabled people experience everyday risk. Within the context of disability, risk is often framed through the lens of control and protection rather than opportunity and growth. Professional practices tend to prioritise safety and liability (Brett et al., 2009; Marsh & Kelly, 2018; Mitchell & Glendinning, 2008), frequently at the expense of self-determination. This prevailing narrative contrasts with the broader understanding of risk as an enabler of growth and happiness. For disabled people, risk is too often viewed as something to be managed rather than embraced as part of a fulfilling life.

This divergence reveals a crucial gap in our understanding of how systemic and interpersonal barriers shape the experience of risk for disabled people and the strategies that disabled people develop to navigate these barriers. Later in this thesis, I address this lacuna by drawing on Snyder's (2002) Hope Theory as a lens through which to explore how risk-taking, when supported by agency and pathways, can foster flourishing for disabled people. Hope Theory, with its focus on the dynamic interplay between motivation and opportunity, provides a framework for understanding how disabled people navigate barriers and create meaningful opportunities in the context of everyday risk.

In the next section, I explore how professional practices, driven by a risk-averse framework, shape the experiences of disabled people and contribute to the challenges disabled people face in pursuing autonomy and personal growth.

Whose risk? Framing risk in disability

The existing literature on risk in disability adopts a professional-centric approach, heavily focused on intellectual disability (Chicoine & Kirschner, 2022; Marsh & Kelly, 2018; Mitchell & Glendinning, 2007). This emphasis misses the distinct challenges faced by people with physical disability, whose experiences of risk remain underexplored in academic and policy discussions.

Risk in disability is predominantly framed through the perspective of healthcare providers, policymakers and disability professionals, while the voices of disabled people, particularly those with physical disability, are marginalised or entirely absent. This imbalance narrows the scope of our understanding of risk and reinforces a dynamic whereby professionals—comprised mostly of people without disability—dominate risk-related decisions without adequate consideration of the lived experiences of disabled people. By concentrating on intellectual disability, the literature perpetuates a limited understanding of disability, overlooking the diversity of experiences across different disability types and further marginalising those with physical disability.

This professional dominance is evident in the language used to describe risk and risk-related decisions in disability contexts. Terms such as ‘allow’ and ‘empower’ subtly reflect a hierarchical dynamic implying that autonomy is something granted by professionals rather than inherently possessed by disabled people (Campbell, 2009; Shakespeare, 2013). Winance (2007) argued that such performative language constructs a reality in which decision-making authority lies with professionals and disabled people are positioned as passive recipients of care and control. By prioritising professional perspectives, the literature not only marginalises disabled voices but also reinforces power imbalances whereby professional interpretations of risk become standard and remain largely unchallenged (Campbell, 2009).

Professionals tend to frame risk through the lenses of safety, protection and vulnerability, driven by policies that emphasise harm reduction and liability avoidance (Alaszewski, 2002; Brett et al., 2009; Knox et al., 2013; Marsh & Kelly, 2018; Mitchell & Glendinning, 2007, 2008). Taylor and McKeown (2013) demonstrated that, while risk assessments aim to protect, they often reduce the complexity of disabled people's lived experiences to procedural steps that prioritise the professional's view of risk. These assessments typically focus on immediate physical harm while neglecting the longer-term ‘everyday harms’ associated with limiting autonomy and personal agency (Smyth et al., 2024). Consequently, the risks of restricting independence, and the subsequent impacts on personal growth and wellbeing, are often overlooked (Kondrat, 2022; Smyth et al., 2024).

This limit-based framing is not unique to professional decision-making but also extends to policy discourse on disability. Sunderland et al. (2009) demonstrated through discourse analysis how policy language often restricts disability narratives to minimum rights-based standards, marginalising disabled people’s pursuit of personal fulfilment and happiness. Similarly, Fisher et al. (2019) highlighted the lack of mutual recognition in disability policies, revealing how formal recognition of rights often fails to translate into autonomy within support relationships. Their work demonstrated that, at multiple policy levels, disabled people’s relationships with disability services and support are framed through compliance, reinforcing professional control over decision-making.

This established protectionist approach is consistent with the medical model of disability, which views disabled people as vulnerable and needing protection (Barnes et al., 1999; Goggin & Newell, 2005; Shakespeare, 2006). Within this model, professionals act as gatekeepers to risk (Campbell, 2009), making decisions on behalf of disabled people, often minimising autonomy in the name of protection (Goggin & Newell, 2005). The question of “Whose risk?” centres on who holds the authority to manage risk-decisions—professionals or disabled people themselves? From the perspective of the medical model of disability, the answer to this question places authority squarely in the hands of professionals.

In contrast to the medical model, the social model of disability reframes disability as the result of societal barriers, advocating for respect for autonomy and decision-making, including the right to take risks (Barnes et al., 1999; Charlton, 1998; Oliver, 1990; Shakespeare, 2017a). The concept of the dignity of risk (Perske, 1972), positioned as a direct challenge to protectionist approaches, affirms disabled people’s right to take risks as part of ordinary life. While initially applied to intellectual disability contexts, the dignity of risk has since been applied across various domains, including mental health (Robertson & Collinson, 2011), aged care (Ibrahim & Davis, 2013; Robinson et al., 2007) and broader disability contexts (Marsh & Kelly, 2018; Mitchell & Glendinning, 2008). However, despite its broader application, perceptions of disability continue to shape how dignity of risk is implemented. While decision-making and risk-taking capabilities are well developed for many disabled people, entrenched attitudes that lower expectations for disabled people often undermine the very dignity the concept intends to support (Campbell, 2009).

Rights-based frameworks, such as the CRPD, further emphasise principles of agency and autonomy, reaffirming disabled people's rights to decision making and full participation in society (Felder et al., 2022; Harpur, 2012; Lawson & Beckett, 2021; MacKay, 2007; United Nations, 2006). Central to these frameworks is the principle of respect for inherent dignity (Honneth, 1992), establishing respect as an ethical and legal obligation (United Nations, 2006). This respect for dignity insists that disabled people's rights to autonomy and decision-making be upheld, recognising that dignity and respect are essential for individuals to make choices and take risks as part of a self-determined life.

Despite this evolution towards rights-based approaches (United Nations, 2006), significant gaps persist between theoretical frameworks and practical application. In practice, professionals often maintain authority over risk-decisions, prioritising safety and harm reduction over agency and autonomy (Clegg & Bigby, 2017; Davy & Green, 2022). This ongoing tension highlights the question, "Whose risk, is it?", and reflects the ongoing complexity of balancing respect for autonomy with protection in disability services. Garland-Thomson's (2022) concept of "dignity maintenance" provides insight into these tensions, highlighting the complex dynamics disabled people must navigate to assert autonomy while managing the often-restrictive expectations imposed by professional, social and political systems. Drawing parallels to W.E.B. Du Boise's concept of "double consciousness”, Garland-Thomson described how disabled people must simultaneously assert autonomy while managing others’ assumptions and lowered expectations. Dignity maintenance, then, emphasises the importance of respect as disabled people navigate systems that often impose control over decisions. Such interactions highlight the gap between theoretical support for autonomy and its inconsistent application in practice, where protectionist attitudes overshadow rights-based perspectives (Friedman, 2018). In summary, while the dignity of risk has influenced policy discussions and promoted respect for autonomy (United Nations, 2006), its practical application remains inconsistent (Mukherjee, 2022).

In many cases, professionals continue to hold authority over risk-related decisions, making disabled people’s autonomy conditional upon professional approval. This professional-centric approach to risk in disability raises critical questions about how risk is understood and managed. If disabled voices were prioritised in these narratives, could that lead to a redefinition of risk that better reflects lived experiences and promotes autonomy? Current risk frameworks mostly emphasise safety and liability at the expense of autonomy, minimising disabled people’s ordinary opportunities for personal growth and well-being.

Disabled scholars and advocates have argued for a broader understanding of risk that extends beyond physical harm to include social, emotional and autonomy-related risks as inherent parts of everyday life (Clegg & Bigby, 2017; Garland-Thomson, 2022; Hulkower, 2022; Mukherjee, 2022; Smyth et al., 2024). Critical Disability Theory (CDT) and Human Rights Approaches (HRA) fundamentally challenge the protectionist views dominating professional practices by positioning risk as a natural and inherent part of ordinary life (Goodley et al., 2017; Meekosha & Shuttleworth, 2009; Shakespeare, 2006; Titchkosky, 2000). These frameworks argue that living a full and autonomous life requires engaging with risks that foster personal growth and self-determination (Clifton et al., 2018; Garland-

Thomson, 2022), including the risks associated with meaningful participation (Hammel et al., 2008) such as engaging in public life, choosing where to live, pursuing relationships and engaging in physical activities.

CDT and HRA emphasise that the right to take risks is a fundamental part of autonomy, equally valued for people with and without disabilities. This approach represents a significant shift from the traditional focus on mitigating risk to a model that supports self-determination and acknowledges the dignity of risk as essential to living a meaningful life (Mackay, 2013; Seligman, 2002, 2011b; Tulloch & Lupton, 2003). Within these frameworks, professionals are encouraged to function as allies rather than gatekeepers, supporting disabled people in navigating risks while fully respecting autonomy. Embracing this approach requires respect as the foundation for every interaction and decision, honouring both the autonomy and inherent dignity of disabled people.

Respect: A foundation for risk and autonomy in disability services

Respect was identified as a significant and unexpected theme in my research, revealing itself as deeply intertwined with how disabled people framed, experienced and navigated risk. Widely regarded as one of the most essential ingredients in fostering meaningful relationships and building just societies (Lawrence-Lightfoot, 2000), respect underpins both autonomy and meaningful participation. Endorsed politically and ethically through civil rights guarantees for all citizens, respect serves as a foundational principle that supports the dignity and rights of persons—a cornerstone of ethical and inclusive societies (Dillon, 2003, 2007). Traditional models often treat respect as a fixed state—an institutional gesture or legal entitlement—rather than a relational practice. As Honneth (1995) argued, respect is a critical form of recognition, necessary for the development of autonomy and self-realisation. When denied, it reinforces social marginalisation and limits individuals' abilities to participate as equals. Accordingly, this section of the review focuses on respect for persons as a foundational construct for exploring autonomy and risk-taking, particularly as these relate to the lives and rights of disabled people.

Respect, often understood as showing regard for another's feelings, wishes, rights or achievements (Merriam-Webster, nd), carries deeper significance in scholarly discourse. As a cornerstone of human rights and social justice, respect underpins the moral values, expectations and interactions that structure civil society (Middleton, 2004; Sennett, 2003) and shapes our attitudes and actions, fostering fairness and affirming autonomy. Philosopher Immanuel Kant was one of the first to place respect for persons at the centre of moral theory—a perspective that continues to shape modern understandings of dignity and autonomy (Dillon, 2007).

In contrast, disrespect manifests as objectification, neglect, or the careless or intentional misidentification of individuals (Dillon, 2003; Honneth, 1992; Schwartz, 2019). Disrespect denies people the recognition they deserve, fostering feelings of humiliation, devaluation and exclusion (Honneth, 1992; Klein, 1991; Middleton, 2004). For disabled people, disrespect often results in a loss of autonomous control over their bodies, denial of rights, or the imposition of social stigmas that limit opportunities and participation (National People with Disabilities and Carer Council, 2009). Disrespect can range from overt acts of discrimination to more subtle but equally harmful behaviours, such as lack of recognition. Regardless of its form, disrespect is an everyday harm that can profoundly impact an individual's sense of dignity and self-worth (Honneth, 1992; Kirschbaum, 1991; Klein, 1991; Smyth et al., 2024).

The disability rights movement has long recognised respect as a transformative response to the historical discrimination and marginalisation faced by disabled people (Charlton, 1998). A landmark moment in this advocacy was the United Nations Declaration on the Rights of Disabled Persons (1975), which asserted the equal right of disabled people to respect and a life free from discrimination. This declaration catalysed global initiatives such as the United Nations International Year of Disabled Persons (1981) and the United Nations Decade of Disabled Persons (1983), which aimed to promote equality in opportunity and participation. These efforts also inspired national policies, including Australia’s Disability Discrimination Act (1992), designed to protect individuals from disability-based discrimination (Human Rights & Equal Opportunity Commission, 2011).

It has been five decades since that first Declaration of the rights of disabled people. Recognition of past failures to protect these rights led to the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2006. The CRPD emphasises respect as a core principle, pledging “to protect, promote and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disability and to promote respect for inherent dignity” (United Nations, 2006, Article 1). Although the CRPD has driven further developments in policies, standards and laws, substantial barriers to true equality and respect persist (Australian Government, 2022).

Within these frameworks, respect emerges as vital, not only as an ethical ideal but as a practical foundation for social justice and inclusion. Genuine respect involves both reciprocity—the equal exchange of ideas, values and benefits—to ensure all individuals have equal status, rights and opportunities, and autonomy—the recognition of each person as an independent moral agent (Sennett, 2003). These principles uphold societal values and establish the expectations that shape interactions across diverse groups (Mackay, 2013; Middleton, 2004; Sennett, 2003). The World Health Organisation (2011) has identified respect as essential to the creation of an inclusive society. However, achieving genuine respect requires confronting ablism and a commitment to dismantling the barriers that continue to marginalise and exclude disabled people from flourishing futures (Friedman, 2018; Goggin & Newell, 2005; Quaquebeke et al., 2007; Schwartz, 2011; Shakespeare, 2017b).

In this context, understanding genuine respect is crucial for appreciating broader concepts like autonomy, dignity and risk, particularly for disabled people. As Kafer (2013a) has argued, disabled people are often framed as having no viable future, limiting possibilities for policy, support and intervention that foster long-term flourishing. This erasure of disabled futures directly undermines respect, as respect requires recognising not only present autonomy but also the right to imagine and shape one's own future. Genuine respect acknowledges that individuals need to exercise their right to take risks, affirming that such risks are integral to a meaningful, autonomous life.

Toward a co-defined understanding of risk

The existing literature provides valuable theoretical and policy frameworks for understanding risk in disability contexts. However, it also reveals critical limitations that highlight the need for a broader, more inclusive research agenda. Empirical research on how disabled people navigate everyday risk remains limited. As previously mentioned, much of the extant work focuses on intellectual disabilities, leaving significant gaps in understanding the lived experiences and practical challenges faced by people with physical disabilities.

Additionally, the voices of disabled people are often marginalised, with policy-driven and professional-centric discourses dominating the field. Methodological limitations, such as a reliance on case studies and professional perspectives, further reinforce paternalistic narratives that frame disabled people as passive recipients of care. While rights-based frameworks, such as the CRPD, advocate for autonomy and self-determination, the translation of these principles into practice is inconsistent. The literature frequently neglects the systemic and cultural barriers that hinder disabled people from exercising their rights to take risks, highlighting a need for research that bridges theory, policy and the lived realities of disability.

These gaps point to the need for a shift in how risk is framed and managed in disability contexts. This involves moving from a model based on professional control to a co-defined approach, where disabled people and professionals collaboratively engage in identifying and managing risk. Such an approach promotes autonomy, personal growth and shared decision-making around risk and safety. This collaborative model recognises, and honours disabled people's inherent right to take risks, with professionals acting as allies rather than gatekeepers. Respect serves as the anchor of this co-defined understanding, embodying an ethical commitment to uphold disabled people's right to self-determination and risk-taking.

The chapters that follow build on these ideas. I explore how professional practices either support or hinder disabled people's autonomy, as well as the strategies disabled people use to navigate risk-averse environments, highlighting the role of genuine respect in fostering an inclusive, rights-based framework for understanding and approaching risk.

CHAPTER 3

Methodology

In this study, I used semi-structured interviews and analysis of interview transcripts and researcher field notes to capture the complexities of ordinary life for disabled people. I chose this qualitative approach not only to generate knowledge but also to contribute to social change by highlighting the need for policies and practices that align with autonomy, dignity and meaningful participation (Goodley et al., 2017). To strengthen the methodological transparency and rigour, I used the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007) to guide the reporting of the study methods and findings. This is particularly useful in disability studies research to ensure research credibility and participant voice representation (Mays & Pope, 2020).

Study design

The theoretical framework underpinning this thesis draws on Critical Disability Theory (CDT) (Garland-Thomson, 2018; Goodley et al., 2017; Pothier & Devlin, 2005; Shakespeare, 2006) and Human Rights Approaches (HRA) (Kayess & French, 2008; United Nations, 2006). This framework enabled an in-depth examination of the mechanisms of exclusion, highlighting both systemic barriers and opportunities for change that support individual agency and systemic reform.

I conducted semi-structured interviews (Brinkmann & Kvale, 2018) to generate detailed accounts, providing participants with flexibility to express their experiences in ways meaningful to them (Britten, 2006). This approach balanced pre-determined questions with space for participants to clarify and expand on their insights. Key interview questions included:

1. Can you tell me about the advice you have received from healthcare or other allied support professionals about living your everyday life?
2. What has been your experience of receiving advice about managing risks in your everyday life?
3. Do you feel your perception of everyday risk is different from that of the professionals who support you?
4. What skills or strategies have you developed to achieve the life you want?
5. What advice would you give to other disabled people about living the life they want?

See Appendix A for the full interview guide.

Participant selection and recruitment

I employed a combined purposive and snowball sampling strategy (Given, 2016; Noy, 2008; Palinkas et al., 2015) to maximise participant reach and diversity. Recruitment began with disability service provider websites and newsletters, supplemented by referrals and word of mouth. To extend outreach, a news broadcast and national radio advertisement aired twice, two weeks apart, across major cities and regional towns in Australian States and Territories. This was followed by a discussion on talk-back radio stations 2GB and 2UE.

The most effective recruitment strategies were word of mouth, news broadcasts and service provider referrals. These efforts generated 49 expressions of interest, including 36 from disabled people and 13 from parents of disabled people. Responses were received from multiple urban and regional areas in Victoria (n=3), Queensland (n=2), South Australia (n=1) and New South Wales (n=43).

I contacted all who expressed interest via telephone or email, after which I sent participant information and consent forms via email or post. See Appendix B for Recruitment and Participant information.

Eligible participants were individuals with physical disability, who met the following selection criteria: self-report of no cognitive or intellectual impairments and aged 12 years or older. Parents or carers of young people with a physical disability were also included.

In total, 24 disabled people provided consent and were included in the final study. Seven parents (six mothers and one father) participated in the study. However, I included only the perspectives of parents of children aged 12 to 16 years (3 mothers and 1 father) in the final analysis, as shown in Table 3.1.

Table 0.1 Participant Demographics by Age, Gender and Role

Category	Male	Female	Parents
Young people (12-16 years)	1	2	Mothers (n=3), Fathers (n=1)
Adults (17-56 years)	3	18	NA

Three young participants, aged 12, 14 and 15, were interviewed alongside their parents, who provided additional insights into navigating accessibility, advocating for support and managing professional interactions. While this study centres the voices of disabled people, parental perspectives offered important contextual insights, particularly in highlighting the systemic barriers families encountered when seeking inclusive opportunities for their children.

Among the 12 disabled people who were not included in the final study, 5 did not meet the study criteria; 3 were unable to schedule an interview within the study period; 4 withdrew due to ill health. Of the 13 parents who expressed interest, I excluded 6 for not meeting the criteria. All participants were informed of the reasons for exclusion, ensuring transparency in the recruitment process.

Characteristics of participants

Consistent with Critical Disability Theory (CDT) and Human Rights Approaches (HRA), I focused on how political and social structures and professional environments shaped the experiences of disabled people, centring the analysis on lived experience within disabling environments, rather than categorising participants based on specific medical diagnoses. A summary of participant characteristics and ages are presented below. All names are pseudonyms.

Participant	Age	Role(s)	Summary
Aaron	38	Youth & family support worker and electronics enthusiast	Full-time support worker for disabled youth and families. Uses a powered wheelchair and explored assistive technology to enhance accessibility.
Alice	28	Journalist and comedian	Works full-time in journalism and part-time as a comedian, creating inclusive social spaces. Uses a powered wheelchair and advocated for access and representation in media industries.
Ashley	23	University student and arts enthusiast	Final-year Arts student balancing academic and creative life. Managed chronic illness and mobility barriers while navigating access structures in higher education.

Breanna	24	Receptionist and community member	Works full-time as a receptionist. Uses a manual wheelchair and is highly engaged in work and social life.
Evie	18	University student and martial artist	First-year Media and Communication student with a black belt in karate. Navigates chronic illness and mobility barriers in education and sport, using adaptive strategies to stay active and engaged.
Grace	24	Artist, volunteer and social welfare student	Part-time community volunteer and part-time student balancing academic and creative life. Uses a powered wheelchair and communication device.
Jana	28	Advocate and writer	Full-time multicultural advocate supporting women with disability. Navigates physical and sensory impairments, using adaptive strategies to stay active in work, travel, and everyday life. Passionate about cooking, writing, and inclusion.

Jaz	56	Community worker and digital accessibility advocate	Works part-time as a web content creator. Uses both manual and powered wheelchair and advocates for inclusive digital and physical spaces.
Kael	14	Student and musician	Balance’s school life with interests in music and computer games. Uses both a powered wheelchair and manual wheelchair to engage in learning and social activities. His parents, Luisa and Hugh, discussed experiences supporting Kael pursue his interests.
Laya	15	Student, traveller, gardener	Year 9 student who loves gardening and traveling with her family. Uses a powered wheelchair and AAC device to engage in school and everyday life. Her mother, Cali, shared her experiences navigating support in education, health, and community settings.
Leah	18	Law student, surfer and model	Disability ambassador preparing to study Media and Law. Uses a manual wheelchair and navigates access barriers in education and

			sport, including surfing and public advocacy.
Lucy	13	Student, model, disability ambassador	Balance’s school life with work as a part-time model, public speaker, and disability support advocate. Uses a powered wheelchair to pursue her interests within school and community. Claire, Lucy’s mother, discussed her experiences for access and support.
Meg	22	University Student and Aspiring Educator	Lives on campus while studying Education and Psychology. Uses walking sticks and a manual wheelchair to manage mobility barriers, actively advocating for accessibility in education.
Mia	23	Office administrator and youth mentor	Works part-time as an office administrator and part-time youth mentor. Uses a powered wheelchair and advocates for greater accessibility in education, employment and community life.
Mikayla	25	Student, Volunteer and Photographer	Full-time university student and part rural fire service volunteer. Uses a powered wheelchair and is hearing-

			impaired, balancing study, creative work, and advocacy across community spaces.
Nikki	26	Peer Mentor and Community Participant	Took part in a community program focused on peer support and inclusion. Works on a local newsletter and supported others in navigating daily life. Uses a powered wheelchair and AAC device to stay active and connected.
Olivia	30	Advocate and Swimmer	Works full-time as a disability and human rights advocate and was about to begin doctoral studies. Uses walking sticks and advocates for access within academic and public spaces.
Poppy	32	Human Rights Educator and Public Speaker	Works full-time in disability and human rights education. As a vision-impaired person, she navigates barriers in professional and public spaces while advocating for inclusive policy and systems change.
Stacey	19	Student and peer mentor	Studies IT part-time at a community college and took part in a peer

			support program while contributing to learning and advocacy efforts. Uses a powered wheelchair and AAC device to navigate physical, sensory, and communication barriers.
Thomas	40	Communications Officer, Advocate and Artist	Works part-time in communications and served on a community health board. Uses a manual wheelchair and worked within urban accessibility networks to promote equitable healthcare and independent living.
Tilda	22	Student, Activist and Performer	Studies Gender Studies and Psychology while engaging in disability rights activism and performance. Uses sign language and an AAC device, navigating physical and sensory barriers in education and public life.
Victoria	34	Government Employee and Community volunteer	Works four days a week in a government department and volunteers on community access committees. Uses a manual wheelchair and is hearing-impaired,

			navigating barriers in work and advocacy while contributing to inclusive policy efforts
William	21	University students and wheelchair sports athlete	Second-year social welfare student and disability support ambassador. Plays state-level wheelchair football and uses a powered wheelchair to participate in sports, advocacy, and student life.
Zahli	21	Business student and peer support worker	Studies a Diploma in Business and engages in a community participation program. Uses a walking frame and AAC device to engage in education and support others through peer networks.

Data collection

I conducted more than half of the interviews (*n*=16) face-to-face at mutually accessible locations, chosen to accommodate participants' individual preferences and needs, such as accessible parking, easy access and proximity to public transport routes. Locations included familiar settings like disability service venues, university campuses, libraries and coffee shops. I conducted the remaining interviews by telephone (*n*=3) and Skype video conferencing (*n*=5). Communications were supplemented by user-initiated social networking platforms such as email, text messaging and MSN messenger.

Interviews lasted between 1 and 4½ hours, with longer sessions split into two or more sessions. For participants aged 12 to 16 years, interviews were conducted with one or both parents present. Similarly, parent interviews were with their child present even when the child was not a study participant.

To address challenges in transcribing and accurately capturing contributions, particularly for participants using augmented and alternate communication (AAC), I incorporated a focus group (Kitzinger, 2006) and follow-up interviews after the initial interviews. These groups provided a more flexible and supportive environment while also serving to ensure that my interpretations of the initial interview accurately reflected participants lived experiences. Five participants took part in the focus group, which was held at the disability support organisation they attended for peer support. An additional 8 participants engaged in a follow-up interview at a mutually accessible location. These discussions helped clarify and refine my interpretations, confirm findings and ensure that diverse communication styles were fully and meaningfully represented as possible in the analysis. This approach is consistent with best practices in disability research (Nind, 2008), which highlights the importance of creating accessible and supportive environments that enable full participation. Flexible methodologies that adapt to participants' needs were central to ensuring all participants could engage fully and comfortably.

Data analysis

I used a 5-step iterative analysis approach (Braun & Clarke, 2006; Maxwell, 2013), adapted from the thematic framework outlined by Nowell et al. (2017). This approach incorporates and emphasises reflexivity, iterative refinement and validation, while aligning with the following structured phases:

- Familiarisation
- Identification of a thematic framework
- Indexing

- Charting
- Mapping and interpretation

Familiarisation involved transcribing interviews verbatim, with each transcript cross-checked against the audio recordings for accuracy. An independent transcription service performed the initial transcription. After each interview, I recorded fieldnotes and researcher journal entries, which provided additional context and clarification during analysis. I reviewed all transcripts with participants for accuracy.

Identification of a thematic framework involved generating initial codes focused on segments of text relevant to the research questions. I grouped codes into categories reflecting broader patterns within the data, informed by theoretical frameworks.

Indexing involved annotating transcripts and sorting data within the thematic framework. Through reflection and constant comparison (Maxwell, 2013), I established themes and patterns. Rather than seeking saturation, in the analysis I embraced ongoing discovery, exploring the depth and complexity of participants' experiences (Varpio et al., 2017).

Charting involved organising the data into relevant sections of the thematic framework. I constructed summaries of experiences and ideas to highlight contrasts and connections. I used poetic transcription (Illingworth, 2022; Prendergast et al., 2009) to explore meaning within the data (Glesne, 1997). An example of a poem is provided as Appendix C.

Mapping and interpretation involved revisiting research questions and themes to define concepts, map idea and identify associations. This process included creating visual representations, such as concept maps, to explore connections and refine interpretations. Regular supervisory discussions and interdisciplinary presentations provided critical feedback, promoting further reflection and refinement of the findings.

Ethical considerations

Ethical considerations were central to this study. Pseudonyms are used to protect participants' identities, and all participants provided informed consent. Accessible formats for consent and participation were offered to ensure inclusivity. All data files were secured using password protected digital storage provided by the University. Ethical approval for this study was obtained from the Human Research Ethics Committee of The University of Sydney (#2-2010/12514).

Limitations

While this study offers valuable insights, several limitations should be acknowledged:

Recruitment and diversity challenges. Despite efforts to include a diverse range of participants, some groups may be underrepresented. Factors such as geographic location, cultural background and access to communication supports likely influenced participation. Recruitment through disability service providers and advocacy networks may have resulted in greater representation of individuals already engaged in disability rights spaces, while those facing added marginalisation (e.g., rural participants, non-English speakers, or those with higher support needs) may have been less likely to volunteer to take part.

Future studies could address this gap by expanding recruitment through trusted community organisations, peer-led networks and targeted outreach to underrepresented groups, such as culturally diverse disabled communities.

Communication access and interview methods. Participants who used AAC devices or alternative communication methods may not have been fully accommodated in traditional interview settings (Nind, 2008). While participants who used AAC and other assistive communication methods were included in the study, time constraints and conventional interview structures may have limited their ability to fully express complex narratives.

Future research could explore longer engagement periods, multimodal data collection (e.g., written, video or asynchronous responses), and co-design approaches with AAC users to better capture their perspectives.

Self-selection and advocacy bias. This study relied on self-selection, meaning participants were likely those who were already engaged in advocacy or had prior experience navigating professional advice and service provision. This could introduce participation bias, shaping the themes that emerged. As a result, the perspectives of those who are less engaged with formal services, more socially isolated, or who have had highly negative experiences with professionals may be underrepresented.

Future studies could incorporate alternative recruitment approaches, such as peer referrals, community-based participatory research (CBPR), and engagement with informal disability networks, to better capture experiences of those who may not actively seek research participation.

Systemic constraints on participation. Some participants withdrew due to ill health, highlighting the challenges of sustained participation in research for people with chronic conditions. This reflects broader structural barriers, where research methodologies—and academia more broadly—are often not designed to accommodate fluctuating health conditions, pain levels or fatigue.

Future studies could offer more flexible participation methods (e.g., shorter sessions, multiple response formats, or extended response timelines) to better include those with chronic or episodic conditions. More broadly, academic institutions should reconsider inflexible research structures and timelines to create space for genuinely inclusive knowledge production.

CHAPTER 4

“They just said it was too dangerous. But how would they know?”: Barriers to autonomy, joy and participation in risk-averse disability systems

Abstract

Risk is a fundamental aspect of everyday life—essential to pursuing joy, making choices, and living fully. Yet within the context of disability, risk is rarely understood as a pathway to growth or flourishing. Instead, it is often treated as something to be minimised, with policy and professional practices prioritising safety and liability over autonomy and opportunity. This divergence in how risk is perceived reveals a critical gap in our understanding of how disabled people experience risk, and how systems can shape, restrict, or deny that experience.

In this paper, I draw on qualitative interviews from a broader study examining how disabled people navigate risk, autonomy, and flourishing within professional systems. The analysis centres on narratives from 28 participants: 24 individuals with physical disabilities (aged 12 and over) and 4 parents of disabled individuals.

Findings indicate that institutional policies and professional decisions often limit choice, undermine autonomy, and obstruct opportunities for everyday flourishing. Reframing risk as a right—rather than a threat—opens new possibilities for individuals and prompts a reconsideration of how support systems are designed and delivered. The real challenge is not whether disabled people can overcome structural barriers, but whether institutions are willing to dismantle the ones they maintain.

Keywords: Disability Rights, Risk, Critical Disability Theory, Hope Theory, Flourishing

Introduction

Risk, defined as exposure to harm or uncertainty, is often associated with danger, hazard or threat (Beck, 1992; Giddens, 1990). However, more recent research reframes risk as necessary for human development and wellbeing (Bundy et al., 2009; Bundy et al., 2011; Niehues et al., 2013) and as an integral part of ordinary life (Mackay, 2013; Seligman, 2011; Tulloch & Lupton, 2003). Everyday risk involves the routine uncertainties of decision-making in daily life and, far from being something to avoid, is closely linked to autonomy, exploration and self-fulfilment. Engaging with risk enables people to test their limits and pursue aspirations (Tulloch & Lupton, 2003). Risk in this context fosters personal growth and human flourishing (Clifton, 2014; Michealis & Soldatic, 2022; Seligman, 2011).

Within the context of disability, risk is rarely framed as a mechanism for growth or flourishing. Instead, risk is often treated as something to be minimised or avoided, with professional practices prioritising safety and liability over autonomy and opportunity (Brett et al., 2009; Marsh & Kelly, 2018; Mitchell & Glendinning, 2008). This protective approach sidelines the developmental and relational dimensions of risk, positioning disabled people as vulnerable, rather than agents of their own lives.

This divergence in how risk is perceived exposes a crucial gap in our understanding of how disabled people experience everyday risk, and how systems shape, limit, or deny that experience. To address this gap, I draw on Critical Disability Theory (CDT) (Garland-Thomson, 2018; Goodley et al., 2017; Pothier & Devlin, 2005; Shakespeare, 2006); Human Rights Approaches (HRA) (Kayess & French, 2008; United Nations, 2006); and theories of hope (Snyder, 2000, 2002) and recognition (Honneth, 1995).

Snyder’s Hope Theory offers a useful framework for understanding the structural and relational conditions that sustain possibility. Hope, in this context, is defined as a cognitive process with two key components: agency (the motivation to pursue goals) and pathways (the ability to identify routes to those goals) (Snyder, 2002).

The theory of recognition (Honneth, 1992) is particularly important. Honneth argued that agency depends, in part, on being recognised by others as full and capable participants in social life. Recognition, in this sense, is not something to be earned, but a basic condition for relational dignity, autonomy, and participation. This understanding is reflected in international law through the Convention on the Rights of Persons with Disabilities (United Nations, 2006), which affirms recognition, autonomy, and participation as fundamental rights, without condition or exception.

Together, these theories frame autonomy and the opportunity for everyday risk not as individual achievements, but as a relational, systemic condition—shaped by recognition, opportunity, and structural support. This theoretical framing provides the analytic lens for understanding how structural and professional practices either sustain or undermine the conditions for ordinary flourishing.

Positioning the study

This paper draws on interview data from a broader qualitative study exploring how people with physical disability experienced risk, autonomy, and flourishing under the influence of professional systems. The larger study had three core aims:

1. To examine how professional advice impacted autonomy, dignity, and participation.
2. To identify the strategies disabled people used to navigate systemic barriers.
3. To investigate the conditions that enabled or constrained meaningful, fulfilling lives.

In this manuscript, I focus on the first and third aims, exploring how risk-averse systems and everyday professional behaviours shaped disabled people’s access to autonomy, recognition, and participation. Drawing on participant narratives, I examine how systems can either support or disrupt the foundations of a meaningful life.

As a disabled researcher with professional experience in disability advocacy and service systems, I approached this work with critical awareness of the gap between institutional narratives and lived experience. This positionality informed the study design, data collection and analysis, enhancing contextual sensitivity and supporting strong rapport with participants. Iterative analysis, research journaling, and peer debriefing, throughout, supported rigour.

Methods

Ethical approval was granted by the Human Research Ethics Committee of The University of Sydney (Ref: 2-2010/12514. To protect participant anonymity, pseudonyms are used in this report.

Study design

I used qualitative thematic analysis to examine the strategies participants employed to reclaim autonomy and self-determination. Critical Disability Theory (Garland-Thomson, 2018; Goodley et al., 2017; Meekosha & Shuttleworth, 2009; Pothier & Devlin, 2005); Human Rights Approaches (Kayess & French, 2008; United Nations, 2006); Hope Theory (Snyder, 2002), and theories of recognition (Honneth, 1992, 1995) informed the analysis.

Participant selection

Participants were selected through purposive and snowball sampling strategies (Given, 2016; Noy, 2008; Palinkas et al., 2015). Eligible participants identified as having a physical disability; self-reported no cognitive or intellectual impairments; and were aged 12 years or older. Parents or carers of disabled adolescents (aged 12-16 years) also participated. Recruitment occurred via community networks, advocacy organisations and public social media calls.

In total, 28 people contributed: 24 disabled individuals and 4 parents of disabled adolescents. All had lived experience with physical disability and spoke about autonomy, risk and professional systems. In this paper, I draw on narratives that most clearly illustrated the themes presented; not all participants are quoted, but all informed the analysis. Table 4.1 provides brief participant profiles for those cited in the findings.

Table 4.1: Profiles of participants quoted in findings.

Participants (alphabetical order)	Age	Role(s)	Summary
Evie	18	University student and martial artist	First-year Media and Communication student with a black belt in karate. Navigates chronic illness and mobility barriers in education and sport, using adaptive strategies to stay active and engaged.
Jaz	56	Community worker and digital accessibility advocate	Works part-time as a web content creator. Uses both manual and powered wheelchair and advocates for inclusive digital and physical spaces.
Kael (parents: Luisa & Hugh)	14	Student and musician	Balances school life with interests in music and computer games. Uses both a powered wheelchair and manual wheelchair to engage in learning and social activities. Kael’s parents, Luisa and Hugh, discussed experiences supporting Kael pursue his interests.
Lucy (mother: Claire)	13	Student, model, disability ambassador	Balances school life with work as a part-time model, public speaker, and disability support advocate. Uses a powered wheelchair to pursue her interests within school and community. Claire, Lucy’s mother, discussed her experiences for access and support.
Mia	23	Office administrator and youth mentor	Works part-time as an office administrator and part-time youth mentor. Uses a powered wheelchair and advocates for greater accessibility in education, employment and community life.

Nikki	26	Peer Mentor and Community Participant	Took part in a community program focused on peer support and inclusion. Works on a local newsletter and supported others in navigating daily life. Uses a powered wheelchair and AAC device to stay active and connected.
Poppy	32	Human Rights Educator and Public Speaker	Works full-time in disability and human rights education. As a vision-impaired person, she navigates barriers in professional and public spaces while advocating for inclusive policy and systems change.
Stacey	19	Student and peer mentor	Studies IT part-time at a community college and took part in a peer support program while contributing to learning and advocacy efforts. Uses a powered wheelchair and AAC device to navigate physical, sensory, and communication barriers.
William	21	University students and wheelchair sports athlete	Second-year social welfare student and disability support ambassador. Plays state-level wheelchair football and uses a powered wheelchair to participate in sports, advocacy, and student life.

Setting

Interviews were held in locations chosen by participants to ensure accessibility, comfort and safety. They included in-person meetings, phone interviews and online interviews conducted via Zoom or Skype. This flexibility aimed to minimise barriers to participation and affirm participant control over the interview environment.

Data collection

I conducted semi-structured interviews (Brinkmann & Kvale, 2018) in person, by telephone or online, according to participant preference. Interviews ranged between 45 minutes and 4.5 hours, with longer interviews conducted in multiple sittings. All interviews were audio-recorded, professionally transcribed and de-identified to preserve confidentiality. To support contextual interpretation, I recorded fieldnotes after each interview.

Data analysis

I analysed the data thematically using a five-step approach (Braun & Clarke, 2006) adapted from the framework outlined by Newall et al. (2017). The analysis identified patterns of meaning related to experiences of respect, autonomy and participation. I manually coded into themes developed through reflective dialogue with members of the research team and disabled peers. The themes reflect multiple stages of review, refinement and theoretical integration. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007) guided my reporting methods and findings. (Tong et al., 2007).

Findings

Participants described three interrelated themes that impacted autonomy, limited participation, and made it harder to live the lives they wanted:

1. Systemic Barriers
2. The Role of Professionals
3. The Minimisation of Joy and Happiness

The barriers reflected in these themes did not occur in isolation. They were built into policies, systems, and everyday decisions that made support feel conditional, controlled or out of reach. Table 4.2 outlines the three main barriers described by participants, the mechanisms through which control was enacted, and the resulting impact on agency, pathways and participants' rights to act, plan, and live on their own terms.

Table 4.2: Summary of key barriers shaping autonomy, participation and everyday risk.

Barrier	Barrier description	Key mechanism	Impacts on autonomy and participation
Systemic barriers	Inflexible structures, rigid policies, and decisions based on administrative reasoning	Survival bureaucracy; precedent-based decisions, fear of liability or saving time and money	Limited choice, blocked pathways, and treated rights as optional or dependent on system approval
Role of professionals	Attitudes, training and risk perceptions shape what support was offered, permitted or denied	Misrecognition, paternalism, protection disguised as care	Undermined agency and trust; people were forced to navigate uncertainty without collaborative or adaptive pathways; lead to strategic withdrawal
Minimisation of joy and happiness	Risk-averse responses to ordinary pursuits of meaning, connection and identity	Professional discomfort with autonomy; quiet refusals or rules no one explains	Suppressed joy as a valid pathway; reduced agency to compliance; disrupted identity and eroded possibility, hope and the right to flourish

Systemic barriers: Inflexible structures, rigid policies and administrative reasoning

Participants described systems shaped by inflexible policies and administrative decisions that made support feel conditional and autonomy elusive. Hugh, both a high school teacher and father to Kael, described how fear and liability shaped professional advice and support. “School is a very fear driven environment now… and that fear really intensified after Kael had a bad fall early in high school. That just realised everyone’s fears.”

For Hugh, that fear influenced decision-making more than the actual needs of the student. Decisions followed a predictable pattern—default to what is cheapest, what is pre-approved, and what avoids precedent:

> The advice they'll give up front is: what's the cheapest option? What pre-prescribed patterns is the person going to fall into? … And will this save us from having to reinvent or to solve issues again? It's survival bureaucracy … but it often doesn't work in the best interests of individuals.

Lucy's experience showed how what Hugh described as "survival bureaucracy" played out in practice. Her right to attend mainstream school was questioned from the start:

> They told mum that I should go to a special school because we were wasting all the public school's money, because I supposedly had everything wrong with me... They're like, 'Hi!' and I'm like, 'Hey, how are you?'… and they're like, 'Oh. She can talk.'

Claire, Lucy's mother, recalled the conversation:

> The counsellor at the local [mainstream] school said I was wasting the money and asked if I'd looked at the special school. I said, 'Yes I have… and Lucy would not suit that school at all.' They said, 'You're wasting the Education Department's money getting disabled access at this school. You shouldn't be sending her here.'

Although Lucy remained at the mainstream school, school policies introduced new barriers. Students below Year 11 were not allowed to use the school elevator independently—a blanket rule likely aimed at managing general student behaviour, but one that had disproportionate consequences for Lucy. As a year 7 student, her movement around the school became dependent on staff availability. "I always had to leave class five minutes early. I used to complain, because I'd miss out on homework instructions, but then I'd get detention because I didn't complete the work."

What should have been ordinary access became something her family had to fight for. Her learning and independence were disrupted, not by her disability, but by policies designed without her in mind.

William, a social work student and full-time powered wheelchair user, described what it meant to live within such systems day to day: “If I abided by all the rules, I’d miss out on living a lot of my life. So, you have to take calculated risks. If you do go against the rules, you have to make sure you do it quietly. But everyone does it.”

For William, success depended less on eligibility and more on knowing how to bend the rules without drawing attention. Navigating these systems meant working out when to ask, when to push, and when to act quietly without permission.

Luisa, a physiotherapist and Kael’s mother, shared how even small acts of inclusion, like attending school sport, required rule bending:

> We had to sign him [Kael] out of school as if he is absent for that afternoon… it’s interesting how we've had to navigate working our way around the system, ‘breaking rules’ really, just so that we can actually get what we need to [have] happen.

Technically, Kael was not absent, but formally, this was the only way to fit his participation into the structure of the school day. Sometimes the workaround extended beyond paperwork. One of Kael’s support workers regularly volunteered his own time and drove the family vehicle so Kael could attend excursions and band camp. Without that, Luisa said, “they’d be excursions and things that he just couldn’t go to—that the other kids can go to.” As Luisa put it, participation was not supported by the system. It came from navigating around it. “We’ve had to bend ourselves—not just the rules” to make participation possible.

Across these narratives, professional systems did not exclude participants outright; rather they filtered access through policies and procedures that prioritised the system over participation and self-determination. Risk was managed, liability was minimised, but autonomy and participation were constrained.

The role of professionals: How attitudes, training and risk perceptions shape outcomes

The logic of survival bureaucracy was not just built into systems; it was carried out by professionals. Their attitudes, training, and understanding of risk shaped not only what support they offered, but how participants' autonomy, dignity, and rights were recognised or denied.

Jaz's experiences showed how early professional responses shaped the way she understood herself. "I was 8 when I discovered that everybody else could swim across the pool and I couldn't". Yet for over 40 years, her concerns were dismissed or misattributed. "I was just seen as hypochondriacal or malingering… so I just got on with it, because what else can you do?"

Professionals encouraged her to walk more, exercise more, and simply try harder, advice not grounded in clinical insight, but in assumption. "I was told I didn't have enough to do; I should get more to do... I tried to get fit. I even got a personal trainer. But it made no difference. I didn't get any fitter; I just got absolutely wrecked."

When Jaz finally received a diagnosis of muscular dystrophy at age 50, things did not get easier, and professional support often disappeared. "Once they couldn't get a diagnosis and everything had been done, the interest waned… Now the advice is 'listen to your body'. But if I did that, I'd just be sitting in the wheelchair all day." The "listen to your body" advice, framed as empowering, came with no support for how to live well. "They say that like it's empowering. But my body is telling me to do bugger all. If I followed that advice, I wouldn't be doing the normal daily activities I do now."

For Jaz, the problem was not individual intent—but systemic design. "That's what the gap is—listening to people for starters, understanding what is needed, and training services to meet those needs."

Training gaps deeply undermined Jaz's trust in professionals. When she sought local physiotherapy support, the response was. "They said they'd go home and read their book on muscular dystrophy… I thought, I don't think I want to go to you."

Jaz summed it up plainly. "You should not have to fight tooth and nail for the things you need to live a normal life."

Nikki's experience shows how professional assumptions about communication can undermine autonomy. When I arrived at Nikki's day program, she was working at her computer. A staff member, aware of our scheduled meeting, approached and—without asking Nikki—moved her into the meeting room. While repositioning her wheelchair, the staff member leaned in and said, "You're cranky today." Nikki looked visibly unsettled.

Later, using her AAC device, she explained. "They do it all the time. They are annoying. Do not listen or give me time to respond. I am 26 years old. They treat me like I am a child." Nikki explained that these were not isolated moments—they were part of a pattern. When asked if she felt safe to raise her concerns, she said "no, they might ignore me. Or just not help me properly."

Stacey also felt misread. While her basic care needs were met, her goals and identity were often sidelined. "They talk to me like I have a cognitive disability. I am not!" Her biggest frustration was when staff didn't listen and made decisions for her. "It just makes everything harder. When they don't listen, I shout. But it's frustrating if they do not take time to understand and just decide for me."

Over time, Stacey began to disengage. "Sometimes it is just not worth it. So, I do not bother and listen to my music instead—or go on social media where I can talk to my friends".

Digital spaces let Stacey be herself, without needing to prove her capacity first. For Stacey, silence wasn't about having nothing to say. It was a form of protection.

Poppy, a fluent communicator and trained advocate, also encountered the same assumptions. The issue, she explained, was not capacity; it was the presence of disability itself that triggered assumptions:

> When I've had positive advice ... it's been because they understood me directly.... Whereas in situations where I have been given negative advice, it has been a lot more based on perception ... and I think the really important thing about that is that that perception has a particular bias. So, it's not just perception, it's the perception that people with disability can't do things.

One incident stood out. "I had this massive argument once about the safest and the best way for a blind person to butter bread [laughs]. It just strikes me as such a waste of time". This moment, though light-hearted, showed how a focus on safety can displace autonomy. As Poppy put it, "professionals often think about risk from the perspective of how they might manage it, not from the perspective of the disabled person."

For Poppy, risk was part of autonomy, not something to be avoided. She explained how risk decisions are often short-sighted:

> Organisations tend to take a very short-term view of risk, which ... in the long-term can do a lot of damage to people. So, for them, thinking about the immediate risk ... well, you know, if you use a knife, for example... potentially you could cut yourself ... whereas it makes a lot more sense, I think, to learn how to use a knife properly ... in a way that's going to achieve what you want.

Poppy was clear:

> You need to be very clear about what you want … and justify it. Because sometimes you can work around professionals, and sometimes you can't. So, you need to get them onside, which is annoying, because they should be onside to start with.

Across these narratives, the issue was not knowledge or capacity, it was misrecognition. Whether participants used speech, AAC, or needed full-time support, they were often treated as less than competent. The result was not just frustration, it shaped who got heard, who was trusted, and whose decisions were respected.

The logic of risk aversion is made real through everyday professional behaviour. It is carried in language, assumptions, rules and refusals. In participants' experiences, these systems often ended up protecting themselves— at the expense of the very autonomy they claimed to support.

The minimisation of joy and happiness: Risk-averse responses to ordinary pursuits of meaning, connection and identity

When professionals enact the survival logic of systems, the outcome was not only exclusion—but erosion. The everyday cost was to minimise joy, spontaneity, and the chance to live a life that felt good. Mia's experience showed how easily joy could be questioned or controlled. One of her simple pleasures was going home alone after work, fast, in her wheelchair:

> I love the feeling of freedom and independence. But the staff are always worried it's too dangerous... What's the difference between them walking home and me doing that? People wouldn't stop them. Or they'd say, 'You're going really fast', and I'm like, 'You know what running is, don't you?'

What Mia experienced as joy and independence, others saw as risk. This was especially painful given the effort it took for her to get there. Earlier in her life, school had been isolating:

> The support unit held you back. The staff would say, 'you've got to do support with us.' You've got no choice… I was just a scared little year seven kid. I didn't know that I had choices.

Eventually, Mia and her family found another school. “I was 16 and, finally, I felt like I had friends. I would come home smiling." That shift was not just about environment; it came from making her own decisions. At age 14, she chose to use a powered wheelchair full-time:

> I’d fall a lot using the walking frame, and it just took so much time and effort. I was much quicker in the wheelchair, and being less tired meant I had more energy for communication and engaging with people.

These decisions were not only about mobility, but also about participation. Mia worked part-time, mentored other young disabled people, and helped families imagine alternatives. “School is about learning and exams and stuff, but once I got out of that school and discovered proper friends—and happiness—that’s what made the biggest difference”.

Evie found joy in movement and challenge. Her first real taste of that joy came at a childhood camp for children with juvenile arthritis. She described the experience as powerful. “Fifty kids on a camp for a week doing all the things that our parents and other people tell us not to do… kayaking, canoeing, sailing, abseiling—the whole shebang.”

Later, she found that joy again through karate—a sport she could do alongside her dad and sister. But her healthcare team warned her to stop:

> The advice was ‘no’—'absolutely stop’; ‘don’t do it;’ ‘it’s too jarring;’ ‘it’ll aggravate it.’ Even continuing on, they’d say, ‘I don’t think it’s a good idea. Rah, rah.’ But it ended up being quite a positive thing in helping me out.

Karate became more than just a physical outlet. It became a source of pride and identity. Evie earned a black belt, became a teacher, and medalled at state-level competitions. But even in success, professional pushback continued. “None of them had ever done karate or even considered what it might mean for someone like me to do it. They just said it was too dangerous. But how would they know?”

Evie’s story was not an exception. Across the study, participants described how joy became risk—not because of the activity, but because of how professionals perceived disability. In this context, participants described how professionals often saw joy as something to monitor, not something to support. In contrast, participants asked: “Would this be risky if I didn’t have a disability?”

For non-disabled people, challenge and happiness are often seen as ordinary. For disabled people, the same pursuits trigger caution, concern, or refusal.

Another participant, not named here for privacy, shared how risk-aversion delayed gender-affirming care. This care was not just about physical health—it was about survival. “Without treatment, I wouldn’t be here telling my story.”

Early on, a medical team raised concerns that hormone treatment might worsen the participant’s physical condition. But the team never shared those concerns. “No conversation. No collaborative planning. No chance to weigh the risks myself”.

Years later, with a new medical team, they accessed the treatment. Their physical health stabilised. Their mental health improved. They described the outcome as a reclamation of life:

> It was a hideous period of my life, humiliating every single minute, every-single-day. I didn’t have the tools to resolve it until I had complete independence. Even then, I did not feel I had the final say. They [the professionals] definitely did. So I went to another specialist, one who was willing to take a risk.

Here risk was not just physical—it was tied to identity, autonomy, and joy. What was framed as protection became quiet refusal to provide support.

> I'm still surprised by the attitude—'we have these concerns, but we are not going to share them with you. We are not going to let you make these decisions. We are not going to bring you into the team to logically have this conversation’.

This kind of professional gatekeeping did not just limit opportunity, it disrupted futures. When life-giving care was withheld in the name of caution, the cost was not only emotional—it would have been existential.

These harms—of joy denied and autonomy withheld, often happened quietly. The situations did not always appear dramatic, but they shaped how participants lived. Nonetheless, joy still surfaced. It was negotiated, insisted upon, or carved out at the systems' edges. Whether it was Jaz's wry persistence, Kael's school excursions made possible through workaround support, or Lucy's social life built within exclusionary policies, joy was there. Not always celebrated but always fought for.

As demonstrated throughout their narratives, participants showed that challenge, meaning, and joy are not extras to be doled out at the whim of a professional. They are part of what it means to live fully. But, in systems governed by caution and control, even ordinary happiness had to be justified.

Discussion

Participants in this study experienced inflexible policies and practices that put up barriers and minimised joy. These barriers were not incidental; they were enacted through the everyday decisions of professionals carrying out policies designed to help. Instead, these policies limited choice, undermined autonomy, and disrupted opportunities for ordinary flourishing.

These findings are consistent with research that positions everyday risk and ordinary flourishing as different for people with disability from those without. Professional and policy judgements often position disabled people as inherently vulnerable, risk as liability, and safety as paramount (Brett et al., 2009; Marsh & Kelly, 2018). For disabled people, the right to engage with everyday risk—to pursue joy, to make choices, and live fully becomes conditional, monitored, and in many cases, denied.

This gap between policy intent and the lived realities of disabled people reflects a broader pattern. In a recent analysis of the Australian National Disability Scheme (NDIS) (2013), Hummell et al. (2025) described that policy intentions grounded in rights and individualisation become diluted by institutional reasoning leaving NDIS participants without the support needed to live the life they wanted. Their concept of *policy drift*—the gradual divergence between reform goals and their implementation—offers a frame for understanding how bureaucratic processes continue to undermine the very rights these policies were designed to uphold. Similarly, Sunderland et al. (2009) has drawn attention to the notable absence of discourses of joy and happiness in Australian disability policy and research settings. This absence reflects a broader discomfort with recognising joy and happiness as legitimate and necessary aspects of disabled people's lives. My findings extend these critiques by illustrating how risk-averse policy and practice not only undermine autonomy but also disrupted the right to engage with everyday risk—to pursue joy, to make choices, and live fully.

Through a critical disability lens (Goodley et al., 2017; Shakespeare, 2006), these barriers are produced and sustained by entrenched patterns of misrecognition, deficit-based assumptions, and paternalistic decision-making (Honneth, 1995; Campbell, 2009; Garland-Thomson, 2018). In this context, professional risk-aversion is not simply a cautious response, as participants have shown, it is a mechanism of control that reproduced inequality by denying autonomy and regulating joy.

Human Rights Approaches clarify (Felder, Davy & Kayess, 2022) what is at stake: the right to make decisions, take risks, and participate fully in life. Participants' stories showed that joy, identity, and pleasure were not optional extras—they were expressions of that right, consistent with the CRPD's (2006) emphasis on participation, inclusion, and self-determination (United Nations, 2006). Yet, in many cases, these expressions were managed, withheld, or made conditional by professionals and the systems they represented.

Hope Theory (2002) adds a final interpretive layer. The gap between policy intention and practice directly disrupts what Snyder (2002) described as the structural and relational conditions necessary for hope. The aspirations available to participants, were not determined by their rights or desires, but by what the system and professionals were already prepared to offer. Personalised ambitions were squeezed into pre-scripted institutional pathways; possibilities were filtered through administrative templates of what was safe, efficient and manageable. In effect, flourishing (Michaelis & Soldatic, 2022; Seligman, 2011) was narrowed to what institutions had already decided they would offer, eroding not only agency and pathways (Snyder, 2002), but the right to imagine and pursue a future on their own terms (Kafer, 2013).

When agency (the will to act) was undermined, and pathways (the means to act) blocked or controlled, participants described feeling stuck, dismissed, or denied. And yet, they also revealed how hope could be reclaimed. Snyder (2002) helped explain how systems designed ostensibly to enable autonomy often actually constrain it. As these findings demonstrate, agency can be undermined by misrecognition, low expectations, and professional gatekeeping, and pathways can be blocked or fragmented by rigid policies, procedural burdens, or limited support. In this context, flourishing is not about internal strength (Clifton, 2014; Michaelis & Soldatic, 2022), it is about whether systems make opportunities for flourishing possible.

Conclusion

Reframing risk as a right demands structural and cultural shifts in how disability is understood and governed across professional practice, policy, and institutional design.

Recognising risk as a right opens new possibilities, not only for individuals but also for how we design and deliver systems of support. The challenge is not whether disabled people can adapt to structural barriers but whether institutions and professionals are willing to dismantle the ones they created.

CHAPTER 5

Strategies disabled people use to reclaim autonomy and flourish in risk-averse systems

Abstract

Disabled people are frequently positioned as passive recipients of care within systems that prioritise safety, compliance and liability. These systems frame risk as something to be minimised rather than an essential part of joy and flourishing.

This paper draws on qualitative interview data from a broader study exploring how disabled people experienced risk, autonomy and flourishing within professional systems. The analysis focuses on narratives from 28 people with lived experience of disability, 24 with physical disability 12 years and older, and 4 parents of individuals with disability.

Findings identify four interrelated strategies used to reclaim autonomy in risk-averse disability systems: becoming proud, understanding rights, reframing risk and uncertainty, and building wise networks. I examined these strategies through the lenses of Hope Theory, Critical Disability Theory and Human Rights Approaches, and interpreted them as acts of resistance and reclamation—challenging deficit narratives, professionalised risk logics, and normative assumptions about support, safety and success.

The findings reframe risk as a right, autonomy as relational, and flourishing as a rightful pursuit. These insights have implications not only for policy and professional practice, but for how autonomy and flourishing are conceptualised in disability research and practice.

Keywords: Disability Rights, Risk, Critical Disability Theory, Hope Theory, Flourishing

Introduction

Disabled people’s lives are frequently shaped by systems that constrain autonomy in the name of protection, care or compliance (Goodley, 2014; Shakespeare, 2006). Across policy, service delivery and professional practice, risk is often positioned as a problem to be managed, rather than a necessary and meaningful part of life (Beck, 1992; Bundy et al., 2015). These risk-averse systems narrow the possibilities available to disabled people, not only by limiting choice and control, but by devaluing joy, uncertainty and everyday expressions of self-determination (Clifton et al., 2018; Garland-Thomson, 2022; Sunderland et al., 2009).

These risk-averse approaches are embedded in structural logics of exclusion, shaped by longstanding assumptions about disability, dependency and safety (Goodley, 2014; Meekosha & Shuttleworth, 2009). Professional judgments often override lived experience (Shakespeare, 2006) and access to ordinary risks—whether physical, emotional, or social—is routinely restricted. As a result, disabled people must navigate systems that both misrecognise their worth (Honneth, 1995; Konrad, 2021) and marginalise their capacity to act (Campbell, 2009).

This paper explores how these dynamics unfold in everyday life and examines what enables disabled people to reclaim autonomy in systems designed to limit it. The analysis draws on three intersecting frameworks: Critical Disability Theory (CDT) (Garland-Thomson, 2018; Goodley et al., 2017; Pothier & Devlin, 2005; Shakespeare, 2006), which critiques the ways in which professional and institutional structures reproduce inequality through misrecognition, paternalism and deficit thinking; Human Rights Approaches (HRA) (Kayess & French, 2008; United Nations, 2006), which asserts that autonomy, dignity and participation are fundamental and indivisible rights; and Hope Theory (Snyder, 2000, 2002), which understands autonomy as rooted in both *agency* (the will to act) and *pathways* (the means to do so). Together, these frameworks reframe autonomy not as individual achievement, but as a relational and systemic condition—shaped by access to recognition, opportunity and support (Honneth, 1995). Importantly, they also highlight that hope is not naïve optimism, but a political and structural claim to the right to imagine and pursue a future on one's own terms.

By centring disabled people's experiences, this paper examines the disconnect between systems that claim to support autonomy and the lived realities of navigating them. It contributes to a growing body of work that challenges risk-averse practice and reframes risk as a vital component of identity, growth and flourishing (Bundy, 2024; Bundy et al., 2009; Bundy et al., 2015; Clifton et al., 2018). This aligns with broader theoretical work on flourishing and the social construction of risk (Seligman, 2011b; Tulloch & Lupton, 2003).

Positioning the study

This paper draws on interview data from a broader qualitative study which examined how disabled people experience risk, autonomy and flourishing within professional systems. The study had three core objectives: (1) to examine the impact of professional advice on autonomy, dignity and participation; (2) to identify the strategies disabled people use to navigate systemic barriers; and (3) to investigate the factors that enable or constrain meaningful and fulfilling lives. This article focuses on the second objective, examining how disabled people reclaimed autonomy and charted pathways through systems shaped by risk-aversion, exclusion and misrecognition.

As a disabled researcher with professional experience in disability advocacy and service systems, I approached this work with critical awareness of the gap between institutional narratives and lived experience. This positionality informed the study design, data collection and analysis, enhancing contextual sensitivity and supporting strong rapport with participants. To ensure rigour and reflexivity, I engaged in iterative analysis, research journaling and peer debriefing throughout.

Methods

Ethical approval was granted by the Human Research Ethics Committee of The University of Sydney (Ref: 2-2010/12514. To protect participant anonymity, pseudonyms are used in this report.

Study design

Qualitative thematic analysis was used to examine the strategies participants employed to reclaim autonomy and self-determination. The analysis was informed by Critical Disability Theory (Garland-Thomson, 2018; Goodley et al., 2017; Meekosha & Shuttleworth, 2009; Pothier & Devlin, 2005), Human Rights Approaches (Kayess & French, 2008; United Nations, 2006), and Hope Theory (Snyder, 2000, 2002).

Participant selection

Participants were selected through purposive and snowball sampling strategies (Given, 2016; Noy, 2008; Palinkas et al., 2015). Participants were eligible if they had a physical disability, self-reported no cognitive or intellectual impairments, and were aged 12 years or older. Parents or carers of disabled adolescents (aged 12-16 years) were also invited. Recruitment occurred via community networks, advocacy organisations and public social media calls.

In total, 28 people contributed: 24 disabled individuals and 4 parents of disabled adolescents. All had lived experience with physical disability and spoke about autonomy, risk and professional systems. This paper draws on narratives that most clearly illustrate the themes presented; not all participants are quoted, but all informed the analysis. Table 5.1 provides brief participant profiles for those cited in the findings.

Table 0.1 Profiles of participants quoted in findings.

Pseudonym	Age	Role(s)	Summary
Aaron	38	Youth & family support worker and electronics enthusiast	Full-time support worker for disabled youth and families. Uses a powered wheelchair and explores assistive technology to enhance accessibility.
Alice	28	Journalist and comedian	Works full-time in journalism and part-time as a comedian, creating inclusive social spaces. Uses a powered wheelchair and advocates for access and representation in media industries.
Evie	18	University student and martial artist	First-year Media and Communication student with a black belt in karate. Navigates chronic illness and mobility barriers in education and sport, using adaptive strategies to stay active and engaged.
Jana	28	Advocate and writer	Full-time multicultural advocate supporting women with disability. Navigates physical and sensory impairments, using adaptive strategies to stay active in work, travel, and everyday life. Passionate about cooking, writing and inclusion.
Jaz	56	Community worker and digital accessibility advocate	Works part-time as a web content creator. Uses both manual and powered wheelchair and advocates for inclusive digital and physical spaces.
Kael	14	Student and musician	Balances school life with interests in music and computer games. Uses both a powered wheelchair and manual wheelchair to engage in learning and social activities. His parents, Luisa and Hugh, discussed experiences supporting Kael to pursue his interests.
Laya	15	Student, traveller, gardener	Year 9 student who loves gardening and traveling with her

			family. Uses a powered wheelchair and AAC device to engage in school and everyday life. Her mother, Cali, shared her experiences navigating support in education, health and community settings.
Leah	18	Law student, surfer and model	Disability ambassador preparing to study Media and Law. Uses a manual wheelchair and navigates access barriers in education and sport, including surfing and public advocacy.
Meg	22	University Student and Aspiring Educator	Lives on campus while studying Education and Psychology. Uses walking sticks and a manual wheelchair to manage mobility barriers, actively advocating for accessibility in education.
Mia	23	Office administrator and youth mentor	Works part-time as an office administrator and part-time youth mentor. Uses a powered wheelchair and advocates for greater accessibility in education, employment and community life.
Olivia	30	Advocate and Swimmer	Works full-time as a disability and human rights advocate and was about to begin doctoral studies. Uses walking sticks and advocates for access within academic and public spaces.
Poppy	32	Human Rights Educator and Public Speaker	Works full-time in disability and human rights education. As a vision-impaired person, she navigates barriers in professional and public spaces while advocating for inclusive policy and systems change.
Thomas	40	Communications Officer, Advocate and Artist	Works part-time in communications and serves on a community health board. Uses a manual wheelchair and works within urban accessibility networks to promote equitable healthcare and independent living.
Tilda	22	Student, Activist and Performer	Studies Gender Studies and Psychology while engaging in

			disability rights activism and performance. Uses sign language and an AAC device, navigating physical and sensory barriers in education and public life.
Victoria	34	Government Employee and Community volunteer	Works four days a week in a government department and volunteers on community access committees. Uses a manual wheelchair and is hearing-impaired, navigating barriers in work and advocacy while contributing to inclusive policy efforts

Setting

Interviews were held in locations chosen by participants to ensure accessibility, comfort and safety. They included in-person meetings, phone interviews and online interviews conducted via Zoom or Skype. This flexibility aimed to minimise barriers to participation and affirm participant control over the interview environment.

Data collection

Semi-structured interviews (Brinkmann & Kvale, 2018) were conducted in person, by telephone or online according to participant preference. Interviews ranged between 45 minutes and 4.5 hours, with longer interviews conducted in multiple sittings. All interviews were audio-recorded, professionally transcribed and de-identified to preserve confidentiality. Field notes were taken after each interview to support contextual interpretation.

Data analysis

Data were analysed thematically using a five-step approach (Braun & Clarke, 2006) adapted from the framework outlined by Newall et al. (2017). The analysis identified patterns of meaning related to experiences of respect, autonomy and participation. Coding was conducted manually and developed through reflective dialogue with members of the research team and disabled peers. The themes presented reflect multiple stages of review, refinement and theoretical integration. The reporting of methods and findings was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007).

Findings

Participants described four interrelated strategies they used to reclaim autonomy and reestablish pathways within systems shaped by risk aversion, exclusion and misrecognition:

- Becoming proud
- Understanding your rights
- Reframing risk and uncertainty
- Building wise networks

These strategies were not linear or sequential. Participants moved fluidly between them depending on context, capacity and opportunity, sometimes returning to earlier strategies with new insight. Rather than offering a singular solution, they reflect diverse ways in which participants adapted, resisted and carved out space for autonomy and joy. Table 5.2 provides a summary of these four strategies, their key mechanisms and outcomes.

Table 0.2 Strategies for reclaiming autonomy and restoring pathways in risk-averse systems.

Strategy	**Primary function**	**Key mechanisms**	**Outcomes**
Becoming proud	Grounds identity in value, resistance and solidarity	Rejection of deficit narratives; Community connection; Evolving self-definition	Confidence, visibility, self-advocacy. Foundations for joy and flourishing.
Understanding your rights	Converts self-worth into action and structural change	Rights literacy; Strategic and relational self-advocacy; Naming and correcting misrecognition	Assertive agency, greater access. Pathways toward meaningful participation.

Reframing risk and uncertainty	Reclaims risk as necessary for growth, autonomy and joy	Distinguishing real versus perceived risk; Challenging overprotection; Valuing uncertainty	Expanded autonomy, creative life planning. Joy and challenge reframed as rights.
Building wise networks	Enhances capacity, confidence and possibility through trusted relationships	Peer-led knowledge exchange; Emotional and practical support; Diverse relational insight	Relational autonomy, informed decision-making. Collective support for flourishing and joy.

Becoming proud

Pride was not just a feeling, but a deliberate and evolving practice used by participants to challenge the idea that disability was something to overcome rather than a natural and ordinary part of who they were. As Aaron described:

> I’m just an ordinary person, living an ordinary life ... I’m proud of the fact that I am a disabled man. It’s when people see disability as a negative thing, that’s what I object to.

For Aaron, pride was a stable and integrated part of his identity. It shaped how he related to others and how he moved through everyday life. His pride was a strategy used against societal narratives that cast disability as tragic or exceptional.

Meg spoke to the fluctuating and developmental nature of pride. Her relationship with disability shifted over time, shaped by changing environments and social expectations. In primary school, she felt “happy and accepting”, but in high school, she became “depressed” while trying to fit in. Now at university, she felt she was “learning new versions” of herself and using her strengths to move toward her goal of becoming a teacher. “I’ve realised that I can’t do everything, and the kids I teach are okay with that … I think everything I feel comes back to who I am as a person and my acceptance of myself.”

For Meg, pride was something she could return to, rebuild and realign with what mattered to her. It reflected a growing confidence in who she was and how she wanted to be seen.

Tilda extended this evolving sense of pride into her creative and political life. She studied Gender Studies and Arts, used sign language as her primary language, and worked with a creative team rooted in trans and queer communities. She remarked, "I have a lovely creative team and together we developed a live performance using poetry, movement and dance. It's on femininity and disability, but rebellion."

Her pride was expressed through visibility, performance and collective resistance, approaches that did not separate identity from activism. This intersectional pride, shaped by disability, feminism, queerness and artistic practice, expanded the possibilities for how her identity could be claimed and celebrated. "My passion really lies in writing. But I really enjoyed the performance".

Similarly, Alice brought the personal-political dimensions of pride into focus—emphasising embodiment, visibility and community connection. For her, pride was not about public approval or conforming to professional ideals of progress. It was about recognising herself on her own terms and showing up fully in the world. She reflected on a conversation with a prescribing therapist who likened getting a new wheelchair to getting new shoes:

> It's closer to getting a new body than it is to getting new shoes. I think that's a ridiculous comparison to make. I mean, they don't understand. It's not just what you sit in, it's how you move, it's how you show up in the world. So, it's not really like getting new shoes at all ... it's part of who I am.

For Alice, pride was self-defined and grounded in what she most valued—relationship, independence, ambition. This shift, she explained, was a kind of "coming out", a personal and political awakening forged through connection with the disability community:

> A huge part of my empowerment as a person with a disability was sharing my life with other people who had a shared experience. Just being part of the disability community is something … for me, there is a shared experience, a shared sense of community … They

> taught me all sorts of things, but also reading about the disability rights movement and other people's stories was really empowering for me.

Quoting poet and activist Laura Hershy, Alice added, "you get proud by practising". This sentiment resonated widely across the study. Pride was not something people were born with. It was built over time, through experience, community, and a refusal to be defined on others' terms. It was shaped by life stage and context and practised in different ways across lives and relationships.

Across the study, pride was described not just as a feeling, but a strategy for identity, advocacy and direction. It was rooted in lived experience, sustained through solidarity, and enacted in everyday life. Pride influenced not only how participants saw themselves, but how they expected to be seen and treated by others. As pride in identity grew, so too did expectations for equity, recognition and full participation. Pride created space for pleasure, self-expression and connection. For many, this marked a shift from internal self-acceptance to external self-advocacy. Understanding their rights and learning how to claim them became a natural extension of pride, and a powerful strategy for navigating systems and cultures that routinely deny disabled people's authority, value and joy.

Understanding your rights

Understanding rights was a strategy participants used to turn pride and self-worth into action. For many, rights were not guaranteed; they were a means for claiming space, correcting misrecognition, and demanding respect on their own terms. Cali and her daughter Layla offered an example of how rights were enacted in everyday life. Their advocacy was relational and insistent, shaped by direct experience of being underestimated:

> A lot of people have those kinds of expectations about Layla—that she'll never do very much. They don't spend enough time with her to know what she is really like … so we've

> had to be strong advocates for her rights. And she is a very good advocate for her own rights. She will let people know: ‘Actually, you are wrong. I am allowed to do that’.

For Layla, rights were not only about access, but also about recognition. What she and Cali described was a refusal to accept low expectations and to let others define Layla’s possibilities. Rights, in this context, became a shared strategy of naming, correcting and holding ground.

Like Layla, Jana framed rights as both a public statement and a refusal to be underestimated. She explained, “You need to stand up for your rights and just show people. I am a person in the world too … I am able to succeed, work and travel.”

For Jana, rights were used to assert value in the face of assumptions, functioning as a claim to both visibility and capability.

For many, rights became visible precisely through their absence. Victoria described one example in which she was failed by an employment service. “They didn’t help me get a job. I asked them, ‘What are my rights?' They were like, ‘Oh no, sorry we don’t know’. I just thought, ‘No, I’m going to do this on my own’.”

Victoria’s decision to act independently was a refusal to accept a system that failed to uphold its own obligations. Her awareness of rights became a form of self-protection and a catalyst for reclaiming agency in the absence of meaningful support.

Several participants spoke of learning their rights through community networks and peer exchange, drawing on collective knowledge to navigate complex systems and failed supports. Rights knowledge was relational, often passed across networks and between experiences, helping people to move through inaccessible systems with greater confidence.

But collective wisdom was not only about strategy; it also carried social responsibility. Leah, for example, described educating others while protecting future interactions for the wider community. “It’s important to know your rights, to educate people when you know they are wrong. I try to do it in a respectful way, because I don't want to damn other disabled people in their eyes later."

What Leah described is how rights advocacy is often negotiated—strategic, relational, and mindful of the broader consequences. Asserting rights, in this context, involved more than correcting misinformation. It meant managing how disability was perceived, received and remembered by others.

Even when participants had the knowledge and resolve to act, asserting rights often came with a cost. Olivia shared her experience of navigating a formal discrimination complaint. "You have to know what you are entitled too. Yes, I have rights, but I also have responsibilities. But the whole complaints process is hard and stressful."

Olivia spoke to the emotional and practical weight of rights enforcement. Knowing one's rights was only part of the strategy; following through required time, persistence and grit which, Olivia explained, many simply could not afford.

While formal mechanisms offered a pathway to justice, they also demanded a level of energy and stability that should not be a prerequisite for fair treatment. Participants were clear that this burden should not fall entirely on individuals. As Jaz explained:

> People with disability must be empowered from day one to take control of their life. They are not … So, people with disability have to develop these advanced skills just to deal with their life, their disability, and then the system. People with disability should not have to develop these skills.

Jaz positioned the need for strategic rights advocacy not as a matter of personal capacity, but as a response to systemic failure. While understanding and asserting rights often emerged from frustration, misrecognition or injustice, participants were also clear about what rights made possible. Claiming one's rights meant opening space for confidence, opportunity and connection. For Layla, Jana, Victoria and others, asserting rights was not only about stopping harm. It was about pursuing joy, enabling the freedom to live, laugh, work, travel, create and belong.

Reframing risk and uncertainty

Risk and uncertainty were not threats to be avoided, but ordinary and necessary conditions for autonomy, growth and joy. Embracing uncertainty became a way to resist overprotection and assert authority in decisions about their own lives. Thomas described how he approached professional advice and overprotection through what he called “gentle interrogation”—a process of unpacking assumptions and asserting his own judgement:

> I interrogate people in an unpacking way. ‘Why have you said that to me? Why are you advising me this?’ Keep asking why until you get to the end … If the answer is ‘It’s the safest choice,’ then I ask, ‘What makes you choose safe for me? Do you think I have chosen safe?’

For Thomas, as for many participants, this was not about rejecting safety, but about questioning whose version of safety was being applied. By reframing these conversations through ‘gentle interrogating’, he shifted the basis of decision-making away from institutional caution to personal context and capacity. Thomas also spoke to the importance of uncertainty itself—not despite risk, but because of it.

> Life is risk. You can fall flat on your face, but that’s life, isn’t it? It’s about what you do in the spaces where things are uncertain—and sometimes, that’s where you find the most joy.

He challenged narratives that framed disabled people as inherently fragile. Rather than eliminating risk, Thomas advocated for shared responsibility, risk negotiated with, not managed for, disabled people.

Poppy extended this critique by distinguishing between *real risk*, which required thoughtful planning, and *perceived risk*, often shaped by professional discomfort or institutional liability:

> If it’s a question of risk around me, I need people who can think about who I am and what I’m able to cope with. If it’s just people being scared, as opposed to something being genuinely risky, then the next step is to take action.

Despite her capacity and competence, Poppy often encountered risk-averse practices that prioritised safety over aspiration. She recalled moments when professional agendas focused on what was “safe” or “achievable”, rather than what mattered to her:

> Sometimes professionals push for safe, easy goals instead of recognising what I’m capable of and how much I enjoy learning new things. They focus on what they think I can do, not what I want to do … I remember having this massive disagreement about the safest way to butter bread [laughs]. It just strikes me as such a waste of time.

For Poppy, learning involved challenge, and challenge involved risk. Risk in her view, was not the opposite of safety, it was part of a meaningful life.

Kael’s parents, Hugh and Luisa, brought a relational lens to risk and uncertainty. They described how their family intentionally prioritised opportunities for growth over minimisation of risk. As Hugh explained,

> We decided very early on that the importance of Kael having a full life was the central issue and that necessarily involves pushing the boundaries that create growth: personal growth, and growth in terms of relationships, self-awareness, and well-being.

Luisa added:

> You determine that there are risks, but you’ve got to balance that against joy. It’s not a life if you’re just sitting in four walls and not out there living it.

Across these narratives, joy appeared not despite uncertainty, but within it. When participants reclaimed the right to take risks, they also reclaimed the right to live expansively—with hope, purpose and pleasure. Risk was not something to be feared, but a necessary component of a full life.

As participants made clear, reframing risk was not about disregarding safety; it was about restoring balance. Reframing risk was not simply about agency—it was about opening up space for joy.

Building wise networks

Building wise networks was a strategy participants used to increase agency, navigate uncertainty, and live more fully, with confidence, connection and joy. As shown through the discussion of pride, understanding rights and reframing risk, networks provided practical knowledge, emotional support and diverse perspectives that helped participants make informed decisions and expand their sense of what was possible. Networks enabled participants to step beyond professional limitations and access the relational tools they needed to act with greater confidence and autonomy.

Peer networks were especially valued for the insight they offered from lived experience. Several participants described how advice from others who had faced similar challenges often felt more meaningful than guidance from professionals unfamiliar with disability. As Evie explained:

> It's good to be able to talk to other people going through the same kinds of issues. I probably rely more on the advice of my network than on the doctor's advice … We've all experienced this firsthand, so it's more useful to hear it from other people who have been there.

Evie highlighted how peer exchange offered not only information but validation. In spaces where professional guidance could feel overly cautious or disconnected from daily realities, shared experience offered something more grounded and immediately applicable.

Participants emphasised the importance of diverse perspectives within their networks. Connections that spanned both disabled and non-disabled people provided different kinds of insights and helped participants think more broadly about their options. Thomas described how support outside traditional systems offered something complementary to clinical advice.

> I got a life coach, and it's one of the best things I could have done. They equal my medical people, but they don't know diddly-squat about the human body. They give me a different perspective that helps me figure out what I need.

Thomas' experience highlighted how informal or non-clinical relationships can play a meaningful role alongside medical or therapeutic supports—offering direction, reflection, and practical tools to navigate complex choices.

Trusted relationships also helped participants act. Several described how encouragement from within their networks gave them the confidence to try new things or take considered risks. Mia shared, "When I decided to go to business college, I had a friend that went there before. She really encouraged me, and I knew if she could do it, I could do it."

In this way, networks did more than provide emotional support; they helped participants translate possibility into action.

For some, wise networks included professionals—though only when those professionals acted in supportive, collaborative ways. Jana described how her network came together following school, supporting her in ways that expanded her sense of agency. "Since leaving school, I've really flourished. My family, my community, and all the support services—they all work well together now. This has helped me a lot."

Jana pointed to the power of collaboration between informal and formal supports, where professionals do not dominate decision-making, but contribute to a network that recognises and supports autonomy, dignity and participation.

Across the study, participants described wise networks as essential to decision-making, learning and growth. These relationships enabled them to weigh options, test ideas, and move forward with greater clarity. In contexts where systems were fragmented or risk-averse, networks became sources of strength—grounded in mutual trust, lived insight and a commitment to autonomy, dignity, and joy.

Discussion

Despite systems that frame risk as danger and constrain autonomy in the name of care, disabled people in this study reclaimed control through grounded, deliberate strategies that resisted risk-aversion, exclusion and systemic misrecognition. These strategies were not reactive adjustments to circumstances, but deliberate, interrelated actions grounded in identity, rights and connection. Each strategy offered a way to resist systemic constraints and reassert agency within systems that routinely denied it. Together, these strategies not only reclaimed autonomy, but opened space for joy, connection, and ordinary flourishing, often in defiance of systems that failed to imagine these as valid outcomes.

As detailed in the findings, these strategies confronted dominant narratives that positioned disability as deficit and risk as danger. Pride was framed as an act of resistance, rooted in identity and solidarity. Rights were not abstract legal concepts but tools of everyday self-advocacy. Risk was positioned as necessary for growth, joy and belonging. And networks were not just sources of support, but sites of wisdom, challenge and shared resistance.

The fluid, non-linear nature of these strategies reflects how autonomy is actively reclaimed—not granted—within disabling systems. Participants moved in and out of strategies as their lives unfolded, often returning to earlier strategies with new insights or renewed strength. Rather than following a prescribed path, they adapted, resisted and created space for joy, often in quiet, persistent ways that were invisible to the systems around them. These strategies did not always lead to systemic change, but they made space for personal autonomy, reclaimed time, and cultivated identity on participants' own terms.

Drawing on Snyder's (2002) Hope Theory, we understand agency not simply as a personal trait, but as a relational, socially mediated capacity to act toward a meaningful future.

Pathways, similarly, are not fixed or linear, but often have to be forged or reclaimed through ongoing navigation and creative resistance. Participants recalibrated their strategies in response to shifting context, capacity and opportunity, sometimes intentionally, other times out of necessity. This process illustrates the ongoing and situated nature of reclaiming autonomy (Konrad, 2021)—not a single moment of transformation, but a continual negotiation shaped by time, relationships and evolving circumstances.

Together, these four strategies reflect broader concepts of political disability identity where pride, rights, resistance and connection operate as intertwined dimensions of self-assertion and structural critique (Putnam, 2005). Consistent with this framework, participants reclaimed identity, autonomy and belonging on their own terms. In doing so, participants made visible the gap between policy ideals and lived realities, where risk is framed as protection but operationalised as restriction.

This analysis contributes to Critical Disability Theory by prioritising disabled people's agency. It challenges systems that frequently misrecognise disabled people's worth. It also aligns with Human Rights Approaches that assert dignity, autonomy and participation as non-negotiable (Kayess & French, 2008; Michaelis & Soldatic, 2022). It exposes the limitations of professionalised risk logics (Shakespeare, 2006) and challenges the assumption that safety must come at the expense of self-determination.

Conclusion

Across policy and practice, disabled people are routinely positioned as subjects of care, risk and control. These findings challenge that framing, showing how disabled people enacted grounded, interrelated strategies to reclaim autonomy and resist systemic constraints.

Flourishing, as described by participants, was not found in predictability or protection, but in embracing uncertainty, navigating risk and reclaiming joy on their own terms. These insights call for a fundamental shift in how autonomy is supported—not by managing risk or limiting options, but recognising and resourcing the dynamic, relational, and often resistant ways disabled people build their lives.

As Jana simply put it, “You’ve got to be happy in life”. Her words remind us that autonomy, risk and flourishing are inseparable, and that happiness is a fundamental right.

CHAPTER 6

Operational respect vs genuine respect: Competing claims in disability policy and practice

Abstract

Respect is routinely cited as a core value in disability policy and professional practice. Yet, disabled people's everyday experiences often reveal a gap between the rhetoric of respect and its lived enactment, particularly in contexts that claim to support autonomy and dignity of risk. This paper examines how respect is understood and enacted within professional and systemic interactions, drawing on disabled people's accounts of autonomy, risk and participation.

Drawing on qualitative interview data from a broader study exploring how disabled people experienced risk, autonomy and flourishing within professional systems. The analysis focuses on narratives from 28 people with lived experience of disability, 24 with physical disability 12 years and older, and 4 parents of individuals with disability.

Findings reveal a critical distinction between operational respect—a compliance-driven, performative approach aligned with institutional priorities—and genuine respect, which is relational, rights-based, and grounded in recognition. Participants described how these competing forms of respect shaped their autonomy, participation and self-determination. These findings challenge assumptions that respect can be mandated through policy alignment alone. Reframing respect as a relational and structural commitment is essential to realising disabled people's rights to autonomy, participation and self-determination.

Keywords: Autonomy, Dignity of risk, Critical disability studies, Human rights,

Introduction

Respect is often treated as a universal good—an inherently positive principle, underpinning human dignity, equality and ethical interactions. It is central to the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), which positions respect as foundational to autonomy, participation and self-determination. Embedded within these rights is the principle of dignity of risk (Mukherjee, 2022; Perske, 1972)—the right to make decisions and take risks, even when outcomes are uncertain.

Yet despite policy frameworks that promote respect, barriers to these rights persist. A recent study by the (Australian Institute of Health and Welfare, 2022b) reported that people with disability were twice as likely to experience discrimination than those without. Among those who experienced discrimination, 82% avoided situations, 74% had lower incomes, and 70% reported high or very high psychological distress. These figures reflect broader patterns. Disabled people are more likely to have poorer health and wellbeing; live in poverty; face exclusion from education and employment, and be denied full participation in political, economic, civic, cultural and social life.

Notably, only 54% of disabled people across all age groups report feeling valued and respected by their community, a figure that declines to 42% among those aged 25-44 years (Australian Institute of Health and Welfare, 2022a). This disconnect between policy ideals and lived experience raises critical questions about what respect means in practice, and how it is understood and experienced within systems that shape disabled people's lives.

To examine how respect can both enable and constrain these rights, it is necessary to engage with how respect has been theorised, particularly in relation to recognition, relational ethics and the political dimensions of power and participation.

What is respect?

Respect is frequently cited in human rights frameworks (United Nations, 2006), disability policy (e.g. National Disability Services (n.d.) and professional codes of conduct (APHRA, n.d.) as a core value. In theory, it signals an ethical orientation toward autonomy, recognition, and fairness—principles widely reflected in moral philosophy (Dillon, 2007), critical theory (Honneth, 1995) and sociological accounts and relational ethics (Sennett, 2003). In practice, however, respect is often applied without clarity or depth, leaving its meaning assumed rather than examined. As Schwartz (2011) cautioned, respect risks becoming a platitude invoked for rhetorical effect without necessarily reflecting meaningful change in how people are treated.

Philosophical and sociological theories of respect foreground its relational, structural and political dimensions. Philosopher Robin Dillon (1992, 2003, 2007) argued that respect cannot be reduced to politeness or procedural civility. Rather, respect is an active form of recognition that affirms a person's moral worth, autonomy and right to participate as the subject—not merely a recipient—of care or services. From this perspective, respect is not a sentiment but a practice, one that either reinforces or dismantles power relations.

Social philosopher Axel Honneth (1992, 1995), drawing on critical theory, argued that recognition is a fundamental human need and precondition for self-realisation and social belonging. He positioned respect as a vital form of moral recognition that is essential to individual self-trust and social life. Where respect is denied or distorted, people become alienated, not only from others, but also from their own sense of worth and agency. In this way, respect functions as a precondition for agency, participation and self-determination.

Sociologist Richard Sennett (2003) highlighted the ethical complexity of respect in practice. Writing from a sociological and philosophical perspective, he argued that respect requires confronting uncertainty, embracing difference and acknowledging the limits of control. It cannot be scripted, mandated or guaranteed by procedure. Instead, respect must be built through relational engagement, reciprocity and the willingness to relinquish professional or institutional control. As Sennett (2003) claimed, respect cannot occur simply by commanding it to happen; it must be felt and convincing.

Together, these theorists position respect as a dynamic and contested process that is inseparable from structures of power, recognition and social value. In disability contexts, where professionals often hold interpretive and procedural authority (Goodley, 2014; Shakespeare, 2006), the form that respect takes can determine whether autonomy, participation and self-determination are supported or undermined.

This paper draws on data from a broader study in which respect was identified as a factor shaping how disabled people experienced everyday risk, autonomy and flourishing. The wider study had three core objectives:

- To examine the impact of professional advice on autonomy, dignity and participation.
- To identify strategies used by disabled people to navigate risks and barriers; and
- To investigate the factors that helped or hindered disabled people in achieving fulfilling lives.

This manuscript focuses on interview data related to the first and third objectives, examining how respect is enacted or withheld in professional and systemic interactions. As a disabled researcher with professional experience in disability advocacy and service systems, I brought a critical awareness of the gap between policy claims and lived experience. This dual perspective informed the study design, data collection and analysis, offering contextual insight and supporting strong rapport with participants. To ensure rigour and accountability, I engaged in ongoing reflexivity through journaling and peer debriefing.

Methods

Ethical approval was granted by the Human Research Ethics Committee of The University of Sydney (Ref: 2-2010/12514. To protect participant anonymity, pseudonyms are used in this report.

Study design

I used qualitative thematic analysis to explore how participants experienced respect in everyday interactions with systems and professionals. The analysis was informed by critical disability theory (Garland-Thomson, 2018; Goodley et al., 2017; Meekosha & Shuttleworth, 2009; Pothier & Devlin, 2005), human rights approaches (Kayess & French, 2008; United Nations, 2006), and theories of relational respect (Dillon, 1992, 2003, 2007; Honneth, 1992, 1995; Sennett, 2003).

Participant selection

Participants were recruited through purposive and snowball sampling strategies (Given, 2016; Noy, 2008; Palinkas et al., 2015). Eligible participants identified as having a physical disability, self-reported no cognitive or intellectual impairments, and were aged 12 years or older. Parents or carers of disabled adolescents (aged 12-16 years) were also invited. Recruitment occurred via community networks, advocacy organisations and public social media calls.

In total, 28 people contributed: 24 disabled individuals and 4 parents of disabled adolescents. All had lived experience with physical disability and spoke about autonomy, risk and professional systems. This paper draws on narratives that most clearly illustrated the themes presented; not all participants are quoted, but all informed the analysis. A summary of participant characteristics and ages are presented below. All names are pseudonyms.

Participant	Age	Role(s)	Summary
Aaron	38	Youth & Family Support worker and electronics enthusiast	Worked full-time supporting disabled youth and families. Used a powered wheelchair and explored assistive technology to enhance accessibility.
Alice	28	Journalist and comedian	Worked full-time in journalism and part-time as a comedian, creating inclusive social spaces. Used a powered wheelchair and advocated for access and representation in media industries.
Ashley	23	University student and arts enthusiast	Final-year Arts student balancing academic and creative life. Managed chronic illness and mobility barriers while navigating access structures in higher education.
Leah	18	Law student, surfer and model	Disability ambassador preparing to study Media and Law. Used a manual wheelchair and navigated access barriers in education and sport, including surfing and public advocacy.
Meg	22	University student and aspiring educator	Lived on campus while studying Education and Psychology. Used walking sticks and a manual wheelchair to manage mobility barriers, actively advocating for accessibility in education.
Mikayla	25	Student, volunteer and photographer	Full-time university student and rural fire service volunteer. Used a powered wheelchair and was hearing-impaired, balancing study, creative work and advocacy across community spaces.
Olivia	30	Advocate and swimmer	Worked full-time as a disability and human rights advocate and was about to begin doctoral studies. Used walking sticks and advocated for access within academic and public spaces.
Poppy	32	Human rights educator and public speaker	Worked full-time in disability and human rights education. As a vision-impaired person, she navigated barriers in professional and public

			spaces while advocating for inclusive policy and systems change.
Thomas	40	Communications officer, advocate and artist	Worked part-time in communications and served on a community health board. Used a manual wheelchair and worked within urban accessibility networks to promote equitable healthcare and independent living.
Tilda	22	Student, activist and performer	Studied Gender Studies and Psychology while engaging in disability rights activism and performance. Used sign language and an AAC device, navigating physical and sensory barriers in education and public life.

Setting

Interviews were held in locations chosen by participants to ensure accessibility, comfort and safety. They included in-person meetings, phone interviews and online interviews conducted via Zoom or Skype. This flexibility aimed to minimise barriers to participation and affirm participant control over the interview environment.

Data collection

Semi-structured interviews (Brinkmann & Kvale, 2018) were conducted in person, by telephone or online according to participant preference. Interviews ranged between 45 minutes and 4.5 hours, with longer interviews conducted in multiple sittings. All interviews were audio-recorded, professionally transcribed and de-identified to preserve confidentiality. Field notes were taken after each interview to support contextual interpretation.

Data analysis

Data were analysed thematically using a five-step approach (Braun & Clarke, 2006) adapted from the framework outlined by Newall et al. (2017). The analysis identified patterns of meaning related to experiences of respect, autonomy and participation. Coding was conducted manually and developed through reflective dialogue with members of the research team and disabled peers. The themes presented reflect multiple stages of review, refinement and theoretical integration. The reporting of methods and findings was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007).

Findings

Three core themes offered insight into how respect—or its absence—shaped participants' autonomy, participation and self-determination. Those themes were:

1. Feeling genuinely respected
2. Experiencing disrespect
3. Navigating operational respect

Feeling genuinely respected

Participants consistently described respect as something that mattered deeply, both in how they saw themselves and how they were treated by others. Moments of genuine respect were not defined by grand gestures or perfect systems, but by mutual recognition, trust and the sense of being taken seriously. As Meg explained:

> My physiotherapist is probably the main person I go to for advice. Even though she is a paediatric physio I still go to her, even over all the specialists and doctors. Mainly because she understands me as a person. She gives me advice, but we work together. She understands that I need to balance things and the fact that I am living a normal life, you know, that I study and things like that. I think that's the biggest thing, finding that balance, which is really hard. But you know she was open to, you know, working together. She trusts me, and I trust her.

What Meg described reflects the relational depth of genuine respect. Her physiotherapist did not merely offer advice, she also built trust, shared power and recognised Meg's life beyond a diagnosis. They made decisions together. Meg felt seen, heard and understood as someone whose aspirations and judgements mattered.

Across participant narratives, respect was grounded in engagement that acknowledged insight, capacity and worth rather than assumed need. This recognition extended beyond individual interactions to shape participants' self-understanding and social positioning—a way of being. For Olivia, respect is not something she hoped to receive but something she actively claimed and protected:

> I now live by the philosophy of 'I don't care what people think of me'. I only care that I do my job well and that I'm respected as a person. If you don't want to respect me, I'm not going to give you the time of day. I came to that realisation in my 30s.

This framing of respect as something expected was echoed by Aaron, who described how mutual recognition shaped his long-term relationships with professionals:

> I have a lot of respect for the doctors and medical people that have looked after me. In a way, because I am complex medically, I have always had the best professionals. But it has got to be based on respect. I do not give people a lot of opportunity in those sorts of circumstances to wander off without hearing what I think is relevant. That tends to build respect.

Aaron is engaged, informed and clear in his expectations. Respect, for him, is not based on deference or professional status but on shared understanding and co-responsibility in problem solving. His engagement is active, not passive; he does not simply ask for respect, he models it. By insisting on being heard, affirming his lived expertise and setting boundaries, Aaron demonstrates that respect is built through relationship, not role. As he noted, "that tends to build respect".

While these narratives emphasise the interpersonal and relational aspects of respect—listening, shared decision-making, recognition and trust—Thomas's experience introduced the role of risk. For Thomas, respect is not only about how others engage with him, but how they respond to the risks that shape his everyday life. Like many participants, he revealed that respect and risk are deeply intertwined, and that the presence or absence of respect determines whether risk is experienced with dignity or control.

Thomas lives with multiple medical diagnoses, each carrying clinical risks, side effects and treatment demands. At the same time, he leads a full and active life, where risks are not something to be avoided but negotiated as part of living well. In this context, respect is not an optional courtesy; it is a prerequisite for autonomy and dignity. As he explained:

> My GP and I work as a team. We have a mutual trust, but I make the decisions. They know that … But respect is really important to me. That mutual respect, if that's not there, then I walk away, even if I need their help.

Thomas's account, like those of others in this study, showed that feeling respected is not about politeness or good intentions. It is rooted in mutuality, trust and the recognition of authority over one's own life. Participants who experienced genuine respect described feeling more confident in their rights to take risks, make decisions and reject supports that did not honour their autonomy. In doing so, they reframed risk not as something to be mitigated for them, but as something navigated with them, on their own terms.

Experiencing disrespect

While some participants described moments of genuine respect—where they were listened to, acknowledged and supported in exercising autonomy—others shared experiences where respect was noticeably absent. These ranged from overt acts of rudeness or intrusion to more subtle forms of exclusion, control or being spoken for. Some moments were abrupt and immediately recognisable; others unfolded more quietly, embedded in policies, routines or "good intentions". In different ways, each experience left participants feeling unseen, overruled or diminished.

Disrespect was often embedded in quiet exclusions, unspoken assumptions and decisions made without consultation. As Leah recalled, when she was faced with the need for surgery:

> I didn't really feel in control. Things were being done without me even knowing, because they didn't want me to make the choice, not to have surgery. I probably would have chosen the same thing, but I never got that choice ... that was the difference.

Leah described feeling powerless, unseen and stripped of her agency. She was treated as a passive subject rather than an active participant in decisions about her own body. And while she acknowledged that she might have made the same decision, the outcome was not the point. What mattered was that she was denied the opportunity to decide for herself, and it was this absence of respect that caused the most harm.

Mikayla echoed a similar dynamic, describing the emotional dissonance of being told she was included while, in practice, she was excluded:

> I know they're trying to include me, but I also feel excluded at the same time, if that makes any sense. It just feels as though they are not really talking to me about the things they do. You know? 'We're doing this because we really want to include you more'. 'We want to do it because it's best for you'. 'We want to make you feel welcome'. I'm a 25-year-old woman, and I'm thinking, you don't know what's best for me.

Here, as Mikayla made clear, respect was not only what was said—in this case, the language of inclusion—but about who controlled the narrative. Like Leah, Mikayla did not reject support outright; rather, she rejected the paternalism that framed her as someone to be managed instead of respected. Both Leah and Mikayla illustrated how disrespect is often enacted, not through overt hostility but through assumptions of incompetence, token gestures and the erasure of decision-making power.

Some participants described moments where even the most basic social cues of mutuality, such as introductions or acknowledgement, were denied. Olivia, for example, recalled a medical encounter where the interaction reduced her to a procedure:

> I don’t want a doctor who’s a genius at fixing things but can’t talk to me. An anaesthetist I didn’t even organise walked in and said, ‘this is what we’re doing’. I said, ‘And your name would be? Tell me your name, I’ll tell you mine, and we’ll go from there. You’re not doing anything to me until I know who you are’.

For Olivia, respect begins with being acknowledged as a person, not an object of intervention. Her refusal to proceed without a basic introduction reflected a deeper demand for reciprocity and dignity.

Other participants also reflected on the longer-term impact of being dismissed. As Ashley explained, “when medical [and other] professionals make you question yourself, I think that’s a difficult and dangerous situation to get into, because how do you then advocate for yourself if you're not sure that you can believe yourself”.

Ashley’s reflection revealed the enduring harms of disrespect—where being ignored or dismissed was not simply frustrating, but destabilising. Over time, these encounters eroded self-trust and undermined a person’s ability to make decisions, speak up, or advocate for their own needs. Disrespect, then, is not just relational. As Ashley made clear, it becomes a barrier to autonomy, participation and self-determination.

While disrespect is often easier to name than respect, participants also described experiences that are hard to pin down—encounters that followed the form of respect but failed to deliver its substance. These blur the lines between inclusion and control, between voice and tokenism. They are not always hostile, but they are still harmful.

Navigating operational respect

While participants were clear about moments of genuine respect and experiences of disrespect, many also described a third, more insidious category of interaction. I refer to that as "operational respect". Operational respect involved encounters that followed institutional scripts of "good practice"—polite language, structured inclusion, professional tone—but failed to engage in the deeper relational work that genuine respect demands.

As Tilda described, "Respect is when people accept my right to decide how I live, not make decisions for me for my own good…I know they mean well, but if you're taking my power away, that's not real respect." For Tilda, what mattered was how respect was enacted—whether others trusted her decisions, whether her risks were permitted, and whether her autonomy and participation were enabled or withheld. Tilda's experiences highlighted the personal cost of having respect reduced to protection.

Others extended this critique to the systems themselves. Aaron, for example, pointed to how hierarchy and decision-making power were embedded in formal service structures. "Whenever there's a policy framework or procedures that must be followed, it creates this kind of dichotomy where we [providers] are the services, and you are the client or patient … It loses mutual respect."

Aaron noted that power imbalances are inherent within most policy frameworks. Operational respect, in this context, preserves professional authority while invoking the rhetoric of rights to legitimise unequal relationships.

Poppy described how this imbalance worked in practice:

When we talk about choice, government departments started using that word. But it meant something different. It's about what they actually mean when they say they want to support you. It looks like choice, but the outcome is already decided.

Here, Poppy highlighted that terms like choice and support were present in language but stripped of substance in practice. To illustrate the disconnect, she recalled being invited to participate in a group activity, only to find her presence became a problem to be managed:

> I had to support them in their emotional work … I was singled out when I didn't want to be and the focus became about how she was going to include me, rather than me participating like everyone else in the group.

Even after raising concerns about the instructor's approach, Poppy found that there was no avenue for naming or addressing what had happened. "There just isn't any way of accounting for it, which means there isn't any way of managing it, which means that in the end a person with disability has to deal with it. So, it wasn't dealt with, really".

Although the instructor used the right language and met institutional obligations, the approach disabled genuine dialogue, foreclosed accountability, and left Poppy without any recourse. Any attempt to critique it risked being framed as disruptive or ungrateful. In the end, Poppy simply left. "There was nothing else for me to do other than to leave, which meant that, you know, I just had to leave the whole thing behind. So, I didn't get to finish things".

Unlike overt disrespect, which could be named and challenged, operational respect rarely triggered alarm. Yet its effects were cumulative—disrupting autonomy, eroding trust and closing pathways for meaningful participation.

Operational respect was not limited to formal services. It also shaped everyday encounters, particularly when guided by scripted behaviour rather than authentic engagement. As Alice described:

> I hate encountering people who have read one of those '*how to communicate with a person with a disability*' books … You know, they stop you and go, 'Hang on, before I talk to

> you, would you like me to stand up or sit down?' … My response is always, 'I'd prefer we weren't having this awkward preamble to the actual conversation'.

These performative interactions showed awareness and effort but lacked insight or impact. Alice described this form of respect as exhausting. "I don't want to live my whole life having to teach people that I'm just the same as them, you know, to teach people to respect other people". For her, respect is not about procedural correctness, but about mutuality, reciprocity and being met as an equal.

Tilda's, Poppy's and Alice's encounters did not fit neatly into the binary of respect versus disrespect. They blurred the boundary—sounding right but feeling wrong. And in some cases, they were harder to challenge than overt disrespect. They looked like respect—using the right words, applying the correct strategies. But they often left participants more isolated, more destabilised, and with fewer avenues for response.

These accounts challenged the assumption that respect is inherently good or that it can be achieved through policy adherence alone. What participants revealed was a form of respect that met institutional expectations while denying meaningful recognition, autonomy and agency.

Discussion

The findings of this study reveal a critical distinction, not merely between respect and disrespect, but between two fundamentally different forms of respect: one that protects systems and the other that supports autonomy, risk and self-determination.

Operational respect vs genuine respect as a critical distinction

Respect, as experienced by participants, was not a singular or universally understood concept. Rather, it was enacted through competing rationalities—compliance versus recognition, performance versus presence, protection versus partnership. These tensions were not semantic but structural, with real implications for disabled people's capacity to exercise agency in their everyday lives. Table 6.1 summarises critical differences between *genuine respect* and what I termed *operational respect* as they emerged from participant narratives.

Table 0.1 Critical distinctions between operational respect and genuine respect

Operational respect	Genuine respect
Procedural: Follows scripts, policies and guidelines	*Relational:* Built through trust, dialogue and mutual recognition
Compliance-driven: Focuses on liability, risk management	*Rights based:* Affirms autonomy, dignity of risk and self determination
Symbolic: Uses inclusion language without structural change	*Substantive:* Redistributes power and enables real decision-making
Hierarchical: Maintains professional control and authority	*Mutual:* Engages disabled people as equal partners and experts
Performative: Enacted through surface behaviours or scripts	*Felt and convincing:* Experienced as authentic and meaningful
Disempowering: Limits negotiation or dissent	*Enabling:* Supports refusal, risk and growth through uncertainty
Gatekeeping: Protects systems more than people	*Liberating:* Challenges norms and enables self-defined flourishing

Participants described how respect was experienced, performed and withheld in systems that claimed to uphold autonomy, dignity and participation. What emerged was not a rejection of respect altogether, but a deep critique of how it is often operationalised. The distinction between operational and genuine respect reflects competing judgements of disability: one that treats disabled people as passive recipients within systems of protection and a second that recognises disabled people as moral agents entitled to risk, recognition and relational accountability.

Operational respect, while often intended as supportive, was actually disempowering and alienating. It mirrored institutional priorities: procedural compliance, risk aversion and reputational maintenance. Participants recalled being offered choices that had already been made, excluded from decisions affecting them, or spoken to in scripted ways that felt hollow. In contrast, genuine respect was grounded in mutual recognition and relational ethics. Participants described professionals who listened, made space for dissent, and supported their decisions even when those choices involved uncertainty. As Dillon (2007), Sennett (2003), and Honneth (1995) contended, genuine respect affirms not just the worth of individuals but their capacity to act, to refuse and to matter.

This analysis challenges the assumption that respect can be achieved through policy alignment alone. Despite decades of rights-based reform (Felder et al., 2022; Kayess & French, 2008), participants continued to encounter systems that disrupted their autonomy under the guise of care or professionalism. These findings reflect what Honneth (1995) identified as misrecognition—a failure to acknowledge people as full moral subjects. Lack of recognition, regardless of its form, can profoundly impact an individual's sense of dignity and self-worth (Honneth, 1992; Kirschbaum, 1991; Klein, 1991; Smyth et al., 2024).

National data align with this critique. According to the Australian Institute of Health and Welfare (2022a), only 54% of disabled people across all age groups report feeling valued and respected in their communities—a figure that drops to 42% among those aged 25-44. This decline reveals a significant gap between the respect promoted in policy and that experienced in the everyday lives of disabled people. This emphasises Sennett's (2002) warning that respect cannot be reduced to procedural acknowledgment; it must be built through shared responsibility and relational engagement. The problem, as participants made clear, is not simply a lack of respect, but the wrong kind of respect being enacted and operationalised.

To realise the intent of the CRPD (United Nation, 2006), respect must be reimagined, not as a checklist of behaviours or scripted politeness but as a structural and relational commitment. This involves shifting from operational forms of respect toward practices that recognise disabled people as knowledge holders, decision-makers and moral agents. Genuine respect requires a commitment to dismantling the systemic barriers that marginalise and exclude disabled people (Campbell, 2009; Friedman, 2018; Goggin & Newell, 2005; Quaquebeke et al., 2007; Schwartz, 2011; Shakespeare, 2017b). It also calls for systems that are willing to share power, tolerate risk and engage with uncertainty.

Conclusion

By naming operational respect in this paper, I offer a framework for identifying when respect functions as control, and when it genuinely enables autonomy. I call on professionals, policymakers, and researchers to ask not just whether respect is present, but *what kind* of respect is at play and whose interests it serves.

Respect cannot be assumed. It must be practised. Anything less risks protecting institutions at the expense of the very people they claim to support.

CHAPTER 7

Synthesis and discussion

This chapter synthesises and discusses the key findings from this study, highlighting their implications and contributions, concluding with my personal reflections.

Overview of the study

This research began with a question rooted in both my professional practice and lived experience: How do disabled people and their families navigate professional advice and services in the context of everyday life, particularly in relation to risk? At its core, the study explored the fine line between support and constraint, autonomy and control, risk-taking and imposed safety. I set out to examine how professional advice and service provision impacted disabled people's ability to navigate risk, maintain autonomy and participate meaningfully in everyday life. The findings revealed a complex web of barriers, strategies and tensions, where professional involvement could either enable self-determination or quietly erode it.

Building with existing literature, this research reframed risk in disability discourse. Traditional models of risk in disability have often positioned risk as something to be controlled, mitigated or eliminated, a framing that has reinforced institutional authority over people's lives (Beck, 1992). I challenged these assumptions by posing two critical questions: 'What risk?' and 'Whose risk is it?' These questions shifted the focus from institutional risk-aversion to disabled peoples lived experiences of risk-taking and autonomy. This reframing aligns with Critical Disability Theory and Human Rights Approaches, which emphasise that risk is not merely a professional concern but an inherent and necessary part of self-determination. This literature demonstrated the subtle ways in which language shapes not only how we understand risk, but also how we approach risk-related decisions in the context of disability. Rather than treating risk as something granted rather than inherent, to be allowed, managed or avoided, I positioned it as a dynamic process of empowerment, one that is navigated and negotiated as part of an ordinary, flourishing life (Clifton et al., 2018; Kafer, 2013b; Mackay, 2013; Seligman, 2011b; Tulloch & Lupton, 2003).

Barriers to risk, autonomy and participation

Chapter 4 examined how professional advice and service provision, rather than facilitating autonomy and participation, often reinforced systemic control over disabled people's lives. Participants shared critical narratives of well-intended interventions that, despite good intentions, constrained their ability to make decisions, take risks and pursue self-directed goals. These restrictions undermined fundamental rights to equal and meaningful participation, treating disabled people as if they were passive recipients rather than active agents in their own lives—a finding consistent with broader critiques of professional authority and the subtle operation of ableism within service systems (Campbell, 2008, 2009; Shakespeare, 2013; Titchkosky, 2020).

Participants described bureaucratic inefficiencies, rigid policies and inflexible professional practices that prioritised organisational compliance over individual autonomy. Instead of facilitating access, these systems often created barriers that disabled people had to work around—often expending significant effort to navigate.

Professional fears of liability and perceptions of risk frequently shaped professional decision-making, often resulting in paternalistic approaches that limited opportunities not only for independence, but also for joy, fulfilment and self-determined aspirations. Policies and professional practices often focused on professionally defined functional outcomes, ignoring the central role of happiness, agency and meaning in a flourishing life. Participants spoke of professionals framing their lives in terms of limitation rather than possibility, sidelining their aspirations in the process.

The failure to prioritise joy, autonomy and risk-taking demonstrated how professional control extended beyond physical safety into shaping disabled people's broader life trajectories. Writing about flourishing after spinal cord injury, Clifton (2018) highlighted how dominant recovery narratives constrain what disabled people are expected—or even allowed—to hope for. These narratives reduce lives to function and recovery, neglecting concepts like virtue, purpose and joy. Like many of the participants in my study, Clifton challenged these narrow framings and called for a deeper recognition of disabled people's right to imagine and pursue flourishing futures on their own terms (Clifton, 2018; Clifton et al., 2018),

The cumulative impact of these barriers extended far beyond individual inconveniences. They functioned as deeply embedded mechanisms of control, shaping professional advice that determined whose decisions were trusted and whose were questioned. Consistent with Konrad's (2018, 2021) concept of access fatigue, participants described the exhaustion resulting from constant negotiation over access, decision-making and meaningful participation—eventually leading them to bargain over what was worth fighting for.

Strategies for navigating risk and reclaiming autonomy

Barriers alone do not define disabled people's lives. Resistance, adaptation and agency play a central role in shaping participation and self-determination. Chapter 5 shifted focus to how participants actively navigated and reframed risk—not as something to be avoided, but as a necessary and deliberate aspect of participation and fulfilment.

A key finding was that risk reframing functioned as a strategy. Participants recognised that calculated risks—in education, employment, social participation or healthcare—were not reckless choices but essential steps toward living full and meaningful lives. This directly challenged dominant institutional narratives that frame risk as a liability to be minimised rather than an inherent part of autonomy and flourishing. By reframing risk as a right rather than a problem, participants demonstrated that self-determined decision-making is not about eliminating risk and uncertainty, but about actively shaping one's own future, even in the face of systemic constraints.

Participants described rejecting risk-averse professional advice when it conflicted with their own expertise, working within or around restrictive systems, and pushing back against deficit-based expectations. These strategies were not merely survival mechanisms but acts of self-determination, directly challenging institutional control over their lives. Some participants leveraged existing structures to their advantage, negotiating supports and bypassing rigid policies to access opportunities. Others circumvented systems entirely, asserting their right to take risks on their own terms. Acts of resistance and adaptation reflect broader patterns of disabled people reclaiming agency in response to exclusionary systems, as described in the work of Clifton (2018), Garland-Thomson (2022), Kafer (2013a) and Konrad (2018).

The role of respect in risk, autonomy and participation

Respect emerged as a significant and, at times, unexpected theme throughout this research, deeply intertwined with how participants framed, experienced and navigated risk. In this context, understanding respect became essential to appreciating broader concepts like autonomy, dignity and risk. Chapter 6 examined the question: What does respect *actually* look like in practice, and what role does it play in shaping risk-taking, autonomy and participation in the lives of disabled people?

A larger pattern became clear. Respect was not merely an interpersonal courtesy. It was an operational force that directly determined whether disabled people could exercise autonomy, take risks and meaningfully participate in their own lives. In this context, I identified a distinction between *operational respect*, which reinforces professional authority and bureaucratic control over disabled people's choices, and *genuine respect*, which functions as a mechanism for opening pathways to self-determination, risk-taking and participation. The distinction between these two forms of respect brings us back to the critical questions: What risk? and Whose risk is it? This is because, ultimately, those who define and enact respect as a mechanism of control or a foundation for liberation are the ones who shape the answers to these questions. In practice, it is respect that determines whose decisions are trusted, whose risks are permitted, and whether autonomy and participation are enabled or withheld.

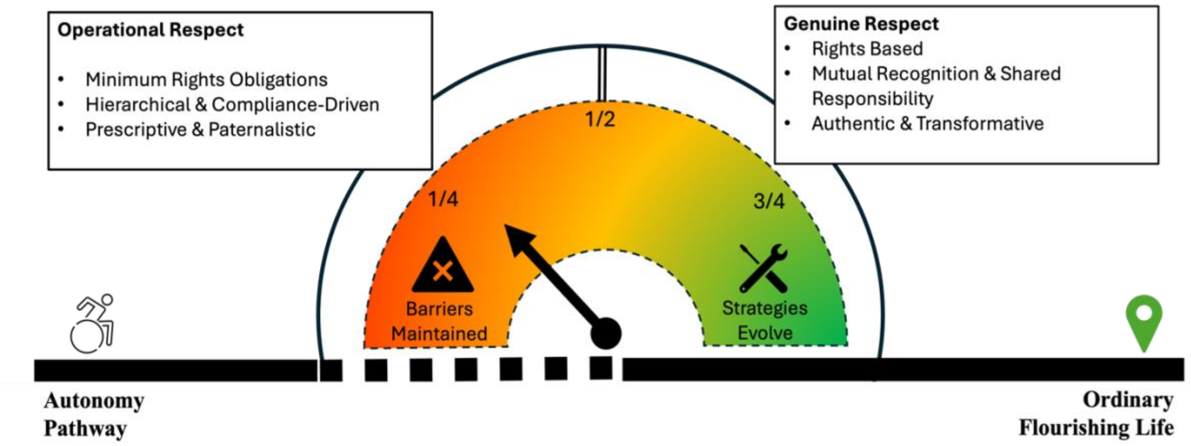
As Kafer (2013a) argued, disabled people are frequently framed as having no viable future, limiting the possibilities for policy, support and intervention that foster long-term flourishing. This erasure of disabled futures directly undermines respect, since true respect requires recognising not only present autonomy but also the right to imagine and shape one's own future. Genuine respect provides the recognition individuals need to exercise their right to take risks, affirming that such risks are integral to a meaningful, autonomous life.

As a driving principle within Human Rights Approaches, respect sets expectations for dignity, equality and meaningful participation free from discrimination. Yet, my findings reveal that respect operates in profoundly different ways depending on how it is practised. This distinction between operational and genuine respect therefore helps explain why systemic barriers persist despite formal commitments to equity and participation (CRPD, 2006) and points to what is required to dismantle them: not only a shift in policy or practice, but a transformation in how respect itself is understood and enacted. While respect is frequently cited in professional codes and rights-based discourse, its practical meaning remains underexamined.

The dynamic model of respect and disability

Figure 7.1 represents my understanding of the dynamic nature of the relationship between respect and disability.

Figure 7.1: A Dynamic Model of Respect and Disability



Drawing on the work of Dillon (1992, 2003, 2007), Honneth (1992) and Sennett (2003), this model illustrates how experiences of respect actively shape disabled people's agency and pathways (Snyder, 2002) and their opportunities for risk-taking toward flourishing (Seligman, 2002, 2011b). Unlike traditional models that treat respect as a fixed state—something to be granted or withheld—the model positions respect as a dynamic force that fluctuates depending on how systems and professionals engage with disabled people's autonomy, decision-making and participation. At the core of this model is the distinction between the two forms of respect. Operational respect acknowledges rights in theory but reinforces systemic control in practice. It is performative, compliance-driven, and often fails to meet even minimum standards. This surface-level recognition fractures autonomy and disrupts the access and engagement needed for risk-taking and ordinary flourishing. When these pathways are obstructed, disabled people often develop strategies not as displays of resilience, but as acts of resistance, reclaiming autonomy in systems that fail to offer meaningful support.

Genuine respect by contrast, reframes access not as a resource granted by professionals, but as a dynamic, relational process embedded in everyday interactions (Titchkosky, 2020). It actively values disabled people's expertise, fostering trust, autonomy and self-determination. Genuine respect is *felt,* c*onvincing* (Sennett 2003) and transformative in its capacity to dismantle paternalistic structures and remove barriers to participation. When respect is authentic, resistance gives way to growth, opening space for exploration, creativity and self-defined success. Rather than merely surviving within limiting environments, disabled people are supported to shape their lives on their own terms.

A key finding was that disabled people predominantly experienced operational respect. To illustrate how respect functions as a relational force that shapes disabled people's opportunities for autonomy and risk-taking, I developed the fuel gauge metaphor shown in Figure 7.1. Operational respect represents a low-fuel state, where disabled people must expend significant energy justifying their rights. In contrast, genuine respect represents a fully fuelled state, where risks are reframed and people are supported to navigate their own pathways toward flourishing.

I have deliberately positioned the gauge at one-quarter full, drawing on the lived experiences of people with disability and their families in Australia (National People with Disabilities and Carer Council, 2009), as well as national inquiries such as the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Commonwealth of Australia, 2020, 2023). These sources clearly demonstrate that even minimum standards of respect are often not met. This highlights an urgent call to action to recognise respect as a driver for systemic change.

The model represents an important conceptual and theoretical contribution to the field of disability studies. By distinguishing between performative respect (operational respect) and transformative respect (genuine respect), it reveals respect as an operational force shaping disabled people's access to autonomy, risk and participation.

At the same time, it is not just a theoretical critique but also a practical tool for change that allows professionals and institutions to critically assess how their policies and practices either perpetuate exclusion or facilitate autonomy. By shifting from operational respect to genuine respect, professionals can move beyond minimum compliance and take meaningful steps toward dismantling systemic barriers. The model invites reflection, not prescription, encouraging both disabled people and professionals to see themselves within it and apply its insights in ways that are meaningful to their own contexts. In doing so, it becomes a living framework, open to critique, growth and continued conversations.

Wishbone Day: A real-life example of risk and respect

Wishbone Day offered a unique opportunity to evaluate this process of respect and disability in practice. It challenged the traditional charity model, particularly its focus on fundraising as the central mechanism of advocacy. By removing fundraising from its approach, the initiative shifted the narrative from dependency and deficit to enablement and agency. While this decision was met with resistance from organisations reliant on traditional fundraising structures, it opened new pathways for the community to define its own priorities, free from external control.

I designed Wishbone Day with respect and autonomy as its foundations, deliberately removing formal structures and placing individuals at the centre. The concept is deceptively simple: tell your own story, join a wise network, and take from that network what you need to move toward self-directed outcomes.

The collaborative structure of Wishbone Day mirrors the principles of co-design and autonomy. Resources were made freely accessible, enabling individuals to adapt them within their local contexts. People within the Wishbone Day community embraced this idea and, over time, it grew into the largest awareness event for people living with osteogenesis imperfecta (OI). Despite this growth, the core concept has remained unchanged. Each year, new communities form, grow and evolve on their own terms. The structure of Wishbone Day is not imposed—it is rooted in respect.

The challenge for me lay in the power I held to shape the structure and in resisting the urge to do more—to build systems, create frameworks and formalise the process. However, you cannot operationalise respect. This research reminded me to go slow with structures and stay anchored in the original intention: respect for people.

This has been particularly hard when confronted with the very real and often devastating barriers that crash into people's lives—rights violations, prejudice, systemic failures, and situations in which people with disability face harmful or even life-threatening consequences. As the community grew, so did our exposure to these realities. Working alongside those directly affected taught me something crucial. The value lies not in solving problems for people, but in creating space for co-creative problem-solving—supporting people as they solve challenges *with* and *for* themselves.

Wishbone Day has allowed me to apply the learnings from this research in real-world contexts across many communities and countries, including in under-resourced regions. I have also partnered with Caring and Living as Neighbours (CLAN) to extend this work further, continuing to explore how respect can drive sustainable, community-led change.

This example highlights how reframing risk and shifting power away from restrictive systems can create new opportunities for autonomy and participation. It provides a practical demonstration of how respect and risk work together in fostering flourishing futures.

Key implications and future directions

Building on these insights, both Critical Disability Theory (CDT) and Human Rights Approaches (HRA) offer essential frameworks for moving beyond tokenistic inclusion toward genuine systemic change. CDT emphasises how institutional structures reinforce paternalistic control, while HRA establishes self-determination as a fundamental right. The Dynamic Model of Respect provides a theoretical foundation for the enactment of these principles in practice. Specifically, it indicates the need for professionals and institutions to:

- Move beyond minimum rights compliance, recognising that legal frameworks alone do not ensure meaningful participation.
- Reframe risk by shifting from an approach based on risk avoidance to one in which risk is understood as an essential part of autonomy and flourishing.
- Engage in co-design by collaborating directly with disabled people to shape policies and services.
- Commit to ongoing learning in which critical disability perspectives and lived experiences are integrated into professional training.

The findings from this study also provide a basis for future research, policy reform and professional practice. Priorities include:

Revisiting and evaluating the impact of the NDIS.

- Examine the extent to which the rollout of the NDIS has shifted the barriers identified in this study, especially in relation to how risk is framed and how opportunities for joy and flourishing are either enabled or constrained.

Testing and refining the Dynamic Respect Model

- Refine the dynamic model in collaboration with disabled people and professionals to ensure it is adaptable and useful across policy, research and service settings.
- Pilot the model in professional practice settings to evaluate its usefulness in identifying and addressing gaps between operational and genuine respect.
- Assess the alignment of existing disability related policies and research practice with the principles of the dynamic respect model and implement changes where necessary.

Reframing risk in disability systems

- Develop co-designed interventions to support professionals and people with disability to reframe risk, not as something to avoid, but as essential to autonomy, participation and self-determination.
- Investigate how disabled people build strategies to navigate risk-averse environments, including how these strategies differ across different disability types, age, and cultural contexts.

Final reflection: The risk of good intentions and the need for real change

This thesis has been many things: an academic project, a contribution to knowledge, a political act and a personal reckoning. It has taken more from me than I expected and changed me in ways I could never have anticipated. What began as an inquiry into how disabled people and their families navigated risk in the shadow of professional authority became something else as well. It became a record of how I navigated those same barriers—not just as a researcher, but as a professional and as a disabled person living out the very questions I asked of others.

The questions that shaped this work—What risk? Whose risk? Who gets to decide? —were not just analytical tools; they became strategies for reframing risk. They helped me stay focused when the work was overwhelming, when self-doubt was loud, and when the weight of representation felt too heavy to carry. They reminded me to stay close to what matters—dignity, autonomy, genuine respect—not the performance of it, but the real thing. The kind that trusts people to know their own lives.

Like the participants in this study, I have had to reframe risk not as something to be avoided, but as a necessary part of autonomy and growth. I have leaned into creativity and adaptability, finding ways to navigate inflexible systems and carve out space for my work, which has not always fit neatly into academic boxes. And I have drawn on hope—not as a promise of success, but as a process of rebuilding fractured pathways, one step at a time.

I have written about flourishing lives, while also feeling the weight of systems that make flourishing conditional. I have examined agency while working within institutions that asked me to surrender mine. And I have explored respect while contending with its absence in the very structures that demand compliance from people like me.

This work is not perfect. But it is honest. It is shaped by the voices and insights of disabled people who showed up with truth, humour, grief and generosity. It is also shaped by my own experience of navigating systems that limited rather than liberated—both as a disabled person on the receiving end of those services and as a professional working within them. I know the tension of holding both positions at once. This dual perspective has not made the work easier, but it has made it more urgent. And it is driven by a belief that we can—and must—do better.

We should not need a Convention to remind us that disabled people have the right to autonomy, participation and dignity. Any yet, even with the CRPD now fully ratified, we continue to see systems that function as though those rights are optional. Many of the experiences shared in this research occurred before the CRPD's implementation, but its absence was never the problem. Its presence has not fixed it. Rights do not materialise through ratification alone, they require people with ethics, with courage, and with willingness to act. What this research reveals, repeatedly, is not the failure of legislation, but the failure of imagination and responsibility.

As I conclude this research, I return to how I introduced myself—not as an object of intervention, but as a person living a full, complex and meaningful life, shaped by the everyday risks that move us toward flourishing. If I could offer anything to the version of myself who began this journey, it would be to hold onto that fullness:

Lean into the strategies shared by those represented in this thesis.

Practise being proud.

Claim your rights.

Take risks and embrace uncertainty.

Build wise networks.

Pursue joy and make room for happiness.

Because the system will wear you down.

It will reward compliance and punish resistance.

It will make you feel like the problem—that if you tried harder, fit better, stayed quiet, you might succeed.

But you will not fit. That is not your failure, it is the system's.

So, take your time.

Rest when you need to rest.

Work in a way that keeps you your-kind-of-well.

Say what you mean.

And keep saying it until someone listens.

Protect the relationships that hold you up.

And more than anything else, hold your ground and refuse to disappear.

Let the system reckon with your presence.

Which brings me back to where I started. I began this thesis with questions, so it seems only right that it ends with an invitation: to think more deeply about the risk of good intentions. Because the challenge is not only to mean well, but to act well—by listening, co-designing and dismantling the very barriers that good intentions too often reinforce.

It is a call to think differently about power, risk and what it means to truly respect one another. It is a reminder that meaningful change begins in relationships that honour complexity, autonomy, and the messy, beautiful realities of disabled lives. I hope something here stays with you. I hope it unsettles, challenges, or even changes something. Because that was the risk I was willing to take.

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Appendices

Appendix A: Interview guide

About You

Can you tell me a bit about yourself?

(For example: who you are, where you live, your age, and your disability.)

In what situations or contexts do you usually receive advice?

(What's going on in your life when advice is given? Who gives it?)

When you receive advice from healthcare or allied health professionals, what do you think influences the kind of advice they give you?

(Do you think aspects of your identity, disability, or situation shape their approach?)

Advice and Everyday Life

Can you tell me about some of the advice you've received about living your everyday life?

(This could include advice about disability, health and wellbeing, school, work, relationships, independence, sexuality, or family.)

What were the consequences of that advice?

(For example: how did it affect your choices, your emotions, or your sense of self?)

How would you describe the attitudes of the people giving that advice?
How did the advice make you feel? Did it help or hinder you? Why?

Can you share an example?

Risk and Autonomy

What has been your experience of receiving advice about managing risk in everyday life?

(This might relate to disability, independence, relationships, work, or general life goals.)

Do you feel your views on everyday risk are different from those of professionals or others around you?

If so, how? Why do you think that is?
What impact does that difference have on your choices or opportunities?
How does it make you feel?

How have healthcare or other professionals responded to the everyday risks you're willing to take to live the life you want?

Can you give an example?

Navigating Advice Over Time

Over time, how have you negotiated or responded to the advice you've received to pursue the life you want?

What has helped you move toward your goals?

What has gotten in the way?

What skills or strategies have you used to navigate systems or people’s expectations?

How do you get the outcomes you want?

Challenges and Resolution

What do you feel is the most difficult challenge in achieving the life you want?

What helps you face those challenges? What makes it harder?

If you’ve experienced conflict (with family, professionals, or others), how was it resolved?

What was the outcome — for you, your family, or your supports?

Appendix B: Participant recruitment and information

THE UNIVERSITY OF SYDNEY

northcott disability services

Are you a parent of a teen or young adult with physical disability?

Are you a teen or young adult with physical disability?

We want to understand your experience of advice about everyday risks and how you negotiate that advice to achieve the outcomes you want in life.

The University of Sydney and Northcott Disability Services are seeking people aged 12 years or older with physical disability and their parents or carers, to take part in a research study called: The risk of 'good intentions'.

We want to interview people about their experience of receiving advice about living their everyday lives.

Interested in telling your story?

Contact Jo Ragen for further information:
Phone 0417 692 070 or email: jo.ragen@sydney.edu.au

Ethics reference # 2-2010/12514

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Participant Information Sheet

Research Project:

The risk of ‘good intentions’: Navigating and negotiating outcomes for people with disability.

1. What is the study about?

This project aims to gain an understanding about how people with disability and their family navigate and negotiate advice and advice giving from health care professionals surrounding their participation in everyday life.

2. Who is carrying out the study?

Jo Ragen is conducting the study. The study will form the basis for the degree of Doctor of Philosophy under the supervision of Professor Anita Bundy and Dr Alex Broom at the Faculty of Health Science, The University of Sydney.

3. What does the study involve?

The study will involve Jo Ragen interviewing you at a mutually agreed time. The interview can be conducted using communication that you feel most comfortable. Examples include a face-to-face interview at a Northcott Disability Services office or the University of Sydney, via telephone call or by using electronic or social networking communication such as Skype, MSN, or email. The interview will explore questions related to your experience of negotiating outcomes in the context of your everyday life. The interview will be digitally recorded and later transcribed.

4. How much time will the study take?

An interview will take approximately 1 – 2 hours to complete. Interviews can be done in more than one sitting.

5. Who can participate?

People who are aged 12 years or older who have physical disability and/or parents or carers of young people with disability are welcome to participate. Participants with disability must be 12 years or older and will not have a diagnosed mental health, cognitive or intellectual impairment.

6. Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to participate. You are welcome to withdraw your consent at any time either before, during or after being interviewed.

7. Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information that could identify you. A report of the study may be submitted for publication, but you will not be identifiable in such a report. For example, you may be given a pseudonym, or your data may be combined with data from other participants.

8. Will the study benefit me?

Not immediately. It is anticipated that the responses generated by the study will be able to effect change in how people with disability are supported in their everyday life. Your ideas will directly contribute to effecting change for generations to come.

9. Can I tell other people about the study?

Yes. You are welcome to tell other people about the study.

10. What if I require further information?

When you have read this information, Jo Ragen will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact either Professor Anita Bundy, Chief Investigator/Supervisor on 02 9351

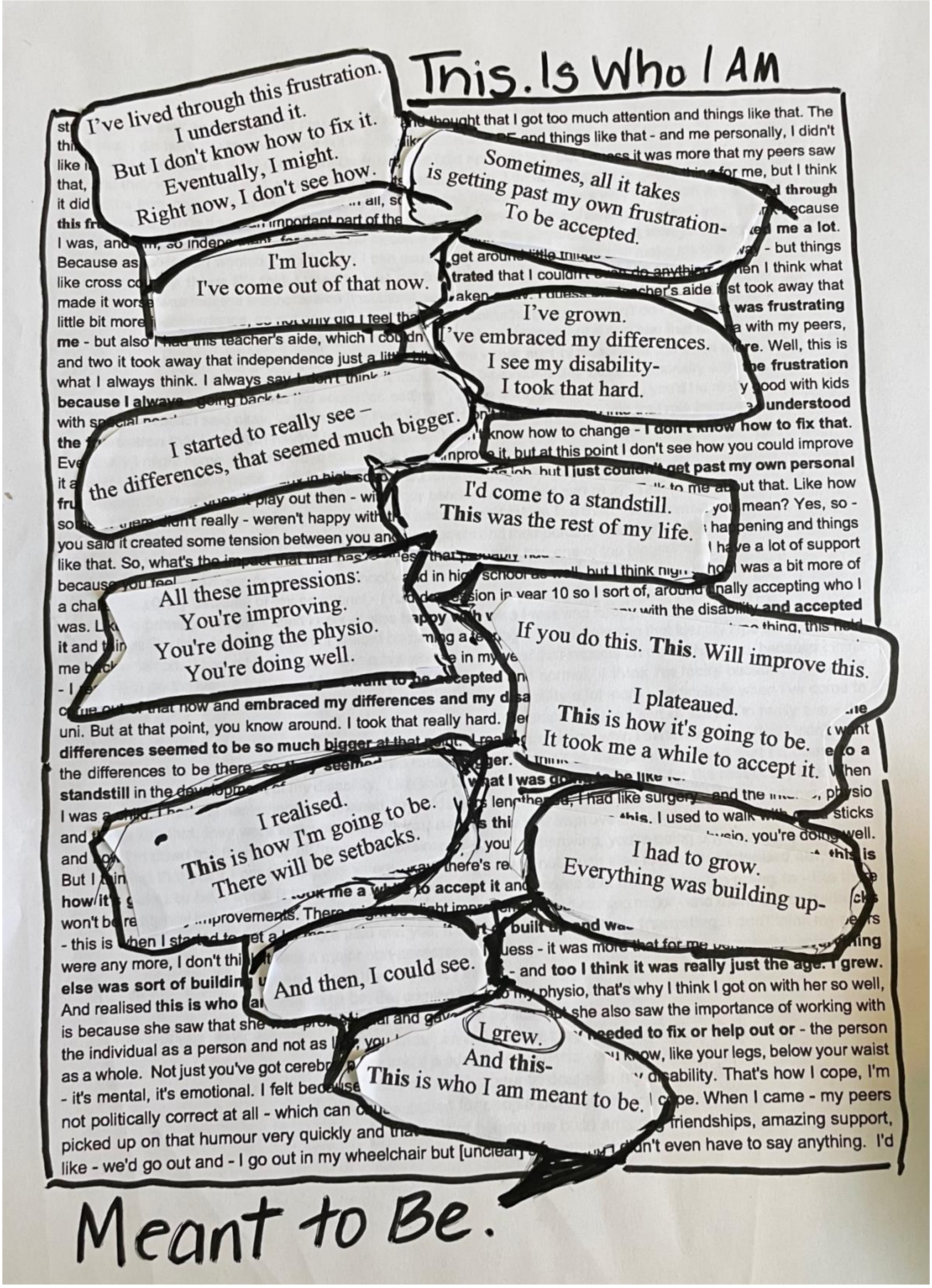
9857 or Jo Ragen, PhD Candidate/Interviewer on 0417 692 070 or email
jo.ragen@sydney.edu.au

11. What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on +612 8627 8176 (Telephone); +612 8627 8177 (Facsimile) or humanethics@sydney.edu.au (Email).

This Information Sheet is for you to keep.

Appendix C: An example of a found poem.



This. Is Who I AM

I've lived through this frustration.
I understand it.
But I don't know how to fix it.
Eventually, I might.
Right now, I don't see how.

Sometimes, all it takes
is getting past my own frustration-
To be accepted.

I'm lucky.
I've come out of that now.

I've grown.
I've embraced my differences.
I see my disability-
I took that hard.

I started to really see –
the differences, that seemed much bigger.

I'd come to a standstill.
This was the rest of my life.

All these impressions:
You're improving.
You're doing the physio.
You're doing well.

If you do this. **This**. Will improve this.

I plateaued.
This is how it's going to be.
It took me a while to accept it.

I realised.
This is how I'm going to be.
There will be setbacks.

I had to grow.
Everything was building up-

And then, I could see.

I grew.
And **this**-
This is who I am meant to be.

Meant to Be.