The embodied and lived experiences of welfare and care for highly impaired, high performance para-sport athletes in Aotearoa New Zealand

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Abstract

Aligning with calls in critical disability studies to bring the body and impairment into disability sport, this thesis examines the welfare and care experiences of highly impaired athletes in high-performance sport. While a focus on athlete welfare has gained some international prominence, and a duty of care is increasingly invoked as an organisational and coaching responsibility, these developments remain largely disconnected from disability.

The research is centred around two main objectives. First, to amplify the lived and embodied experiences of highly impaired, high performance disabled athletes as they prepare for, train, and compete in sport, and those who support them. Second, to understand how sporting institutions and regulations (within the broader context of government funding and national health care provision) influence welfare and care practices for high performance disabled athletes.

Crip methodologies and Indigenous Māori storytelling methodologies such as pūrākau centres lived experience as a site of resistance and knowledge production. Using a reflexive, qualitative approach, including semi-structured interviews, autoethnographic vignettes, and visual ethnography, I expose how impairment effects are managed in ableist sporting environments that valorise normative athlete ideals. I interviewed 11 high-performance para-athletes, seven organisational representatives and two support workers.

The research highlights the material, emotional, and temporal labour of care in high-performance sport. Findings are organised around three core themes: the embodied labour of care, impairment effects and interdependence; the tension between crip time, care time, and performance time; the intersecting structural, institutional, and ableist barriers that shape and constrain highly impaired athletes' participation in disability sport.

The first theme shows how high-performance sport privileges autonomous, efficient, and normative bodies, while marginalising those whose messy, gritty embodied impairment effects demand more time, support, and interdependence. The findings bring to the fore biosocial, psycho-emotional costs of navigating care and its impact on athlete welfare. The second theme uncovers how the rhythms of highly impaired bodies disrupt the linear, clock-bound time of high-performance sport, revealing the incompatibility between care time and high performance cultures. It highlights the vital yet invisible labour of support workers, unacknowledged in contemporary sporting discourse. The third theme addresses the barriers that highly impaired athletes face when navigating ableist institutional and organisational structures. It exposes the complexity of the ableist disability sporting landscape and the gap between duty of care rhetoric and practice.

Ultimately, this thesis calls for a radical reimagining of disability sport, one that centres interdependence, affirms bodily difference, and addresses the structural failures that marginalise highly impaired athletes.

Acknowledgements

Mā te rongo, ka mōhio; Mā te mōhio, ka mārama; Mā te mārama, ka mātau; Mā te mātau, ka ora.

"By feeling something, you come to know. Through knowing, you are enlightened. Through enlightenment, you come to understand. Through understanding, you come to be truly alive" (Stephens, 2021, December 12).

This journey would not have been possible without the support of my beautiful whānau. Gemma, Lola, Ziggy and Clare - I love you to the moon and back. I have missed you.

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Preface

On the 7th March 2013, I dived off my surfboard, hit a sandbar and broke my neck. It was six days after the birth of our youngest daughter Ziggy. I remember everything.

I heard the crunch and instinctively I knew what I'd done. I was lying face down in the water holding my breath, watching sand and shells gently swirling in front of me. I tried to push myself up, but my arms and legs wouldn't work. It was strange. I was calm. I decided that, if worse came to worse, I would breathe in water. I had heard that was a better way to go.

I had come surfing with a Spanish friend Miguel. Miguel was visiting Aotearoa New Zealand for two weeks and I wanted to show him a good time for a couple of days before returning to Gemma and our new baby. I'd promised Gemma that after this I'd be by her side looking after her and our new baby. She had supported me through a masters degree and it was her turn to be nurtured.

But instead, I was helpless, holding my breath, holding onto life. In my head I kept calling, 'look up Miguel, look up Miguel' — hoping he was watching. Luckily, he was. He turned me over, and I saw the sky. I could breathe. I wasn't dead.

With Miguel's hands under my armpits, and my head cradled in his elbows, my friend dragged me onto my surfboard and begun to wade towards the shore. I wanted to close my eyes, but Miguel stroked my face and urged me to stay awake. On the beach, people gathered to help lift me. I heard someone calling an ambulance. Then I heard my three-year-old, Lola, crying. I wanted to comfort her, but I had no voice. I longed for someone to lay her on my chest, so she would know I loved her, so she would know it was going to be okay. I remember everything.

I remember the day before the accident climbing down from Lola's top bunk. I remember looking down at my body, thinking that was a good body, a strong body. It had held me up for 20 years through the intensity of commercial cooking, carried me 840 km across Spain in the Camino de Santiago. It had enabled me to be a mama, a yogi, kite surfer, a motorbike rider and a surfer. I loved my life and always took time to recognise how blessed I was to have such a cool and loving family and to live in an incredible environment.

In the ambulance I chatted with the officer as he stabbed me with pins I couldn't feel. I knew I was done, that nothing would be the same. In the Emergency Department they cut off my wetsuit. I asked them not to cut my bikini – I really liked it, and a part of me still thought I'd be wearing it next week. I remember everything.

A new life began the moment I broke my neck. I suffered a 110% anterior dislocation, with C6 coming to rest in front of C7. My spinal cord did not rip or tear; instead, it stretched like a bungee. The medical diagnosis is tetraplegia. All four of my limbs are affected. I am paralysed from my chest down. I have no bladder or bowel control, and no core, so I cannot cough or sneeze or sit up. I have no temperature regulation, so I don't sweat or get goose bumps. My legs don't work and, hardest of all, my hands don't work.

Now, every time someone asks 'what happened to you', every time I tell my story, I am telling them what they want to hear and what I want to be true. I had an accident. which was the beginning of a new life. In this new life I never give up.

In this new life I use sport to push myself and my body, to find its edges and possibilities. I will never stop trying to be more. I do it for my family and I do it for me.

Why? I want to prove the medical specialists wrong. The ones who said I would be in a power chair with minimum ability to function. I interpreted that as meaning a minimum ability to contribute, a minimum ability to parent, and a minimum ability be a partner, a lover, a human. The moment I was classified 'disabled' – a C6/C7 tetraplegic – my story had already been written. I felt like there wasn't any scope for deviation.

Involvement in sport has allowed me to rewrite and redirect my story. I am the athlete who tells the story of how sport has helped me to break through the limitations of my disability, to live a more normal and productive life. But it is not that simple.

I had 42 years in a fabulous, functional body. My own ableist lens shapes how I see myself. When I introduce myself, I assume I will be seen as *less than* because I'm sitting down. So I go big. I say 'I'm a mama, a PhD student, an athlete — I play wheelchair rugby, I swam for New Zealand'. I say this so I won't be seen as weak, dependent, or defective. Through my own ableist eyes, I don't want to be seen as *that kind of gimp.*

I see now that people like me help to maintain those limiting categories of disabled and able. In an ableist society I am proof that if disabled people tried harder, they would be able to achieve everything and anything. The truth is nothing is the same. My body locates me in a different space. The truth is my engagement in high-performance disability sport *magnifies* my difference and, even more challenging, it *classifies* my difference from the norm.

This embodied, lived experience, and my ongoing journey navigating my body, situates my research. While local access to para sport has been a transformative space for my family and me, my transition to high performance sport was problematic. There had never been a swimmer as impaired as me represent Aotearoa New Zealand. While Paralympics New Zealand (PNZ) welcomed me, they didn’t know what to do with me. They had no insight into the embodied experiences of a highly impaired athlete. That absence – that failure – is what drives this work.

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Chapter One: Introduction

The exploration of disability is a “lightning rod for fundamental questions about normalcy and societal inclusion” (Le Clair, 2009, p. 205). Globally, disability as a social category is characterised by a lack of access to employment opportunities, education, community participation, and a denial of many basic human rights. For many disabled people, the reality is one of discrimination, isolation, marginalisation, social exclusion, inactivity, poor health and poverty (DePauw, 1997; Le Clair, 2009; Thomas, 2016).

The unique focus on the embodied experiences of highly impaired athletes is necessary and timely as, globally, athlete welfare becomes a priority for sporting organisations. While ‘duty of care’, athlete well-being, and welfare are terms that are part and parcel of high performance sport, in this research I am ‘looking under the hood’. That is, I wish to understand the perspectives of the bodies that need bodies - of those who actually need and receive care in its most varied and intimate forms - to shed light on the intersections of disability, sport, and care. Furthermore, given that sporting organisations have a ‘duty of care’ to support their athletes’ physical and psycho-emotional welfare (see for example, Grey-Thompson, 2017), care becomes a powerful tool to examine the enactment of welfare in high performance disability sport. To date, no research has considered highly impaired athletes’ embodied experiences of welfare and care in high performance sport, or even care in the context of disability sport or in relation to any para-athletes. This is an arena with much to offer beyond understanding highly impaired athletes.

In this thesis, I intentionally use the term *highly impaired athlete*. This choice is both political and personal. It reflects my own position as a highly impaired athlete and a crip. It asserts the visibility of bodies and experiences that are often erased or sanitised within disability sport. I name impairment directly, rather than deferring to the more clinical or policy-oriented label *athletes with high support needs*, which is commonly used by non-disabled authors and institutions.

My decision is grounded in a recognition that I too, am shaped by ableism. Having lived 42 years in what I once understood as a ‘fabulous able body’, I am deeply aware of how societal norms and my own internalised ableism frame disability as less-than. To claim *highly impaired* is to name the embodied realities of those of us who live at the sharpest edges of exclusion within high performance sport, confronting the ableist structures that render us invisible. This terminology is part of my broader commitment to crip theory and cripistemology: to speak from, with, and for a position that disrupts normative understandings of disability, care, and what constitutes an athlete.

While sport is lauded as a vehicle for enhancing the visibility of disability (DePauw, 1997), by its very nature it excludes people with severe or degenerative impairments (DePauw & Gavron, 2005; Fitzgerald & Joblin, 2009; Howe, 2008). Aligning with wider calls in critical disability studies to bring the study of the body and, therefore impairment, back into disability discourse, this thesis explores highly impaired athletes' experiences in high performance disability sport. Such a focus is important in the broader study of disability sport. Many do not conform to the aesthetics of the 'normative' disabled athlete often feature on the media websites and interviewed on television. Highly impaired athletes do not run on blades, are not just missing a limb, and most do not have bodies that resemble the idealised idea of 'athlete'.

My specific focus in this research is on athlete welfare and care in Aotearoa[1] New Zealand. Internationally, this is a critical issue and the welfare and care of athletes has become central to discussions shaping policy and practice in high performance sport. However, these discussions rarely focus on disabled athletes and even less so on highly impaired athletes. In this research I focus on highly impaired high performance athletes', including my own, experiences of welfare and care, bringing to light unacknowledged work of carers who are vital, yet unrecognised, in this arena. Capture these complexities this research drew on different methodological tools such as semi-structured interviews, autoethnography and visual ethnography. Along with athletes from multiple sports, situated across the country, I interviewed coaches, national and sporting organisational representatives, including an athlete life advisor from high performance sport, who detail their differing experiences and perspectives working with and alongside these athletes. The participants are all based in Aotearoa.

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[1] Aotearoa is the Māori name for New Zealand which is often used on its own or alongside New Zealand. Throughout this thesis, I use the term Aotearoa as a personal preference, in acknowledgement of the pre-colonial history of my country. However, you will note that most organisations and government departments typically use "New Zealand" on its own or "NZ," with "Aotearoa New Zealand" only used occasionally.

Highly impaired athletes, while breaking records and breaking down barriers, have support structures, like families and friends, who provide care that is invisible to the sporting audience. These highly impaired athletes not only need high levels of supportive and enabling care to participate and function in everyday life, but the need for care is multiplied in the high performance environment. Highly impaired athletes might require a range of material supports; many cannot get out of bed, get dressed, shower, or toilet unaided. As a result, coaches and the structures and organisations under which they operate often do not know how to respond and support these athletes. Thus, being highly impaired in the high performance sporting space challenges common understandings of what it is to be an athlete as well as existing consensus on the appropriate arrangements and practices required to sustain athlete wellbeing/welfare.

The examination of high performance disability sport (as a stratified social field) provides a unique lens to understand and explore lived realities of impairment, and the structures, supports, and practices required to sustain disabled athletes' welfare. Focusing on the lived experience of high performance sport and those who have 'impairments that disable' (Hargreaves, 2000), prior to entering the social world, will illustrate how sport, while a reflection of dominant values and norms and a site for the reproduction of social inequalities, also provides opportunities for resistance. In response to DePauw's (1997) challenge to see individuals as athletes regardless of impairment, this thesis makes space for highly impaired athletes to share lived experiences of training, travel, and competition in high performance disability sport, opening up possibilities for new knowledge and understandings of athlete care. I believe that the voices and stories from highly impaired athletes, operating in ableist high performance spaces, will be a powerful tool both to educate, and to interrogate and subvert understandings of both disability and welfare and care.

I whakapapa[2] to Ngāpuhi and my daughter to Ngāti Porou and Tūhoe. My academic background is grounded in the critical schools of labour studies, feminist theory, and Indigenous rights. From my undergraduate Marxist labour studies perspective, exploring inequality in employment, through to a feminist Indigenous examination of Māori

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[2] Whakapapa is a fundamental principle and Māori culture that "links all animate and inanimate, known and unknown phenomena in the everyday and spiritual worlds. Whakapapa binds all things mapping relationships so that mythology, legend, history, knowledge, tikanga (custom), philosophies and spiritualities are organised, preserved and communicated from one generation to the next" (*Māori Dictionary*, 2020).

involvement in policy for my master’s research, critical social theory has shaped my journey in academia. It took me eight years post-injury to make my way back to academia. My whānau[3] and I needed time to make sense of my new body and find a new way of being in the world. The addition of this theory has given me another lens and the language to help make sense of my experiences. My work both in and out of university, before and after my injury, has focused on the inclusion/exclusion of minority groups in Aotearoa. But it was my embodied experiences, and the experiences of other highly impaired athletes whom I know well, that led me down the path towards doctoral study. My PhD is informed by both my critical conceptual skills and lived experience to bring to light the ‘bodies of knowledge’ held by highly impaired disabled athletes, many whom have experienced similar things to me.

While my difficult experiences of high performance sport ‘fired me up’, there is authenticity and realness in them. I do not do this work in isolation; athletes and support workers spoke from the heart, without filters. Our vulnerability and openness capture the essence of this thesis. Furthermore, the use of a range of methods, including narrative and visual ethnography allowed me to bring to light the messy lived experiences of highly impaired athletes and the people who care for them, facilitating a broader understanding of their embodied experiences in high performance disability sport.

This chapter consists of six sections. Section one sheds light on the concepts and context central to this thesis. I then introduce the athletes that are central to this research in ‘Highly Impaired Athletes in Disability Sport.’ Section three details the State of the Nation: Disability Sport Provision in Aotearoa, followed by the subsection ‘Disability, Welfare and Care’ in Aotearoa, where I detail my research objectives. The section on ‘Fractured Foundation’ details the theoretical approach upon which this research is grounded. I finish this chapter by outlining the ensuing chapters that make up this thesis.

Context

The idea that coaches, medical staff, sporting organisations have a ‘duty of care’ for the athletes they work with is widely accepted by national governing bodies (Rhind et al., 2015). Internationally, duty of care is recognised in various legal and ethical frameworks, though its implementation varies. Some countries have strict regulations enforcing athlete welfare,

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[3] Whānau is the Māori word for family.

while others rely more on voluntary codes or cultural norms. The recent focus on safeguarding athletes — highlighted by high profile cases of abuse, burnout, and inadequate support — has driven stronger policies and global discussions about responsibility in sports (Fitzgerald, 2021; McCulloch, 2020; Tuakli-Wosornu & Kirby, 2022). Yet, as Cronin and Armour (2019) highlight, governing bodies, coach educators, and coaches have little academic direction of how they should actually ‘enact care’. There are, however, generalised ideas from the literature which suggest that care (while complex and dynamic) embodies a meaningful practice which is centred on: doing no harm; open dialogue; and, being focused on, concerned about, and where appropriate, meeting athletes’/learners’ needs (Cronin & Armour, 2019; Jones, 2009; Noddings, 1988, 2016). Thus, while care theory is gaining increasing momentum in sporting literature (Cronin, 2023; Cronin & Armour, 2019) particularly in 'mainstream’ sport coaching discourse, arguably these theories do not capture the physical, physiological, psycho-emotional, and interdependent aspects of care experienced by highly impaired disabled athletes, nor are they linked to athlete welfare.

My contention throughout this thesis is that for highly impaired athletes, care looks and feels different to the highly sanitised approaches embedded in either organisational policy or theoretical discourse. For example, for the process of managing a bladder and bowel routine – termed ‘cares’ – requires not only ‘open dialogue’, but, for some, intimate physical support from carers. As such the highly relational focus of broader care theory perhaps does not capture the materiality, the intimacy and indeed the necessity of care in a disability context. For example, symptoms associated with ‘cares gone wrong’ can be life-threatening if not properly managed (Bourke et al., 2015; Burns et al., 2015; Pryor et al., 2021). Yet, these experiences remain almost unspeakable (point to examples of disability sport/care research in which these are not discussed). Even the use of the terms ‘impairment effects’ and ‘cares’ tidy away and mask the actual participants’ bodily activities (Lowry et al., 2022). When such forms of care are unspeakable, so too are the athletes who require them. This silence produces policy blind spots, institutional neglect, and ultimately a performance model that rewards only those bodies that can pass as low-maintenance.

To better understand the experiences of highly impaired bodies in sporting spaces, I draw on a range of explanatory theories throughout this thesis. For example, the theories of abjection are a vital tool that, in this thesis, serve to destabilise binary discourses of inside/outside of bodies (Douglas, 1966; Grosz, 1989; Kristeva, 1982; Longhurst, 2001). Words such as ‘shitting’, ‘urinating’, ‘faeces’, are never referred to in the literature. These words are abject; that is, they threaten to “spill, soil, and mess up” (Longhurst, 2001, p. 90) more ordered and palatable sport and disability studies (and other disciplines), and perhaps more poignantly reflect a knowledge-value system in which disability is overlooked or ignored. Academics and organisational representatives still “cannot talk easily about the weighty, messy materiality of flesh, or the fluids that cross bodily boundaries” (Longhurst, 2001, p. 90) and are implicated in the day-to-day dynamics and practices of care in high performance sport for disabled people. This work responds to those gaps, contributing empirically and theoretically, providing a fleshy, messy, embodied and altogether confronting (materialised) perspective of care. I do this to challenge and expand what ‘care’ actually means and its use in high performance disability sport and the related impact on athlete welfare and wellbeing.

Sitting alongside notions of care, athlete welfare — and its adjacent terms such as well-being — has become a ‘hot topic’ both internationally and within Aotearoa New Zealand. Social philosophers and psychologists conceptualise welfare as multidimensional, encompassing interconnected aspects of physical, mental, and social well-being (Angner, 2010; Naci & Ioannidis, 2015). This shift is reflected in the recent reorientation of High Performance Sport Zealand‘s (HPSNZ) strategic priorities, where well-being has been elevated as a central pillar in response to athlete advocacy and growing public scrutiny. The ‘Heron Report’ (Heron, 2018) was commissioned following multiple athlete welfare controversies and further underscores the systemic neglect of athlete well-being in high-performance environments. Yet, what remains surprisingly absent from both policy and research is any substantive engagement with the embodied experience of athlete welfare, particularly for disabled athletes (Fitzgerald, 2021). Neither HPSNZ’s revised approach nor the Heron Report meaningfully accounts for para-athlete realities, whose care needs, impairment effects, and support dependencies disrupt normative frameworks of athletic independence and welfare. In this context, disabled athletes are once again rendered peripheral, spoken of in the abstract but structurally excluded from the welfare reforms that claim to centre athlete flourishing.

The current research on athlete welfare focuses mostly on the power imbalance between athlete and coach and the ability of those in power who take advantage or abuse those in their care (McCulloch, 2020; Rhind et al., 2015). While acknowledging that those power imbalances and related practices can and do exist in para sport, my concern with welfare is more in line with Reeve’s (2020) understanding of psycho-emotional disablism which takes welfare away from the hands of psychologists and professionals and links it to impairment effects and the lived experience of internalised oppression and disablism. From a social relational perspective Thomas (2007) explains this approach as important because “disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (p. 60). Hence, while I use well-being and welfare interchangeably, I locate both within the broader system of privilege and power that marginalises disabled people in sport, that is, ableism and the resulting practices that impact on disabled people, that is, disablism.

Building on this understanding Reeve (2020) highlights how environmental and structural forms of disablism are easy to identify, challenge, and change; whereas the psycho-emotional dimensions deeply embedded in ableist “societal and individual unconscious” (p. 84), are much more difficult to address. Thus, psycho-emotional disablism becomes a useful lens to explore how the management of impairment effects in ableist sporting spaces generate private, ‘inner’ barriers that impact the welfare of disabled sports people. However, in order to fully understand and excavate the experiences of high performance sport for disabled athletes, it is necessary to situate this research within critical disability scholarship that foregrounds embodiment, care, and structural marginalisation of highly impaired athletes navigating ableist sporting systems.

Moving from this foundational understanding of highly impaired athletes in high performance disability sport, the discussion now shifts to the national context, examining disability sport provision in Aotearoa and the broader institutional factors shaping the experiences of these athletes.

Highly Impaired Athletes in Disability Sport

Critical researchers note that worldwide there are fewer opportunities available and a disproportionately smaller number of highly impaired athletes participating in high performance sport when compared with disabled athletes who are more functionally able (Brittain & Beacom, 2018; Dutia & Tweedy, 2021; Howe, 2008; Slocum et al., 2018). As a result, highly impaired athletes are disproportionately affected by the removal of events at the Paralympic level, limiting or even eliminating their chances of winning a medal (Dutia & Tweedy, 2021; Howe, 2015; Slocum et al., 2018).

In what appeared to be an attempt to ‘level the playing field’, the 2019–2022 International Paralympic Committee [IPC] Strategic Plan committed to “[e]ncourage worldwide para sport participation especially for athletes with high support needs” (IPC, 2019, p. 11). However, in complete contradiction to this assertion, National Paralympic Committees (NPCs) were notified that there would be a reduction in low classification swimming and track events at the Paris 2024 Games compared to the Tokyo 2021 Games (see Fig. 1). Disappointingly, the individual swimming events that were eliminated were in the most highly impaired categories—classes S1 and S2—where athletes experience conditions such as complete quadriplegia or severe cerebral palsy (Dutia, 2021). In contrast, no individual medal events were cut for athletes with the least severe impairments — classes S9 and S10 — who may, for example, be missing part or all of a hand (Dutia & Tweedy, 2021).

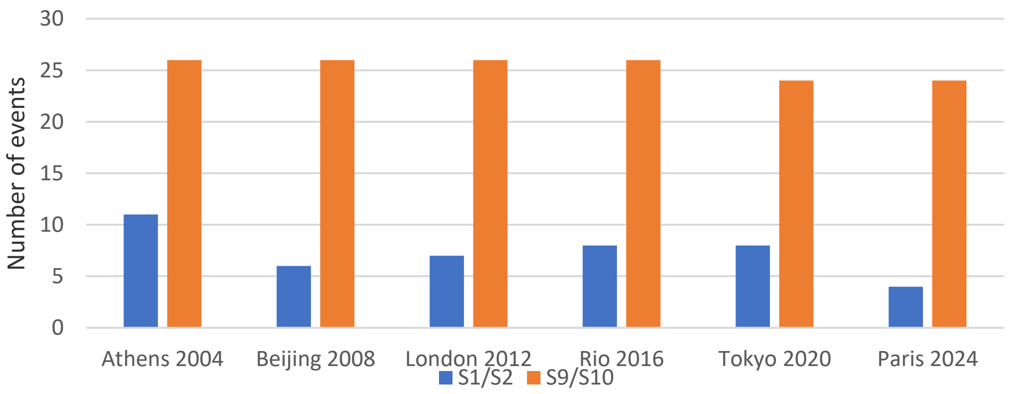

Figure 1 - Number of Individual S1/S2 and S9/S10 Events on the Paralympic Programme

Adapted from Dutia and Tweedy (2021).

Despite the IPC advocating for greater inclusion of highly impaired athletes for over two decades (Slocum et al., 2018), these are examples of how the limited enactment and narrow interpretation of inclusive policy have instead hindered meaningful participation. Thus, the IPC while speaking the rhetoric of inclusion are simultaneously failing to address the practices that reproduce inequity and discrimination.

Yet the marginalisation of highly impaired athletes is not a distant or abstract phenomenon. The following turns to the local context to critically trace how these global dynamics of exclusion are entrenched in the structures, priorities, and practices of high performance disability sport in Aotearoa.

‘State of The Nation’: Disability Sport Provision in Aotearoa

Two key documents guide Aotearoa’s disability policy. These are the United Nations Convention on the Rights of Persons with Disability (UNCRPD, 2006) and the New Zealand Disability Strategy (2016-2026). Both have strong principles pertaining to inclusion, accessibility, and equality in all aspects of life, including sport and leisure. The Sport and Recreation Act (2002) is the foundational legislative framework that governs the administration of sport and recreation in Aotearoa. It underpins the establishment of key organisations, such as Sport New Zealand (SNZ), outlining their role and setting broad goals for promoting participation, physical activity, and excellence in sport. Further, it provides a legal foundation which shapes expectations around the provision and planning of recreation, sports, places and spaces, programmes and services nationally. In 2018, a review into the provision of disability sport and active recreation in Aotearoa highlighted how the fragmented, poorly coordinated system lacking strong, collective leadership and clear roles limited disabled people’s access and participation in sport (Cockburn & Atkinson, 2018).

As a result, in 2019, SNZ committed to the Disability Plan (2019), a targeted strategy that works within the framework of the New Zealand Disability Strategy to bolster inclusivity and equity for disabled individuals. Despite these commitments, the Aotearoa disability sport and active recreation sector, like other ‘developed’ nations, is “complex and fragmented”, characterised by a diverse range of “specialist and non-specialist” sporting organisations vying for attention and funding, as they seek to shape the nature of sports provision for disabled people (Thomas & Guett, 2014, p. 390). Those providers and organisations occupy multiple positions in terms of their longevity, financial stability, resources, personnel, and commitment to or understanding of disabled peoples’ needs. Thus, these organisations’ policy commitments to athlete well-being and welfare are important to highlight as they play a pivotal role in development pathways to high performance sport. In Aotearoa, the structure of high-performance disability sport involves multiple intersecting actors, most notably PNZ, HPSNZ, and individual National Sporting Organisations (NSOs). Historically, PNZ held responsibility for para sport pathways across codes, but recent structural changes have seen most pathways—excluding sports like shooting—integrated into NSOs. McBean (2023) illustrates the complexity of the current landscape of disability sport in Aotearoa New Zealand in Figure 2[4].

Of significance to this work, this shift towards integration has reconfigured lines of responsibility, particularly around athlete care and welfare, with accountability for support increasingly devolved to organisations that may lack the expertise or infrastructure to meet the complex needs of highly impaired athletes. As such, the majority of this study's data, drawn from the pre-integration period, captures a system in transition.

HPSNZ provides support to both able-bodied and disabled athletes who are identified within their respective Olympic and Paralympic pathways, and has a comprehensive programme and dedicated staff to support athlete welfare and care. Yet, there remains no official charter or review that outlines what 'care' actually looks like in practice, and how it might differ for para–athletes (HPSNZ, 2024). On behalf of SNZ, Cottrell (2018) reviewed elite athletes' rights and welfare. Of note was that national sporting organisations have a duty of care in relation to athlete safety and to ensure that rights are being respected and welfare needs are met. The consensus, however, among elite athletes and sporting professionals was that there was an issue in Aotearoa concerning athlete welfare and that athletes "generally 'suck it up'" because of the perception of reprisal, and the fact that "there is nowhere else to go" (Cottrell, 2018, p. 23). Cottrell (2018) was advised that the "focus of Paralympics New Zealand and the para sports bodies was on the athletes' immediate physical training and competition needs as opposed to the athletes' wider welfare needs, for example, career development or other off-field wellbeing needs" (p. 102). In terms of my research, the reference to the lack of attention to 'off the field well-being needs' is a red flag that raises questions about the organisational neglect of para-athlete welfare and care requirements.

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[4] The Figure highlights the range of organisations operating at both national and regional levels – from those solely dedicated to disability sport provision, to those that share responsibility for delivery, and others that offer no opportunities.

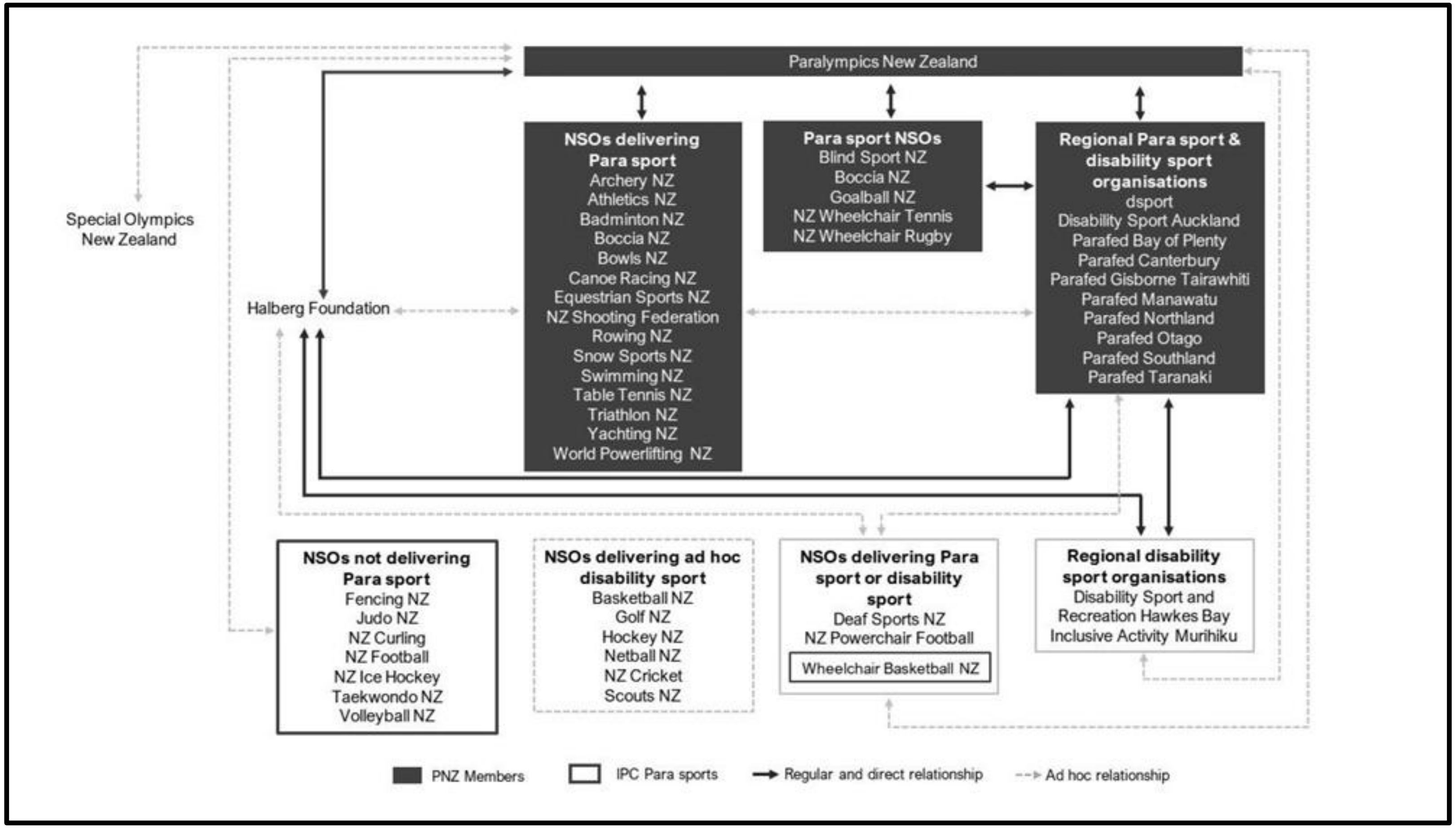

Figure 2 – Aotearoa Para Sport and Disability Sport Delivery

(McBean, 2022, p. 90.)

Disability Welfare and Care

Disabled athletes in Aotearoa are impacted by sport provision and ideological approaches to welfare and care, while simultaneously situated in the healthcare field. Support is a key element of highly impaired people's lives. When one is able-bodied, independence is framed as being capable of doing things by oneself. But when one is disabled, the ability to control the care received – the interdependence with support workers is independence – is freedom. Here in Aotearoa, those with acquired injuries receive support and care from the Crown entity Accident Compensation Corporation (ACC) (which is a 'no fault' insurance model, funded by nationwide industry specific injury levies), whereas Te Whatu Ora/Ministry of Health (MOH) (funded by tax and government contributions) supports those whose symptoms or impairment are not caused by accident.[5] Insurance models, like ACC, provide the financial means for a 'big life', whereas public provision is primarily focused on maintaining health (Chin et al., 2018 658; Goodyear-Smith & Ashton, 2019 666). In a review by the MOH (2020), they acknowledged the inequity in the health and disability system, and are working to improve it.

In order to access government funded disability supports from ACC or the public health system, people must first meet the MOH (2023) definition of disability and undergo a needs assessment. The information from the assessment is used to establish the level of need the person has, such as very low, low, medium, high, or a very high level of needs. This basic survey is then translated into care hours, which is adjusted over time if there is a significant change to needs and/or circumstances (MOH, 2023). To date, what has not been considered in disability sporting research is the impact that health provision has on the opportunities for aspiring highly impaired athletes, an important aspect that will be examined in this research. Moving from the Aotearoa institutional context, the following section introduces my theoretical and methodological approach to this thesis.

Fractured Foundations

It is well noted that disabled athletes' voices are largely absent from the disability sport sociology literature (Allan et al., 2019; DePauw, 2000; Peers, 2012; Thomas, 2004). There has

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[5] For further information around eligibility for New Zealand's healthcare see: https://www.tewhatuora.govt.nz/corporate-information/our-health-system/eligibility-for-publicly-funded-health-services/eligibility-explained#health-and-disability-services-eligibility-direction-2011

been research ‘done for us’, there has been research ‘done on us’, but there is very little ‘research from us’, and highly impaired athletes are even more marginal to this assertion. Extending this finding, Hardin (2007) and Peers (2009) note that like mainstream sport, institutionalised disability sport both *resist* and *reinforce*, sexist and ableist ideologies. Thus, this research is shaped by the voices of highly impaired athletes, as well as my own voice and identity as a disabled Māori researcher.

To support the athlete’s voice to be visible, this research draws from a qualitative crip approach and is informed by several critical methodologies. These include, cripistemology (Hickman & Serlin, 2019; Kafer, 2013; McRuer, 2006); feminist theory (Garland Thomson, 1997; Haraway, 1988; Young, 2020); abjection (Grosz, 1989; Kristeva, 1982; Longhurst, 2001) and embodied approaches (Ahmed, 2013; Pink, 2015; Sparkes, 2004), and a kaupapa Māori Indigenous storytelling approach called pūrakaū (Lee, 2008). Thus, this research is unapologetically critical. It rejects hierarchies, embraces reciprocity, and insists on methodologies that foreground respect, ethics, and social justice.

The social relational model as articulated by Thomas (1999) is a useful lens to highlight the complex tensions experienced by highly impaired athletes navigating physical and psycho-emotional impairment effects (Reeve, 2020). This model acknowledges how the management of impairment effects impacts the social lives and agency of disabled athletes. Living with an ‘impairment that disables’ means that care and interdependence are a vital part of life – and that need for care is intensified with participation in sport.

Cripistemology underpins this thesis as both a methodological and political commitment. It affirms the tangible, lived experiences of disability as valuable knowledge while interrogating how certain disabled identities are privileged at the expense of others. Rooted in Haraway’s (1988) concept of ‘situated knowledges’ and Kafer’s (2013) assertion that “my future is written on my body” (p. 1), cripistemology challenges dominant ways of knowing and exposes the social construction of disability itself. This approach drives the critical orientation of this chapter, positioning the lived experiences of highly impaired athletes as central to transformative, activist, and justice-driven research that confronts ableist norms.

Research Objectives

This research builds on the seminal works of Hargreaves (2000), and Thomas (1999), extending into the sociology of disability sport literature to encompass the lived realities of highly impaired bodies. The research objectives are to:

1. offer an intimate and self-reflexive autoethnography to illustrate my embodied and everyday lived experiences of care needed when training as an elite, highly impaired athlete;
2. highlight the lived and embodied experiences of highly impaired, high performance disabled athletes as they prepare for, train, and compete in sport, and those who support them;
3. examine how sporting institutions and regulations (within the broader context of government funding and national health care provision) influence welfare and care practices for high performance disabled athletes.

In the chapters that follow, I address these objectives through a spatial scaling approach: beginning with the deeply personal, embodied experiences of high-performance disability sport; expanding to include the relational experiences of others; and finally, examining the broader institutional and structural landscape in which this all unfolds. Chapter Four, Cripping Care in Disability Sport, responds to Objective One through an intimate autoethnography. Chapter Five, the Embodied Experiences of Highly Impaired Athletes in High-Performance Sport, addresses Objective Two by exploring shared experiences of athletes and their support networks. Chapter Six, Organisations and Athletes' Care: An Uneven Playing Field, engages with Objective Three by critically examining the institutional frameworks that shape care and welfare provision in para sport.

The research approach comprised a mix of qualitative methods, such as semi-structured interviews, autoethnography, and visual ethnography. I interviewed 10 athletes, four coaches, one administrator, a sport New Zealand representative, high-performance athlete adviser, and two wheelchair rugby carers. All of the participants are based in Aotearoa.

Thesis Overview

The first chapter in this thesis has detailed the sporting context in Aotearoa and critically examined how high performance sport continues to marginalise the care needs of highly impaired athletes. In doing so, I have located the focus of the study and raised some critical questions at the intersection of disability, sport, care and impairment. The second chapter is a critical Literature Review that interrogates dominant framings of athlete welfare, care, and impairment in high-performance sport, followed by Chapter Three Crip Methodology, which outlines the crip-informed methodological approach that underpins this research foregrounding embodied knowledge, reflexivity, and the political stakes of researching from within. Chapter four Cripping Care in Disability Sport is the first empirical chapter, setting the stage for the research, centring on my experiences of care in high performance disability sport. The chapter also includes visual representations of my personal care regimes, thus detailing – literally - multiple touch points required for me to swim, and care for my body.

Chapter five, The Embodied Experiences of Highly Impaired Athletes in High performance Sport, focuses on impairment effects, detailing the embodied experiences of receiving and delivering care from the perspective of athletes and the people who care for them. Chapter six, Organisations and Athlete Care: An Uneven Playing Field, focuses on how national sporting policy, healthcare provision, and national and international disability sporting institutions impact highly impaired athletes' sporting experiences.

In the seventh and final chapter, I provide a concise Conclusion of the main findings that emerged from the chapters and reflect on the limitations of the research. In my final conclusions I revisit my research objectives and address each one with consideration of the opportunities for this research, and the possibilities for further research.

Chapter Two: Literature Review

This chapter critically engages with the politics of knowledge to illustrate how highly impaired athletes' bodies are excluded from research. I review the literature on disability sport, care, and policy, with a specific focus on the experiences of highly impaired athletes. By bringing to light the experiences of 'bodies that need bodies', this review interrogates the silences and gaps in current research.

Despite the increased attention given to the body in disability sport literature in recent years (Apelmo, 2017a; DePauw, 2023; Lawson et al., 2023; Powis, 2020; Sparkes & Smith, 2002), the use of contemporary disability theories to understand disabled athletes' experiences remains limited (Campbell & Brown, 2021; Howe, 2015; Powis et al., 2023; Townsend, Huntley, et al., 2018). This gap in the literature reflects a broader reluctance to engage with the complexities of disability, especially in the context of high performance sport. As Powis (2020) suggests this omission may be due to "apathy, confusion, or trepidation" (p. 36), illustrating that there is a politics of knowledge embedded in high performance disability sport that reinforces a certain squeamishness around the complexities of 'certain' disabled bodies. Disability sporting scholars, such as Apelmo (2017b) and Brighton et al. (2021) recognise that the lack of attention to embodied experience of athletes in disability sport has resulted in the diversity of experience being marginalised and rendered invisible. As McRuer (2006) argued, "it is precisely those bodies that are best positioned to refuse 'mere toleration' and to call out the inadequacies of compulsory able-bodiedness" (p. 31).

Grounded in critical disability studies, and informed by crip theories and abjection, I argue that highly impaired athletes' crip bodies are both absent and present in the production of sport and disability studies. The highly impaired crip athlete exists as 'the Other' in order to normalise 'acceptable' disabled bodies in the construction of knowledge (Schalk, 2016) and the practice of disability sport. Drawing on the powerful embodied work by Paralympian Peers (2012a), I aim "to open up new possibilities of imagining, narrating and doing disability otherwise" (p. 175) by including the lived experiences of those most marginalised in high performance disability sport.

In order to garner the complexity of literature, this chapter is divided into seven sections. Section one details Disability Sport, with a subsection Resistance, Resilience, and Recognition.

The second section brings to light the Hierarchies of Bodies in disability sport, with three subsections, Identity, Gender, and Classification. Section three, examines the different Development Pathways para-athletes experience based on impairment, with a subsection detailing the psychoemotional elements athletes face in Disabling Development. Section four illuminates para-athletes' relationships with their coaches in Coaches, Coaching and Duty Of Care. This section has two subsections, Highly Impaired Athletes and Coaching, and Organisational Duty of Care. Welfare and Care is the following section, with a subsection grounded in the local context, Aotearoa: Place Matters. The fifth section highlights the Embodied Experience of Impairment Effects. Section six, Doing the Dirty Work: The Role of Carers, has two subsections, Interconnection and Care in Sport. The chapter concludes with a brief summary.

Disability Sport

Sport is a part of society. It therefore reflects both the culture and the dominant norms, values, and standards of the society in which it is embedded (DePauw, 2023). Consequently, historical critical debates about disability sport are polarised around ableist binary discourses such as 'ability–disability' (Apelmo, 2017b; DePauw & Gavron, 2005; Fitzgerald, 2009; Huang & Brittain, 2006; Marcellini, 2018); 'empowerment–disempowerment' (Peers, 2009; Silva & Howe, 2012a); and 'elite sport–disability sport' (DePauw & Gavron, 2005). But, as Campbell (2009), McRuer (2006) and Powis (2020) highlight, the ableist, simplified able-bodied/disabled binary is so deeply embedded and normalised that it happens unconsciously. McRuer (2006) extends the analysis suggesting that the prevalence of this dichotomy reinforces compulsory able-bodiedness. While these dichotomies highlight social inequality and different groups' marginal status in sport, they fail to draw attention to the complex divisions within disability sport on the basis of impairment (Apelmo, 2012; DePauw, 2023; DePauw & Gavron, 2005; Howe, 2015; Powis, 2020; Powis et al., 2023). While these authors note there is a hierarchy of impairment, there have not been further studies into the lived realities of those marginalised by disability sport research and practice, which this thesis intends to address.

The field of disability sport studies has been significantly advanced by the work of key scholars who challenge traditional notions of identity, power, and ability. Among these, critical sporting sociologist DePauw's (1997) groundbreaking contributions explore the intersections between disability, sport, and society. Her influential works (DePauw, 2008: DePauw, 2023; DePauw, 2000; DePauw, 2023b) delve into the social construction of ability within sport, providing a foundation for understanding how societal norms shape athletic participation. Specifically, DePauw argues that the focus on these norms exclude or Other disabled athletes reinforcing the ‘able/disabled’ binary. They argue for a shift beyond inclusion, advocating for a critical analysis of how power, identity, and embodiment shape the experiences of disabled athletes.

Building on such critical foundations, Peers (2012a) adds a deeply personal dimension to the literature, with their powerful autoethnographic contributions from their time as a Canadian Paralympic basketball player. Drawing on the emotional lived experience of sport classification Peers (2012a) critically interrogated the “(re)production of disability and the disabling cultures that sustain it” (p. 186). Their use of classification brings to light the medicalised understanding of disability in disability sport classification and the power of ‘our tragic’ disability creation “stories that give meaning to disability…create disabled people, disability truths, disability experts, and entire disability industries” (Peers, 2012a, p.176). Their work positions the Paralympics as a divisive mechanism that perpetuates the ‘freakshow’, justifying and concealing the “unequal relationships of power in and through which disability is enacted and experienced” (Peers, 2012b, p. 295). They push for a reimagining of disability and athletic participation through inclusive and transformative paradigms, “to open up new possibilities of imagining, narrating and doing disability otherwise” (Peers, 2012a, p. 175). While their engagement with high performance sport provides valuable critical insights into how existing frameworks often reinforce exclusion and inequality (Peers, 2012b; Peers & Eales, 2017; Peers et al., 2020; Peers, 2015), they focus primarily on the experiences of the more able disabled ‘supercrips’. I will extend their work, adding to it the experiences of highly impaired athletes who are further marginalised in the high performance sport system.

Adding to this rich discourse is Paralympian, journalist, and sociologist Howe (2015), whose work examines the cultural and social constructions of disability within sport scholarship, highlighting issues of identity, classification, and power. Throughout their multiple publications, Howe (2008, 2011, 2015, 2023) critiques classification for privileging commercially viable elite athletes while marginalising those with more ‘severe’ impairments;

reinforcing a paradox of inclusion and exclusion, contradicting the principles of equity embedded in Paralympic ideology. Howe (2011) highlights the increasing impact of money and technology in shaping the modern disability sporting landscape, privileging the elite supercrip athletes and ‘sporting cyborgs’, further undermining equitable inclusion. In the current neoliberal ableist high performance sporting environment, “the most attractive and commercially viable product” is “sold to the highest bidder”, further marginalising those who cannot live up to the supercrip ideal that “some bodies are worth watching, others are not” (Howe & Silva, p. 205). While they discuss integration as a positive move to bring greater sporting equity, they also argue that policy and legislation alone cannot drive change and called for athlete-led reform (Howe & Silva, 2015). Over the past 20 years, Howe’s work has flagged the underrepresentation of athletes with higher levels of impairment; yet, disability sporting research has not endeavoured to understand why. This is an area my research will begin to address.

Resistance, Resilience, and Recognition

Despite the complexities, it is well documented in the literature that involvement in disability sports allows people with impairments to resist dominant ideologies about disability being weak, fragile, passive, and dependent; minimising the difference between themselves and their able-bodied counterparts (Apelmo, 2017b; Berger, 2009; DePauw, 1997; DePauw, 2023; Huang & Brittain, 2006; Smith et al., 2016; Sparkes & Smith, 2016). Berger’s (2008, 2009) extensive research on wheelchair basketball athletes highlighted the social construction of disability sport, emphasising how athletes navigate their identities through embodiment, stigma, and status hierarchies shaped by classification.

Huang and Brittain’s (2006) life history study, examines British and Taiwanese high performance powerlifting, track and field athletes, detailing the dynamic and fluid nature of identity in disability sport that enables athletes to navigate, challenge stigma, and reconstruct their identities in response to societal perceptions of disability. Powis’s (2020) research with visually impaired athletes touches on every aspect of their journey, from classification, bodily hierarchies, identity, and embodiment. All these articles detail how involvement in sport is a site of empowerment and resistance, providing athletes a profound positive sense of identity, increased physical and mental self-empowerment, as well as health and fitness benefits which lead to a greater sense of control over their lives and their bodies.

DePauw (1997) positively discusses how athletes with disabilities' presence in sport has changed broader ideas about and images of sport by challenging dominant ableist narratives. Her work expands notions of athleticism and highlights the need for more inclusive sporting structures and representations. The 'Visibility of Disability' framework DePauw (1997) analyses the complex ways athletes with disabilities are perceived and included in sport, highlighting how ableist norms can render disability both invisible and hyper-visible. This framework examines how factors, like media representation and access to resources, shape the recognition and legitimacy of disabled athletes, ultimately advocating for a more integrated and equitable sporting landscape.

Thus, disability sport is a powerful transformative mechanism both for the participants and audience, paving the way for alternative thinking and changing perception of difference (Berger, 2009; DePauw, 1997). Importantly as DePauw and Gavron (2005), Fitzgerald (2009), Peers (2012b), and Powis et al. (2023) suggest, sport provides an opportunity to recognise and challenge the underpinning hegemonic political, economic, and ableist perspectives that shape and mould the world: "to hijack/challenge and/or reframe disablist discourses" (Wedgwood, 2014, p. 8).

While disability sport ostensibly offers a platform to challenge ableist norms and celebrate athletic achievement, it simultaneously replicates and reinforces the very power structures it seeks to dismantle. This is evident in the hierarchies that exist within disability sport itself, where certain impairments and athletes are privileged over others, leading to the marginalisation of those whose bodies do not conform to dominant ideals. The following section explores these hierarchies in detail, examining how they shape the experiences and opportunities available to athletes with different impairments, particularly those with high support needs.

Hierarchies of Bodies

Sport does not occur in a vacuum, it is influenced by dominant views and taken for granted perspectives that shape and frame individuals' understandings of the world (DePauw, 2000; DePauw & Gavron, 2005; Fitzgerald & Joblin, 2009; Peers, 2009, 2012b; Townsend, Cushion, et al., 2018). Predictably, those who are most likely to participate in sport (and society) are those who are easily accommodated within existing ableist systems and structures (Berger, 2008; DePauw, 2023; Hammond et al., 2019; Hardin & Hardin, 2004; Howe, 2015). It is the bodies that are closer to the norm; the autonomous, self-sufficient able-disabled supercrips, and the cyborgs (athletes who use prosthetics) that are seen as legitimate Paralympic athletes, holding a privileged position within para-sport (Howe, 2023; Howe, 2011; Pullen et al., 2019; Purdue & Howe, 2013).

Unsurprisingly, this ableist focus not only undermines the emphasis on more highly impaired athletes in high performance sport but is perpetuated by sporting research, which often prioritises the experiences and achievements of less impaired or more 'normative' athletes (Howe, 2015; Lowry et al., 2022). As widely documented in the literature, this inherent inequality directly informs the understandings of value and status attached to particular bodies in disability sport (DePauw & Gavron, 2005; Howe, 2015; Marcellini, 2018; Peers, 2012b; Powis, 2020; Townsend, Cushion, et al., 2018). Multiple disability sport authors extend DePauw's (1997) foundational work, detailing the hierarchy of disability, where athletes with acquired or lesser impairments 'rank' above those with congenital or more severe impairments (Apelmo, 2017b; Fitzgerald & Joblin, 2009; Howe, 2023; Purdue & Howe, 2013).

An outlier in disability sporting research is Purdue and Howe's (2013) study on Paralympic athletes with 'severe' impairment. Conducted with 20 Paralympic officials, researchers, and athletes, their study exposes the complexity of the IPC's pursuit of an "entertaining spectacle at the cost of those individuals who possess more significant impairments" (Purdue & Howe, 2013, p. 29), while simultaneously striving to fulfil their ethical and inclusive vision and mission statements. They detail how some athletes with low classifications struggled to be recognised as elite sport performers as they did not "perform in an aesthetically pleasing manner" (p. 31). Highly impaired athletes identified in this study were framed as 'problematic' because they were not perceived as 'marketable' nor did they fit normative understandings of 'elite athlete'. High performance sport's institutional bias, and its economic dependency on a market that recognises, centralises, and rewards ability, creates an "ecosystem for the nourishment of ableism" (Goodley, 2014, p. 34). Apelmo (2017b), Howe (2023), and Jefferies et al. (2012) extend this observation, discussing how both the general public and other athletes with disabilities express negative perceptions of highly impaired athletes' athletic abilities and social competency. Thus, while a paraplegic swimmer with an acquired injury and a boccia player with cerebral palsy both can become 'high performance athletes', they will have vastly different experiences of sport and pathways to participation (Legg et al., 2022;

Patatas et al., 2021; Sales, 2022). As Lowry et al. (2022) note, highly impaired athletes' lived experiences within high performance disability sport have been largely overlooked. This gap underscores the necessity of the current research.

Highly impaired athletes disrupt the idealised images of perfection that underpin high-performance disability sport. They do not reflect the symbolic order this system seeks to uphold and instead occupy marginal, unsettling spaces, what Kristeva (1982) terms "the between, the ambiguous, the composite" (p. 4). Paradoxically, high performance disability sport becomes a mechanism that generates and maintains the 'most able' forms of disability which, in turn, marginalises and excludes athletes that do not conform to these narrow norms (Apelmo, 2017b; Campbell & Brown, 2021; Goodley, 2017; Howe, 2015; Powis et al., 2023; Smith et al., 2016). For many highly impaired athletes, this 'governance through loathing', as Butler (2006) frames it, manifests as symbolic violence and material violence that is embodied and lived (Tyler, 2021).

The hierarchies evident in disability sport, where certain bodies are privileged while others are marginalised, have profound implications for the construction of identity among athletes with impairments. The following section explores how these hierarchical structures, coupled with societal expectations and media representations, shape the ways in which athletes with disabilities, particularly those with high support needs, come to understand and experience their sporting selves.

Identity

Athlete identity in high performance disability sport is a contested and complex terrain, forged through embodied experiences, societal expectations, and the ever-present gaze of the able-bodied world. In their extensive research on men with spinal cord injuries, Sparkes and Smith (2016) and Sparkes et al. (2018) emphasise the crucial role that sport plays in the process of re-embodiment or 'restorying' of the self post injury, where individuals learn about what is and is not possible in their new bodies. Multiple disability sport researchers support this assertion, noting that involvement for those with acquired injuries enables opportunity to nurture a positive disability identity (Berger, 2008; Fitzgerald & Joblin, 2009; Howe, 2015; Lindemann & Cherney, 2008; Lumsdaine & Lord, 2021; Papadimitriou, 2008; Smith & Sparkes, 2005), where "they view themselves more as athletes than as people who are disabled" (Berger, 2008, p.650).

Pullen et al. (2019) examined the relationship between media, sport, and disability representation in their analysis of the United Kingdom's public television Channel 4, broadcast of the Rio 2016 Paralympics. Drawing from interviews, qualitative content, and image analysis, they found that 'Paralympic spectacle' was based on "the inclusion of certain disabilities… that provide an acceptance of the 'right kind of disability'" (Pullen et al., 2019, p. 719). These kinds of ableist, biased Paralympic representations celebrate supercrips, the 'able disabled' athletes who have the "capacity to transform to approximate ableism and thereby become national attractors" (Pullen et al., 2019, p. 732) yet, serve only to Other those who cannot approximate this ideal. Darcy et al. (2017) and Quinn et al. (2023) extend this observation arguing that the ableisation of para sport has led to the "elimination of sports and events where athletes with higher needs compete", and some athletes being 'classified out' of para sport pathways (Quinn et al., p.1). Building on the neoliberal underpinnings of high performance disability sport, they like Pullen et al. (2019) they suggest this practice is prevalent to offer more 'media friendly' sporting experience for audiences and to manage the size of events; yet, this practice contradicts the fundamental principles of Paralympics (Quinn et al.,2023).

In the context of disability sport, the term 'supercrip' refers to a stereotype that portrays athletes with disabilities as brave 'objects of inspiration' overcoming their disability to achieve sporting success (Sterba et al., 2022; Wheeler & Peers, 2023). Alternatively, it is a patronising term for a person with a disability who is simply performing everyday tasks (Grue, 2016; Howe, 2011; Schalk, 2016; Young, 2014). The ideology of supercrip is intimately related to Young's (2014) notion of 'inspiration porn', where disabled people are objectified for the benefit of nondisabled people. Both phenomena exploit narratives of overcoming adversity, positioning disability in negative ways and reinforcing ableist norms. Berger (2008) asserts how stories of supercrip athlete success foster "unrealistic expectations about what people with disabilities can achieve, what they should be able to achieve if only they tried hard enough" (p. 648).

A growing body of literature critiques the dominance of the 'supercrip' narrative in media representations of disability sport, highlighting how this framing systematically marginalises athletes with higher levels of impairment. Critical discourse and media analysis of Paralympic coverage (Brown & Pappous, 2021) demonstrate that visibility is largely reserved for those who conform to elite, inspirational ideals leaving athletes with complex care needs rendered invisible. Similarly, Falcous and Scott (2023), adopting a political economy lens, show how media and institutional logics of marketability privilege para-athletes who are seen as commercially viable, often those with less visibly confronting impairments. French et al. (2018), in her media discourse analysis, reveal how portrayals of disabled athletes swing between tragedy and triumph, offering little space for nuanced, relational, or care-based depictions. Quinn and Misener (2023) bring an empirical dimension to this critique by combining media analysis with athlete interviews, exposing how those who do not fit classification norms or performance expectations are routinely excluded from media narratives. Finally, Silva and Howe (2012b), drawing on critical cultural studies, argue that Paralympic media continues to rely on inspirational tropes that reinforce ableist ideologies and erase the embodied realities of disabled athletes who do not align with these narrow ideals. Thus, while many contemporary disability sport scholars detail the predominance and coercive nature of able-bodied normativity embedded in disability sport (DePauw, 2023; Falcous & Scott, 2023; Quinn et al., 2022; Silva, 2023; Townsend & Cushion, 2020), many have not engaged with the group of athletes that are marginalised due to this ableist ideology.

Athletes in high performance disability sport navigate complex social landscapes that shape and frame their identities, rendering some more acceptable and palatable than others. Narratives that appear empowering often perpetuate harmful stereotypes that serve to marginalise athletes whose impairments defy conventional norms of athleticism and independence. This marginalisation is further compounded by the intersection of disability with other social categories such as level of impairment and gender.

Gender

It is well recognised that disability sport is an embodied practice reflecting the stereotypical norms of athletic masculine attributes that both disabled and female athletes must contend with (Culver et al., 2022; DePauw, 2023; Richard et al., 2023; Smith, 2013; Sparkes & Smith, 2002). Manderson and Peake (2005) highlight how becoming disabled can challenge traditional gender norms. They argue that “traditional notions of woman and disability converge” around characteristics like “vulnerability, sexual passivity or asexuality, dependency”; and that for men, when disability includes incontinence, it places disabled men “closer to the feminine, leaking body with its indeterminate borders” (Manderson & Peake, 2005, pp. 234-235). The association of impairment with characteristics deemed ‘feminine’ and ‘messy’ (Lindemann, 2010; Manderson & Peake, 2005) further reinforces the precarious position of both male and female highly impaired athletes, whose bodies defy the idealised, contained, and hyper-masculine image celebrated and researched in high performance sport. These authors highlight how gender is not a fixed trait; rather, as Butler (2006) suggests, is an active and ongoing process – a performative act that produces and reinforces identity. This is particularly relevant in the context of disability sport where, like able-bodied sport, the celebration of skill, speed, endurance, and strength results in images and ideas of athleticism that are strongly associated with masculine identity and physique (Berger, 2009; DePauw & Gavron, 2005; Pullen et al., 2019; Slocum et al., 2018).

In their studies examining masculinity in wheelchair rugby, both Lindemann and Cherney (2008) and Sparkes and Smith (2014) detail how disabled sportsmen are able to compensate for their perceived loss of physical capital through their involvement in sport, where they emulate able-bodied sexuality, affirming their masculinity through demonstrations of heteronormative prowess and aggression. As feminist scholars DePauw (2023) and Hargreaves (2000) assert, female athletes who demonstrate the same level of physical prowess are not celebrated, but perceived as masculine and less feminine. This stark inequity exposes the deeply entrenched sexism within sport, where disabled women are denied the same opportunities as their male counterparts. Interestingly, a study on heroic masculinity following spinal cord injury, Hutchinson and Kleiber (2000) highlight the paradox that physically impaired male athletes identify with the same norms of masculinity and physical prowess that oppress them.

Thus, it is well acknowledged in the literature that the universal nature of gendered power relations combined with ableism marginalises disabled sportswomen to a greater degree than disabled men (Culver et al., 2022; DePauw, 2023; Hardin, 2007; Hargreaves, 2000). Apelmo (2017a) examines sporting bodies and gender, and details that many disabled women who participate in mixed-gender disability team sports must overcome the sexist norms inherent in able-bodied men’s team sport such as crude sexist language and jokes about appearance and weakness, simply to gain acceptance. DePauw (2023), Duarte and Culver (2014), and Slocum et al. (2018) build on this finding, noting that while there is a well-known gender component to the underrepresentation of women in mainstream elite sport, female para-athletes experience compound marginalisation on the basis of both their impairment and gender which Slocum et al. (2018) termed “double discrimination” (p. 373). This term, however, fails to fully capture the lived experiences of highly impaired women in sport, as it overlooks the hierarchy of disability. Given that highly impaired female athletes are rarely afforded opportunities to break free from the confines from what Hardin (2007) termed the “disability ghetto” (p. 42), perhaps triple discrimination is more apt.

Beyond the challenges posed by heteronormative patriarchy, disability sport further involves sets of practices that differentiate, institutionalise, and, ultimately, classify athletes according to their impairments, further defining and shaping disabled athletes’ identities. To fully grasp the nuances of these athletes’ experiences, I consider the classification system, a cornerstone of disability sport.

Classification

Grounded in the medical model, classification is the key component of the pathway into high performance disability sport (Howe & Jones, 2006; Howe, 2008; Van Dornick & Spencer, 2020), ‘defining’ the highly impaired athletes that are the focus of this work. Classification is the vital link between impairment and activity that lies at the core of Paralympic participation, underpinning both disabled athletes’ “*access to*, and *achievement in*, parasport” (Van Dornick & Spencer, 2020, p. 4) [emphasis added]. Given the functional diversity of impairment, the purpose of classification is to ensure that winning or losing is a result of function of skill, talent, fitness and training rather than disability-related variables such as absence of limbs, paralysis, or spasticity (Howe & Jones, 2006; Sherrill, 1999). The complexity is multiplied as classifiers must focus only on sports specific function across multiple forms of impairment (Howe & Jones, 2006; Marcellini, 2018; Van Dornick & Spencer, 2020; Wu & Williams, 1999). In Marcellini’s (2018) study of the impact of athlete classification and the “technologization of the impaired body” (p. 96), they determine that the overarching aim of classification is to enable fair and equitable competition for athletes of all abilities, “rather than a one-sided predictable competition in which the least impaired athlete wins” (PNZ, 2024c)[6].

Yet, despite classification being an essential element of para sport it remains a controversial process. Smith’s (2014) critical sociological analysis provides a useful approach to tease out

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[6] For more details about the classification process see https://www.paralympic.org/classification

the complexities embedded in the classification process. They emphasise how viewing disability through a biological reductionist lens ignores how ideas of 'normal' and 'natural' are shaped by sociocultural norms, which can affect individuals in both positive and harmful ways (Smith & Perrier, 2014). Disability and impairment are "experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning" (Hughes & Paterson. 1997, p. 335). Disability is as Hughes and Paterson (1997) highlight, is one's body is one's window to the world – disability is felt from the perspective of impairment; "the impaired body is not just experienced, it is the basis of experience" (p. 335).

Peers (2012a) critically exposes how power and truth embedded in the medicalised treatment of disabled people serve to "discipline and shape the disabled subject into an increasingly normalised, productive and docile form" (p. 176). In the process of classification, athletes are complicit in the process as they compose their "tragic disability origins, our athletic successes despite them, our heroic striving towards hyper-ability, our inspirational hope for full normalcy and our categorical difference from those who have not overcome" (Peers, 2012a, p. 186). In their autoethnographic study of a Paralympic athlete, Campbell & Brown, (2021) build on Peers (2012a) critical understandings of classification, details the athletes' 'bittersweet' emotional experience of the sense of exhilaration and joy as they are accepted into the Paralympic programme, yet sadness as they are medicalised; legitimising and reaffirming the extent of their disability in the process.

As both Peers (2012a) and Campbell (2021) assert, para-athletes' internalisation of harmful emotions to compete at the highest level starkly exemplifies how ableism dominates the power structures of elite sport. Inevitably, classification is an uncomfortably intimate process for athletes, where power imbalances not only profoundly shape their sporting trajectories but are a regulatory necessity that they must undergo in order to compete (Howe & Jones, 2006; Peers, 2009; Van Dornick & Spencer, 2020).

Ironically, while some authors are critical of the classification process, framing it as an oppressive system that hijacks agency (Campbell & Brown, 2021; Howe, 2023; Peers, 2012a), others discuss the positives of classification that give disabled athletes a sense of pride, identity, and belonging (Powis, 2020; Townsend, Huntley, et al., 2018; Van Dornick & Spencer, 2020), based on a shared recognition of difference in ability (Van Dornick & Spencer, 2020).

The sport category provides athletes with an important sense of identity indicating, "'who I am in this sport', the group to which I belong (among others), and my place in relation to those of others" (Marcellini, 2018, p. 101). As such, multiple authors note how a positive sporting identity provides low classification, highly-impaired athletes with a means to distance themselves from the pervasive social stigma associated with disability more generally (Apelmo, 2017b; Fitzgerald & Joblin, 2009; Howe, 2023; Purdue & Howe, 2013). As articulated by a 'low point' wheelchair athlete in a study by Goodwin et al. (2009):

> We're sport minded, even though we're disabled we still just go at it hard and play a game that kind of defines us. When you think of a wheelchair "oh so fragile" and we beat the living snot of each other, and it's kind of fun. (p. 112)

The complexities are summarised by Campbell and Brown (2021) who highlight that Paralympic classification creates a paradox, presenting to the world how physically 'able' athletes are "through a system that specifically exposes how disabled they are" (p. 126). While classification is central to eligibility and competition, its implications extend far beyond the field of play. Classification shapes how impairment is recognised, measured, and legitimised; processes that directly influence the level and type of care support athletes are deemed to require. Yet, despite its central role in para sport, few studies have explored classification's impact on athlete welfare (Van Dornick & Spencer, 2020), and none have explicitly linked it to care. My study offers a unique opportunity to examine this connection.

The outcome of classification becomes a marker of identity and hierarchy that follow athletes on their sporting journeys. The following section details the complexity of para-athlete development pathways.

Development Pathways

An expanding field of inquiry has examined the developmental pathway of para-sport athletes (Dehghansai et al., 2017; Legg et al., 2022 704; Patatas et al., 2021; Sales, 2022; Storli et al., 2022). Yet this research has primarily focused on those with acquired impairments (Lindemann & Cherney, 2008; Papadimitriou, 2008; Smith & Sparkes, 2005; Sparkes et al., 2018; Sparkes & Smith, 2016). Those with acquired impairments became disabled via accident, whereas those with congenital impairments were born with their disabilities, and those with degenerative impairment experience the progressive deterioration of physical or cognitive function over time typically due to disease. Howe (2015) notes that those who enter the high performance realm as a result of accident are socialised differently than those born with congenital impairments or degenerative impairments, with different opportunities and affordances available. This distinction is more than biographical; it becomes structurally significant later in this thesis, as the type and onset of impairment directly shape access to care, and long-term inclusion within development pathways. Critically, the pathways available to those with congenital and degenerative impairments are often more precarious, under-resourced, and overlooked within both sport policy and research; a gap this work aims to expose.

For individuals with congenital impairment, the journey to sports participation is often marked by social, financial, and environmental barriers that they and their families must navigate (McKenzie et al., 2021). Apelmo (2017b) asserts that if congenitally impaired youth are immersed in an inclusive schooling environment, they can begin their journey with sport through adaptive physical education classes. The finding, however, is not in keeping with other research that has shown that many teachers and/or physical education practitioners do not know how to facilitate inclusive physical education (Buffart et al., 2009; McKenzie et al., 2021; Orr et al., 2018; Sienko, 2019). Furthermore, there is a growing body of evidence that suggests while youth with impairments may start sport earlier, they commonly have difficulty finding clubs or sports facilities with the necessary resources or inclusive policies to keep them engaged (Buffart et al., 2009; Patatas et al., 2021; Sienko, 2019).

A unique study that focused on 345 Brazilian elite para-athletes representing 15 para-sports found that athletes with acquired injuries progressed through the "developmental phases of an athletic career" pathway faster than athletes with congenital impairments; "4.5 years compared with 6 years for athletes with congenital impairment" and remained at the elite phase for longer (Patatas, 2021, p. 619). The authors surmised that the shorter developmental trajectory could possibly be explained due to "residual motor skills" developed prior to impairment, but did not establish the limitations experienced by those with congenital impairment (Patatas, 2021, p. 619).

Disabling Development

Building upon the observed differences in developmental pathways for athletes with different impairments, similar research has sought to understand the underlying psycho-emotional factors contributing to these disparities. Scarpa and Palumbo (2017) undertook an intensive study that examined the "physical self-concept in athletes with congenital versus acquired disabilities" (p. 1). The study recruited 201 athletes aged between 12 and 28 years, with acquired disabilities, and 185 athletes with congenital impairment. They found that athletes with acquired disabilities exhibited markedly greater physical self-concept and self-esteem impaired to those with congenital impairment (Scarpa & Palumbo, 2017). The authors suggest that athletes with acquired impairments draw from their positive sense of self established in their 'years without disability', which impacts positively on their sense of self-esteem. Participants with congenital impairments (that are stable over time) reported lower self-esteem, which the authors attributed to a complex interplay of factors: lifelong stigmatisation, overprotective care, and limited chances to develop physical skills, resulting in feelings of isolation and discrimination (McKenzie et al., 2021; Scarpa & Palumbo, 2017). Positively, all of the athletes in the study, irrespective of impairment, expressed an acceptance of disability and articulated how their involvement in disability sport allowed them to discover value, and flourish (Scarpa & Palumbo, 2017).

Notwithstanding the growing scholarly focus on athlete development and welfare, these conversations largely fail to critically address or problematise para sport, nor do they reconcile athlete development models with the specificities of care and welfare. A notable gap remains in the literature concerning how psycho-emotional disablism and impairment shape the performance pathways of marginalised athletes. Dehghansai's (2020) contention that evidence-based models of para-athlete development require a deeper understanding of disability-related nuances highlights an important, yet underexplored, avenue of inquiry. Central among these overlooked nuances is the role of care – and its absence, in shaping the developmental trajectories of highly impaired athletes.

Together, this literature illustrates directly how the relationship between impairment and disability impacts and shapes disabled peoples' access to, and progression in, disability sport pathways. Another key aspect of athletes' journey to high performance disability sport is their relationship with their coach.

Coaches, Coaching and Duty of Care

Coaches are undeniably important in shaping the sporting experiences of disabled athletes (Martin, 2013). However, a critical review of the disability sport coaching literature reveals a concerning disconnect between coaching practice and the lived experiences of disabled athletes. In their qualitative studies, Townsend et al. (2015) and Allan et al. (2019) highlight how the majority of the literature focused on disability sport coaching is largely descriptive and 'coach centric', where coaches learning experiences have been examined extensively, yet largely disconnected from the athletes themselves. As a result, much of the established work in disability coaching literature often sidesteps direct engagement with impairment – relegating disability to the background (Cushion et al., 2021; Tawse et al., 2012). Extending this finding, coaching research drawn from varied methodologies – theoretical, critical disability studies models (Townsend, Huntley, et al., 2018), qualitative life histories (Allan et al., 2019), and online surveys (Dehghansai et al., 2017), revealed a recurring pattern. Coaches were found to distance themselves from discussions of disability or impairment; instead. relying on experiential knowledge of coaching or being an able-bodied athlete rather than specific knowledge of disability. This generalised approach is problematic as a lack of understanding of the "unique difficulties faced by athletes with a disability due to their impairment" (Dehghansai et al., 2017, p. 85) hinders coaches' ability to maximise performance outcomes, ultimately undermining athlete welfare (Townsend et al., 2022).

Multiple disability sport scholars argue that coaches' inability to connect with the athlete embodied experience of impairment is underpinned by the dominance of the medical model in coach education, perpetuating the view of impairment as an individual tragedy and a defect to be remedied (Allan et al., 2019; Cronin et al., 2018; DePauw, 2000; Smith & Perrier, 2014; Townsend & Cushion, 2018; Townsend et al., 2015; Wareham et al., 2017). Yet, as Hughes and Paterson (1997) and Townsend and Cushion (2018) highlight, when used in an informed way, the medical model is a useful tool for impairment specific knowledge underpinning 'athlete centred coaching'. Thus, they stress it is important "not to write the body out of our theorising" (Townsend & Cushion, 2018, p. 51).

While the benefits of athlete-centred disability sport coaching are widely acknowledged (Cushion et al., 2021; Kohe & Peters, 2017; Tawse et al., 2012; Townsend & Cushion, 2018, 2018; Townsend et al., 2022), the shift from traditional, coach-driven approaches is complex. As (Cousin, 2006, p. 4) stresses, given that "we are what we know" (p. 4), assimilating new understandings into our biography requires an ontological and conceptual shift – reshaping how we see, how we feel and ultimately who we are. Drawing from case studies of elite coaches, both Kohe and Peters (2017) and Tawse et al. (2012) found that coaches who make the effort to empathise and understand disability both gained insight for athletes' lived experience of disability and generated greater credibility and relatability with their athletes which impacted positively on performance outcomes. Therefore, athlete-centred, collaboration is key and occurs when coaches and athletes co-construct knowledge on the basis of mutually shared goals and beliefs (Allan et al., 2019; Kohe & Peters, 2017; Tawse et al., 2012; Townsend & Cushion, 2018). Supporting this finding, when exploring para-athlete perception of how coaches shaped sporting experiences, Allan et al. (2019) found that coaches can "positively contribute to athletes' psycho-emotional well-being by demonstrating genuine interest in and care or concern for athletes" (p. 561).

Another paradox emerges. Despite care being recognised as an "essential aspect of coaching", it remains undeveloped in the literature (Cronin & Armour, 2018, p. 17). Yet a coach's 'duty of care' is widely accepted, and often mandated by sport's governing bodies (Grey-Thompson, 2017; Kavanagh et al., 2021; Rhind et al., 2015). Expanding on this complexity, Cronin and Armour (2018) argue that governing bodies, coach educators, and coaches are offered little academic guidance on how to *practically implement* care. Although care is recognised as complex and dynamic, the literature outlines general principles that position it as a meaningful practice rooted in doing no harm, fostering open dialogue, and being attentive to and meeting athletes' needs where appropriate (Cronin & Armour, 2019b; Cushion et al., 2021; Jones, 2009; Townsend & Cushion, 2018; Townsend et al., 2015). It appears at this stage, that understandings of 'duty of care' are grounded on 'taken for granted' teaching practices rather than centred on athlete and coach embodied experiences. Cronin (2023) is a key author who discusses the multifaceted nature of care in sports coaching (Cronin & Armour, 2018; Cronin & Armour, 2019a, 2019b; Cronin et al., 2018; Cronin et al., 2019). They, and other leading disability sport coaching authors, like Fairhurst et al. (2017), Fisher et al. (2019), and Townsend and Cushion (2020) fail to address the lived experience of impairment effects or para-athletes' care requirements. This omission is concerning, particularly given the coach's pivotal role in athlete welfare and performance.

As critical actors in the welfare and care of para-athletes, it is concerning that coaches and coaching research largely overlook notions of care as it intersects with disability. As a result, the complex needs of highly impaired athletes remain largely unaddressed in disability sport coaching literature.

Highly Impaired Athletes and Coaching

In their studies on elite coaching, both Bredahl (2010), Cregan et al. (2007) and Hammond et al. (2019) expose the systemic bias within coaching, where coaches prioritise athletes who require less support, perpetuating inequalities and limiting the participation and development of athletes with higher support needs. While this might be well-known in coaching practice, the omission remains largely undeveloped in the literature, with only a few articles briefly mentioning coaching or sporting experiences of athletes with higher support needs. Cushion et al. (2021), and Downs (2015), are two of the few authors that mention the complexities that come with coaching a small pool of athletes with higher level impairments. While Hammond (2019) articulated the need for coaches to adapt their approaches for para-swimmers requiring "additional support" (p. 318), the specifics of such support remain unclear. Such ambiguity highlights a critical shortcoming in the literature, underscoring the need for future research to define types of support – read care – required by athletes with higher levels of impairment. Without concrete examples or frameworks that detail the care needs of athletes requiring 'additional support', coaches are left to interpret athlete needs in a variety of ways, potentially leading to inconsistent and inequitable coaching practices. Generating greater understanding of athletes with additional support needs are an aspect that this research aims to address.

While not centred on elite sport, Darcy et al.'s (2017) work provides a useful point of reference for further developing coaching research for those with higher levels of impairment. The research highlights that participation in sport and for those with higher support needs is often constrained by contextual factors such as a lack of personal support, transport funding and access, reliance on support workers, and a lack of recognition of impairment effects by providers (Darcy et al., 2017). Importantly, the participants in Darcy et al.'s (2017) study did not "inherently regard their impairment as a constraint" (p. 36) but advocated for enabling policies and greater access to attendant support. Like my research, Darcy et al. (2017) underscored how impairment effects are "not uniform across disability types or level of support needs" (p.36), necessitating unique considerations to address constraints, enhance participation, and develop inclusive pathways. These omissions in the literature highlight a critical need for further research and resources to support coaches to understand and address the unique welfare and care needs of highly impaired athletes.

While elite disability sport strives for excellence, and critical disability studies researchers actively challenge ableist norms embedded in coaching practice, the experiences of highly impaired athletes have gone without note. Bridging this gap requires a commitment to 'a duty of care' grounded in athletes' lived experiences.

Organisational Duty of Care

In contemporary sporting literature it is recognised that sporting practice has not always been aligned with human rights protections, thus sustaining conditions in which violence, abuse, bullying and coercion of athletes have been able to flourish (Cottrell, 2018; Kavanagh et al., 2021; Lang, 2020). There has been a spate of elite athletes speaking out about unethical sports environments that perpetuate violence, such as abusive coaches, dangerous training regimes, over emphasis on winning and lack of care for athlete welfare and well-being (Cottrell, 2018; Fitzgerald, 2021; Kavanagh et al., 2021; Lang, 2020; McCulloch, 2020). In their in-depth review of duty of care and welfare practices in Olympic and Paralympic sport, Kavanagh et al. (2021) detail how athletes from across the world spoke of "bullying, racial, sexual and gender abuse" (p.3). This occurred alongside other forms of discrimination perpetuated "under the banner of a no compromise approach to performance" (Kavanagh et al., 2021, p. 3).

Extending these findings about the culture of disability sport, Tuakli-Wosornu and Kirby (2022) focused on centring para-rights and found that "athletes with disabilities had the second highest percentage of psychological abuse and the highest percentages of physical and sexual abuse" (p. 9), and 66% of para-athletes experienced neglect in sport. Although existing research has not explicitly linked para-athlete experiences of neglect in high performance sport to a lack of care or 'additional support', this study seeks to establish that connection.

Grounded in a human rights approach, the notion of a duty of care has been proposed as a solution to both Olympic and Paralympic athlete 'challenges' encountered throughout the high performance sporting pathway. A duty of care mandates that sports organisations and the individuals who work within them take all reasonable steps to ensure the emotional and physical welfare of athletes during sports or physical activities (Cottrell, 2018; Fitzgerald, 2021; Grey-Thompson, 2017; Kavanagh et al., 2021; Lang, 2020; McCulloch, 2020; Rhind et al., 2015). Failure to do so, makes them accountable.

From a legal perspective, duty of care can be understood as a commitment to prevent and mitigate foreseeable risk (Kavanagh et al., 2021). From a moral perspective, duty of care aligns with the feminist approach to an ethics of care in which engagement and behaviours act to promote well-being, the flourishing of others, and enhanced relationships (Cronin & Armour, 2019b; Fisher et al., 2019; Kavanagh et al., 2021; Lang, 2020; Noddings, 2010). Accordingly, one could argue that a human rights approach underpinning sport provision necessitates a fundamental commitment to a duty of care, ensuring the well-being, dignity, and protection of *all* individuals involved in sports activities.

In an attempt to concretise the tenets that underpin organisational 'duty of care,' in 2017 researchers in the United Kingdom published the *Duty of care in sport: Independent report to government* (Grey-Thompson, 2017). The review, penned by Paralympian Grey-Thompson (2017), highlights the need for an inclusive approach to duty of care, ensuring that all athletes, including para-athletes, are adequately supported in their sporting pathways. The review recognised that para-athletes often faced additional challenges due to their impairments and called for enhanced measures to ensure their well-being (Grey-Thompson, 2017). With this report, sporting organisations are tasked with taking greater responsibility in "fostering a duty of care in practice" which includes supporting athlete well-being: "Putting people – their safety, wellbeing and welfare – at the center of what sport does" (Grey-Thompson, 2017, p. 4). Arnold and Fletcher (2021) note that despite all the possible benefits of such an approach, duty of care has garnered minimal attention within the sporting literature and its "meaning has not been clearly articulated" (p. 313). It is, however, generally accepted by multiple sporting scholars that sporting organisations have both a moral and legal responsibility both to safeguard athletes from harm and incorporate human rights principles (Bundon et al., 2018; Cottrell, 2018; Kavanagh et al., 2021; Lang, 2020).

Consequently, while disability sports organisations and coaches are proclaiming a duty of care for the athletes in their charge, their lack of knowledge and ensuing inability to address the specific welfare and care requirements of 'athletes with high support needs' demonstrates a fundamental breach of this obligation. As such, it can be reasonably argued that in a para sport/disability sport context 'duty of care' is a taken-for-granted or critically under-theorised aspect of athlete welfare, particularly with regards to the institutions tasked with supporting para-athletes.

In this context, ‘duty of care’ becomes a rhetorical device – invoked but rarely enacted, particularly in relation to those athletes who fall outside normative, low-support models of high performance. Despite policy rhetoric and human rights frameworks that affirm care as central to athlete well-being, the practical realities of high impairment are rendered invisible, and structurally unsupported. This research intervenes by explicitly naming this gap and repositioning care not as ancillary, but as integral to any meaningful enactment of organisational duty of care in para sport. In doing so, it contributes to a much-needed reframing of athlete welfare – one that centres the lived realities of those whose impairments demand sustained, embodied, and relational forms of support.

Welfare and Care

Over the past few years, there has been a global shift in prevailing attitudes and policy approaches towards a more comprehensive approach to athlete welfare (Lang, 2020). This shift positively acknowledges that sports have both a moral and legal obligation to protect athletes from harm and help them flourish (Cottrell, 2018; Kavanagh et al., 2021; Lang, 2020; Mountjoy et al., 2016). In 2016, the International Olympic Committee (IOC) published a Consensus that noted the “additional needs” of disabled athletes as “specific vulnerabilities” which, if ignored, may result in “non-accidental violence or intentional harm” for disabled athletes (Mountjoy et al., 2016, p. 5). These vulnerabilities included:

> (1) making uninformed assumptions about the care needs of athletes, (2) exploiting the athletes’ dependence on personal care (e.g. communication requirements, travel requirements and competition logistics), and (3) blurring of the roles and responsibilities in the coach-athlete relationship. (Mountjoy et al., 2016, p. 5)

Each of these concerns is acutely relevant to highly impaired athletes, underscoring the central role of care in safeguarding para-athlete welfare. Yet, nearly a decade later, this critical dimension of athlete protection remains conspicuously absent from both academic inquiry and high-performance sport policy. The ongoing neglect of care risks reproducing the very harms that welfare frameworks claim to prevent, particularly for athletes with high support needs. If para sport is to genuinely align with the principles set out in the IOC Consensus, there must be a deliberate and sustained focus on the lived realities of highly impaired athletes.

Their experiences offer essential insights for advancing policy, informing best practice, and embedding care as a fundamental component of para-athlete welfare. This research directly responds to that need.

Place Matters: Aotearoa

In their examination of how sporting organisations are currently engaging in treating elite athletes in Aotearoa, Cottrell (2018) noted, at a broader level, high performance sporting organisations are starting to, at least rhetorically, recognise that athlete welfare is a necessary condition for maximising performance. Further, that welfare and performance are mutually reinforcing and it is possible to achieve both, not one at the expense of the other (Cottrell, 2018). Thus, while there is general consensus that the broad concept of athlete welfare encompasses overall health, safety, well-being, and welfare of individuals involved in sport, there are differing approaches on how to enable positive outcomes (Cottrell, 2018; Grey-Thompson, 2017; Lang, 2020). Notably, throughout the literature, welfare and well-being are often used interchangeably to describe the overall health, safety, and quality-of-life of individuals. This practice arguably skews their distinct meanings and such conceptual imprecision undermines approaches to achieve these important aims (Trainor & Bundon, 2023a).

When seeking to understand the approach to para-athlete welfare, it is interesting that much of the disability sport literature focuses primarily on well-being and safeguarding, grounded on the vulnerability of disabled athletes (Fitzgerald, 2021; Mira et al., 2022; Puce et al., 2023; Trainor & Bundon, 2023b; Tuakli-Wosornu & Kirby, 2022). As Fitzgerald (2021) notes there is, “scant attention and less understanding” (p. 184) of the welfare of disabled people in sport. They highlight that while there has been an expansion of disability rights-focused legislation and policy, enabling disabled people a more equitable life experience, that the focus of welfare in sport have yet to filter down into disability sport (Fitzgerald, 2021). Campbell and Brown’s (2021) ethnographic study of an elite para-athlete extends this assertion, detailing the additional challenges an athlete faced in her 9-years of high performance sport. They argue that despite advances in well-being provision for elite athletes, such support remains underpinned by ableist norms – reflecting and reproducing the broader cultural and political systems in which para sport is embedded (Campbell & Brown, 2021). As a result, the failure to recognise the importance of personal support –impacts heavily on both para-athlete well-being and performance (Campbell & Brown, 2021).

Extending the exploration into elite para-athlete well-being, Miller et al. (2024) examined the experiences of 21 United Kingdom elite para-athletes in mixed sports with acquired and congenital impairments. Like (Fitzgerald, 2021), Miller et al. (2024) notes that “para-athlete well-being has been comparatively under-researched” despite the recognition of para-athletes’ need for ‘specialised support’ (p. 126). When describing athlete experiences of accessing support they note that many “felt they had to justify themselves as “disabled enough” to apply and qualify for the benefits” (Miller et al., 2024, p. 135), and often the support they did receive was “often insufficient or specific enough to meet their needs and requirements” (Miller et al., 2024, p. 131). Disappointingly, despite interviewing some highly impaired athletes, their understanding of ‘specialised support’ referred only to supportive coaching and familial relationships, decentralised training facilities, and empathetic coaches, with less attention given to the wider network of care in which athletes are situated (Miller et al., 2024). This finding highlights a critical omission in both disability sporting literature and practice, that is the lack of recognition of the interrelationship between impairment and care, and the ongoing provision of care based on normative notions of athlete. This oversight is important, with research illustrating the cost of institutional neglect of the complex realities of impairment which impacts heavily on the psycho-emotional welfare of the most marginalised athletes (Lowry et al., 2022).

A psycho-emotional focus in the study of para-athlete welfare is warranted, specifically given the focus in critical disability studies (cf. Goodley, 2014; Kafer, 2013; Reeve, 2020; Thomas, 1999, 2007). However, the majority of articles specifically reviewing the welfare of elite para-athletes primarily focus on psychological welfare (Kohe et al., 2022; Lang, 2020; Miller et al., 2024), offering only limited discussion of the para-specific care needs of athletes (Campbell & Brown, 2021; Kohe et al., 2022; Lowry et al., 2022). Only a few authors like Campbell and Brown (2021), Cottrell (2018), and Jaarsma et al. (2014) note the psycho-emotional and physical barriers generated by lack of personal support. Cottrell (2018) clearly states that while “disabled athletes have the same rights and welfare needs as able-bodied athletes [they] have additional requirements that need to be met depending on the nature of their disability” (p. 5). These findings highlight another concerning paradox. While the literature acknowledges the presence of ‘additional support needs’ of some para-athletes, this awareness fails to translate into research that explores the lived realities of those athletes, revealing the persistent disconnect between theoretical understandings of welfare and care and meaningful action within high performance disability sport.

The neglect of highly impaired athletes’ care needs in both research and practice arguably underscores the ableist distaste to engage with ‘messy’ bodies, requiring specialised support and accommodations. Messy bodies cannot be trusted in public spaces governed by those who have “secure autonomous rational bodily boundaries” – “bodies that are in control” (Longhurst, 2001, p. 2). Longhurst (2001) asserts that “ignoring the messy body is not a harmless omission, rather a political imperative” (p. 40), that keeps ableism intact, and subsequently contributes to limited research exploring what ‘care’ specifically entails for this group of athletes.

While a great deal is known about high performance athletes who are non-disabled, there has been a “collective failure to engage with innovative theoretical and methodological frameworks” (Powis et al., 2023, p. 1) and tap into the lived experiences of disabled athletes and the people who support them. While there is some understanding that physical impairment effects are unique to each disabled athlete (Culver & Werthner, 2017; Darcy et al., 2017), and directly impacts on how that person engages in the world, largely unexplored in disability sport research, is recognition of the psycho-emotional elements of impairment and its links to welfare and care. Attending to the embodied experience of impairment sheds light on how these physical and psycho-emotional dimensions shape not only performance, but the everyday realities of disabled athletes’ lives.

Embodied Experience of Impairment Effects

Drawing on embodied theoretical frameworks (Thomas, 1999), there is growing awareness within the sport discourse of the ableism embedded in disability sport (Allan et al., 2019; Powis et al., 2023; Smith & Bundon, 2018; Townsend & Cushion, 2020; Townsend et al., 2022; Van Lindert et al., 2023). As Smith and Perrier (2014) emphasise, the importance of this approach is underscored by an understanding of disability that “the body is more than biological. It is *also* experienced, socially constructed, and culturally fashioned, thereby making impaired bodies simultaneously biological, lived, social, and cultural” (p. 102). They suggest that to ignore para-athlete lived experiences, one becomes complicit in perpetuating, an ableist, often neoliberal, individualistic and disembodied way of knowing disability sport (Smith & Perrier, 2014). Thus, while self-confessed ‘critical’ scholars are increasingly grounding disability sport research on the lived experience of para-athletes, providing opportunity to challenge dominant taken for granted assumptions and ableist theories of disability embedded in disability sport (Allan et al., 2019; Campbell & Brown, 2021; Peers et al., 2020; Powis et al., 2023; Smith & Perrier, 2014; Townsend & Cushion, 2020), engagement with and through the disabled body is less forthcoming. While lived experience and impairment effects have been discussed in the literature there has been no reference to athletes embodied experience of impairment effects other than Lowry et al. (2022). For example, Peers et al. (2020) focuses on institutional structures, discourse, and representation, detailing how para-athletes are managed, celebrated, or excluded in ways that reinforce neoliberal ableism. While this work powerfully critiques the discursive construction of disability and exposes systemic exclusion, it engages less with the messy, embodied realities of impairment (Peers et al., 2020). Here, the body functions more as a symbolic battleground than as a lived, affective, contingent site requiring care.

Campbell and Brown (2021) similarly explore narrative disruption, highlighting how para-athletes resist dominant ableist tropes and reclaim agency through storytelling — a vital contribution to challenging objectification and promoting visibility. However, this attention to narrative stops short of examining how impairment is lived through the body, particularly in high-performance sport. The work gestures toward voice and resistance but leaves underexplored the embodied negotiations of impairment, and how these intersect with training, welfare, and care (Campbell & Brown, 2021).

The research that does detail impairment effects experienced by highly impaired people is primarily from a medical perspective, concentrating on the physiological aspects of spinal cord injuries in the general population (Bourke et al., 2015; Braaf et al., 2017; Conti et al., 2022; Nevedal et al., 2016; Pryor et al., 2021). These findings, however, remain relevant when examining the experiences of highly impaired athletes with diverse forms of impairment. These articles highlight the complex nature of impairment, encompassing a wide range of effects, including bladder and bowel care routines (often requiring assistance), fatigue, pain, fluctuations in function, weakness, temperature regulation difficulties, time constraints, pressure sores, mental fatigue, and a perceived lack of control (Bourke et al., 2015; Braaf et al., 2017; Conti et al., 2022; Nevedal et al., 2016; Pryor et al., 2021).

Drawing primarily from medical literature, for those with spinal injury, cares is a time consuming, labour-intensive process often requiring caregiver support, impacting the pace of everyday life, as well as independence and autonomy (Burns et al., 2015; Lowry et al., 2022; Nevedal et al., 2016). Unique to individuals with high level spinal cord injury (above T6, the sixth thoracic spinal level) is autonomic dysreflexia (AD). AD is triggered by expansion of either the bladder or the bowel, pressures on the skin or temperature change, which, if left untreated, may cause a heart attack or stroke (Conti et al., 2022; Sparkes & Brighton, 2020). Consequently, people with all forms of high level impairment must constantly observe of their bodies to identify and interpret symptoms, some of which require immediate action and assistance (Conti et al., 2022). Understandably, the complex management of impairment effects impact social and emotional well-being, creating barriers to physical, work, social and leisure activities (Bourke et al., 2015; Braaf et al., 2017; Conti et al., 2022; Pryor et al., 2021; Thomas, 2007). This research is important in highlighting the often invisible and sometimes dangerous demands of personal care, and underscores the unique temporal realities faced by highly impaired athletes.

To further understand the implications of impairment effects on sporting practice, Slocum et al. (2015) reviewed high performance athlete experiences of injury across multiple forms of impairment. They found that athletes with cerebral palsy typically had increased spasticity or muscle tone which impacts the range of motion in joints, increasing the risk of overuse injuries, noting that similar impairment effects are also seen in athletes with traumatic brain injury or stroke (Slocum et al., 2015). Building on this finding, a study by Aviram et al. (2022) that explored the physiological barriers and facilitators of physical activity for young people with congenital impairment, found that 64% of participants experienced musculoskeletal pain, which influenced their function and often undermined their participation in sport. From a biomechanical and wheelchair sports performance perspective, Mason et al. (2013) and Mauerberg-deCastro et al. (2016) note that athletes with amputations who use prosthetics (i.e., sport wheelchair users) often face significant problems with sensory loss, which leads to serious impairment effects such as skin breakdown and pressure sores. Furthermore, as expected with any athlete population, athletes with disabilities come from differing economic conditions, and some reside in countries that do not provide treatment or prevention opportunities (Mauerberg-deCastro et al., 2016). These authors stressed that for many of these athletes, chronic problems arise from repeated impairment effects which may lead to serious consequences over time (Mauerberg-deCastro et al., 2016).

In the previous section I highlighted a range of research that touches on the complexity of impairment within a sport setting. This is important as the implications of impairment for personal care needs can be all-encompassing, time-consuming, unpredictable, and often labour-intensive. For example, bladder and bowel care regimes (the term medicalised as ‘personal cares’ by health practitioners and shortened to ‘cares’ by those living with or dealing with spinal impairment) feature prominently within disability discourse yet have received little focus within sport (Lowry et al., 2022) with few exceptions.

Despite this valuable emphasis on impairment effects, the lived and embodied experience of impairment effects remains largely theoretical in much of the disability sporting research. My research seeks to expose how ableist understandings of elite para-sport renders invisible the ‘messy, gritty’ embodied experiences of impairment effects. To date, other than Lowry et al. (2022) publication, there has been no acknowledgement of the lived, material, and psycho-emotional impact of impairment effects experienced by highly impaired athletes in high performance sport. In this research Lowry et al. (2022) draws on cripistemology and autoethnography to centre my lived experience as a highly impaired athlete, exposing how care is marginalised in both the literature and practice of high-performance disability sport. By foregrounding impairment effects and interdependence, the article challenges ableist assumptions embedded in duty of care frameworks and exposes the normative temporality of elite sport through the lens of crip time (Kafer, 2013; Katzman et al., 2020; Morris, 1997). The vignettes disrupt the silence around care, illustrating that participation at this level is not despite impairment, but made possible through complex, often invisible, practices of care (Lowry et al., 2022). In doing so, I position highly impaired athletes not as exceptions, but as necessary disruptors of para sport’s exclusionary systems (Johnson & McRuer, 2014; Peers, 2012b). Cares is not an innate practice; rather, it is learned over time by both the support worker and the disabled person (Lowry et al., 2022). The article demonstrates that cares are a particular site of vulnerability, impacted by access, logistics, personnel, and funding. They are not static, but a relational, affective, and often unpredictable process shaped by social, emotional, and institutional conditions. It also documents the physiological and psychological impacts of impairment in sport, including blood pressure drops during care routines, muscle spasms, racing fatigue, and the emotional toll of managing one's body in public and high-performance settings (Lowry et al., 2022). As such, it reframes care not as supplementary to high performance, but as integral to understanding how disabled athletes train, compete, and survive within elite sport contexts.

One study highlights the embodied complexity of impairment effects in high-performance sport, challenging simplistic framings of both care and cheating. In their qualitative study, Sparkes and Brighton (2020) conducted in-depth interviews with 10 male wheelchair rugby athletes who had a spinal cord injury above T6, examining their experiences with AD in elite sporting contexts. Through narrative analysis, the study explored how athletes understood and managed the risks of AD, and how some engaged in the banned practice of 'boosting', that is, intentionally triggering AD to increase blood pressure and enhance performance. While the condition is medically dangerous, Sparkes and Brighton (2020) found that athletes often viewed their decisions pragmatically, negotiating the fine line between real physical danger and opportunity for competitive edge.

Drawing from Kafer's (2013) understanding of crip time, managing impairment effects requires new patterns of feeling, thinking, and being in the world. As Samuels (2017) articulates, disability has the power to remove one from "linear progressive time" (para. 3) and occupy the bodies of crip time. Kafer (2013) added "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (p. 27). Consequently, due to the lack of acknowledgement of highly impaired athletes' embodied experiences, in the current high performance sporting environment carers and/or personal assistants are considered a luxury rather than essential for life. As Campbell and Brown (2021) note, para-athletes are forced to rely on a limited supply of "donated talent" (p. 128) for vital care workers. It is imperative that the complexities of impairment effects and care requirements are meaningfully acknowledged in the literature to foster more inclusive sporting practices and to protect highly impaired athletes. The diverse and often overlooked impairment effects experienced by this group — routinely ignored in both high-performance disability sport research and practice — demand recognition and structural accommodation.

Such acknowledgement is essential if the IPC (2024) is to genuinely deliver on its mission to enable ‘all’ para-athletes to “achieve sporting excellence” (p. 15).

Building on these challenges, the following section, Doing the Dirty Work, delves into the intimate realities of care for highly impaired athletes, and the people who care for them. As detailed in Lowry et al. (2022) often-invisible labour encompasses managing basic bodily functions– tasks essential for athletes’ participation in both everyday life and sport.

Doing the Dirty Work: The Role of Carers

Care has been researched in a number of disciplines including: health (Van Dongen & Elema, 2001); feminism (Kelly, 2013); disability (Edwards, 2020; Morrison, 2021); labour studies (Hebson et al., 2015; Wolkowitz, 2006); sociology (Cluley, 2020; England & Dyck, 2011; Thomas, 2016); and, sport coaching (Cronin, 2023; Cronin & Armour, 2019a; Fisher et al., 2019; Meziani et al., 2017). The connection between athlete welfare, care, and performance outcomes has been widely explored in relation to able-bodied athletes, particularly in terms of psychological support, medical provision, and organisational responsibility (Cottrell, 2018; Cronin & Armour, 2019b; Kavanagh et al., 2021). In these contexts, ‘care’ is often operationalised through professional roles, such as coaches, sports psychologists, and medical staff, or framed within institutional environments tasked with safeguarding performance. However, care as a conceptual framework, especially one that accounts for the relational, embodied, and affective dimensions of support, has received less attention, particularly in para-sport contexts. While recent research acknowledges the need for different approaches to foster para-athlete welfare and achievement (Campbell & Brown, 2021; Fitzgerald, 2021; Howe, 2023; Lang, 2020; Lowry et al., 2022; Peers, 2009; Powis et al., 2023), the conceptual interrelationship between welfare, care, and duty of care remains underdeveloped. My research addresses this gap by critically examining care not only as a professional obligation or service provision, but as a lived, negotiated, and deeply relational practice that fundamentally shapes the experiences and possibilities of highly impaired athletes in high-performance sport.

As noted in the preceding sections, largely unexplored in the disability sporting literature is how care is a vital ingredient for highly impaired athlete success (Lowry et al., 2022). The broader concept of care is complex and multifaceted. It has physical, emotional, moral, and economic components; it is layered with social norms around altruism, political notions of ‘public good’, as well as gendered expectations (Duffy et al., 2013; Hebson et al., 2015; Hochschild, 1983, 2012; Rakovski & Price-Glynn, 2010; Stacey et al., 2015; Thomas, 2016). In a large body of work around caregiving, feminist geographers, disability scholars, and sociologists have shaped the definition, recognising that care is a unique form of labour and not simply an economic transaction or physical labour, but it is embedded in relational dynamics and emotional connections that frequently transgresses typical relational boundaries (Duffy et al., 2013; England, 2005; Morrison, 2021; Stacey et al., 2015; Thomas, 2016). Sociologist, Wolkowitz (2006), describes how the body is the “immediate site of labour, involving intimate, messy contact with the (frequently supine or naked) body, its orifices or products through close proximity” (p. 147). From this perspective, care is a form of intimate bodywork, where the caregiver’s body is the direct instrument of care and the body of the cared for is the object of the worker’s labour, and often the focus of economic activity (Twigg, 2000; Wolkowitz, 2006).

Some authors discussing the dynamics of care recognise that while care work is primarily based on interdependency and reciprocity, one cannot overlook the inequalities of power that frequently occur in giving and receiving care (Bowlby, 2012). To better understand the complexities, one must locate the caring relationship within wider socio-economic relationships which influence the power of both parties (Bowlby, 2012; Wolkowitz, 2006). Milligan and Wiles (2010) tease out this complexity, noting that while highly impaired people are dependent on support workers, “the low pay received for care work” means that support workers “often occupy a lower social status than that of the person they care for” (p. 737). Disability scholar Kittay (2011); human geographers Milligan and Wiles (2010); and labour economists Watson et al. (2004) all note the paradox of care manifests as “interlaced frameworks of power and powerlessness” where the “care recipient may be dependent” on the support worker to meet their everyday needs, the support worker is vulnerable to both the care recipient and the priorities of their employer as well (Kittay, 2011, p. 561). Human geographers add to this understanding, emphasising how the relational and material dynamics of specific environments shape, and are shaped by, the practices and experiences of caregiving. The crucial connection between support work, care, and place, offers a valuable perspective to tease out the interplay between high performance sporting environment and caregiving practice. As Bondi (2008) asserts, “care connects people” via place, “whether they desire such connectedness or not” (p. 250).

Tapping into the relational, embodied approach to care, Cluley (2020) expands this understanding detailing how care work involves more than just bodies. Care has an intimate physical presence that involves flesh which is touched, washed, caressed, moved, and more (Cluley, 2020). While there is stigma attached to ‘dirty work’, there is also recognition of the “mutual connectedness” (Wolkowitz, 2006, para. 9), that can be generated through caring and touch (Grosz, 1994, 2020; Shildrick & Price, 2002; Twigg, 2000), and support workers often express satisfaction from their proficiency dealing with the more physical and messy elements of their role (Rakovski & Price-Glynn, 2010; Stacey, 2005). Care work when theorised and assessed at the ontological level (Betcher, 2010) considers the “flesh as a flexible, tangible and relational thing”, offering an opportunity to engage with embodiment and the “fluidity and connectedness of life” (Cluley, 2020, p. 9). These understandings lie in stark contrast with the ideology of high performance athletes as autonomous and independent; an ideology that often disregards dependency or relationality. Morrison (2021), in an autobiography of caring for her young disabled son, discusses how “embodied emotions saturate the experience of giving and receiving care”, describing care as a multifaceted interplay of “emotionally felt experiences, bodily practices, deeply embedded in “social politics”, that inherently “connect people” to one another (p. 1). Thus, the lived experiences of care in disability sports challenge ableist norms and expose the urgent need for systemic change to protect the welfare of highly impaired athletes.

Interconnection

Drawing from critical disability studies literature, for the highly impaired interconnectedness is a central component of the human condition that most people do not have to acknowledge. Miller (2019) highlights “the relational nature of life” (p. 95). When care is combined with “an ethic of justice” (Miller, 2019, p. 95) it prompts a reimagined understanding of independence, not as self-sufficiency but an opportunity to have choice and “control over how help is provided” (Morris, 1997, p. 56). Mitchell and Snyder (2000) summarise how “the interdependency of disability living” (p. xii) is an important factor in achieving independence and autonomy. Thus, the role of care is difficult to reconcile in a western culture that celebrates independence as many equate receiving care to dependency; incompatible with stories and beliefs of the free, autonomous citizen (Bowlby, 2012; Ellis et al., 2019; Fineman, 2004; Kelly, 2013; Miller, 2019; Morris, 2001). This tension is particularly pronounced in high performance disability sport, where the ableist values of autonomy, self-reliance, and unyielding competition often clash with the lived realities of interdependence and care that underpin the experiences of highly impaired athletes.

Care in Sport

Meziani et al. (2017) are the only authors in the disability sport literature to discuss care as defined in the context of my research. They focus on caring ecology, and discuss how caring in disability sport is often 'task centred' rather than emotional. The authors note that in this context there is often a "reversal of power relationships" where caregivers become a "mere tool for accomplishing" the rights of care receivers (Meziani et al., 2017, p. 12). Kittay (2011) beautifully summarises this sentiment describing care provision as a form of 'prosthesis' that facilitates the independence of disabled people. To examine the links between disability and care they draw on the work of Sen (1999) and Nussbaum (1988) who stress the power of capabilities and empowerment. Caring for people means "facilitating their autonomy [which is] understood as the effective freedom to achieve well-being through valuable options" (Meziani et al., 2017, p.11). This creates a situation of "relational autonomy and reciprocal dependence" (Meziani et al., 2017, p.13).

Highly impaired athletes, therefore, are marginalised within high performance disability sport. Their care needs are rendered invisible within dominant high performance sport frameworks. Similarly, the essential contribution of support workers remains undervalued and obscured reflecting broader systemic inequalities that further marginalise both groups despite their centrality to the system. The current study provides insights into these vital aspects of highly impaired athletes' sporting lives.

Summary

In this chapter I examined the epistemological underpinnings of disability sport, exposing how the production of knowledge within the critical social sciences of disability sport has neglected the embodied experiences of highly impaired athletes. It argued that despite increasing attention to the body in disability sport literature (DePauw, 2023; Lawson et al., 2023; Powis, 2020; Sparkes & Smith, 2002) there is a reluctance to engage with embodiment and the complexities of impairment (Apelmo, 2017a; Brighton et al., 2021). This inattention is due to an ableist politics of knowledge that privileges normative disabled bodies and athletic performances (DePauw, 1997).

This review centres the lived experiences of highly impaired athletes whose voices remain absent or peripheral in mainstream disability sport research. Conceptually, it offers a grounded and embodied account of care, moving beyond abstracted notions of support and toward a more relational, affective, and interdependent framing of welfare (Lowry et al., 2022). Furthermore, existing research notes that despite a widespread theoretical acceptance of organisational of duty of care to support athlete welfare (Grey-Thompson, 2017; Kavanagh et al., 2021; Rhind et al., 2015), its practical application remains inconsistent. The pervasive ableist ideology in disability sport undermines a genuine connection between organisational stated duty of care commitments and para-athlete lived realities of care. In what follows, this research offers an empirical contribution by foregrounding the lived experiences of highly impaired athletes. These experiences are currently excluded from shaping the care frameworks and policy decisions that govern their participation.

While impairment effects are referenced in the literature, the dominant focus remains on structure and agency, underpinning the social relational theoretical model (Thomas, 1999). As a result, the ‘messy, gritty’ embodied experience of impairment and the effects of cares, ‘crip time’, interdependence. and psycho-emotional disablism remain largely invisible in research and sporting practice (Lowry et al., 2022). The lack of recognition of the interrelationship between impairment effects, interdependence, and care, further marginalise highly impaired athletes and the carers who support them. Empirically, the focus on the embodied experiences of these athletes offers a rare and necessary insight, providing a unique opportunity to extend these understandings.

Theoretically, this review exposes the ableist neglect of highly impaired athletes’ embodied experiences in disability sport scholarship and practice (Lowry et al., 2022). By centering these perspectives, my research offers a more nuanced understanding of ableism’s impact and internal hierarchies, empirically and theoretically linking care to athlete welfare. Practically, it may inform coaching and disability sporting organisational policy by providing crucial insights into the unique needs of this marginalised group, fostering more equitable and inclusive sporting environments.

While the existing literature provides important insights into disability sport, it remains limited by frameworks that often fail to centre the complex, embodied, and relational realities of highly impaired athletes. In response, this research turns to a crip methodology – one that refuses normative assumptions, foregrounds lived experience, to generate deeper sporting insight.

Chapter Three: Crip Methodology

Throughout this research I draw on a variety of qualitative methods, to expose the complexities and contradictions of disabled athletes' experiences and bring forward a range of perspectives on the dynamics of care in disability sport. In so doing, I anchor my work within a crip methodology, and draw on cripistemology. I do this as a form of 'crip intervention' to challenge ableism and centre the voices and lived experiences of disabled athletes.

To the best of my knowledge this methodological approach is unique within the field of disability sport research. Drawing on the powerful insights of crip methodology, the research weaves together: autoethnography; visual ethnography; and 19 interviews with high-performance athletes, carers, coaches, and organisational representatives (e.g. High Performance Sport Athlete Life Advisor, Sport New Zealand representative, and Wheelblacks administrator) to provide a nuanced and multi-faceted understanding of disability in high performance sport. Data analysis and presentation is organised via spatial scale, beginning with my lived experience as a high performance disabled athlete, then to the experiences of other athletes, carers, and coaches; and, finally, examines the national and international structures and institutions that deliver disability sport. Spatial scaling allows for a deeper understanding of how ableist assumptions embedded in sport shape and frame all participants' embodied experiences. Reflexive thematic analysis was used to interpret the data.

This chapter has six sections. First, the epistemological approach of Cripistemology and Crip Positionality is outlined, including a subsection on Reflexivity and Insider Status. To understand the application of crip methodology in this research, section two examines the underpinning multimethod approach, including the Indigenous research method, pūrākau. The third section details my approach to autoethnography, including a subsection, Seeing through My Eyes: Visual Ethnography. Participants and sampling has three subsections describing: Data Collection; introducing the Participants – athletes, carers, coaches, and organisational representatives - who are the centre of this study. The fourth and fifth sections are Data Collection and Data Analysis respectively. The sixth section, Pūrākau: Athlete Creation Stories, holistically introduces the athletes who are the focus of this research, prioritising their voices, sharing the narratives that shaped their journeys to elite disability sport. The chapter ends with a brief summary.

Crip Intervention

Disability sport research often overlooks the power dynamics that are often part of the research process. While disability sports studies have begun the journey to expose the ableism embedded in high performance disability sport, there remains a silencing of disabled athlete voices, particularly those most systemically marginalised. This research proposes a 'crip intervention' to centre the voices and subjectivities of highly impaired athletes, clearing the way for more inclusive and representative scholarship (Lowry et al., 2022; Powis, 2020; Silva, 2023). To disrupt ableist practices, I use cripistemology to destabilise traditional research methodologies and pre-existing categories of academic knowledge (Hickman & Serlin, 2019; Johnson & McRuer, 2014; Kafer, 2013; McRuer, 2006; Minich, 2016; Schalk, 2013). Building on Hickman and Serlin (2019), crip methodology actively seeks to expand disability knowledge and empower its community of scholars and activists. Crucially, it asks who is empowered by this knowledge? It employs diverse methods of description — written, tactile, verbal, audio, and visual — to foster intersubjective understanding (Hickman & Serlin, 2019).

Cripistemology challenges the notion of a universal, objective truth, arguing instead that knowledge is always situated and embodied (Haraway, 1988; Hickman & Serlin, 2019; Linton, 1998; Schalk, 2013). Kafer's (2013) assertion, "my future is written on my body" (p. 3) underscores the need for disability histories written *by* disabled people, not *for* them. This understanding enables the celebration of the diversity of disability experiences, resisting any attempt to impose an objective truth or a 'correct' way of *being* disabled or *doing* disability otherwise (Kafer, 2013). Minich (2016) and Schalk (2013) supported this proposition, describing cripistemology as both a theoretical framework, and a method that grounds the research on the lived experiences of disabled athletes. This need is echoed in critiques of high performance disability sport and research where, despite the work of allies (DePauw, 1997; Smith & Sparkes, 2005; Townsend et al., 2015) research 'from us' remains scarce.

Crip intervention aims to transform disability sport methodologies through athlete-centred crip perspectives and, in doing so, address the shortcomings in disability studies, disability sport studies, and the sociology of sport. Ultimately, it seeks to disrupt narrow definitions of disability and challenge the "socio-political ideologies that assign more value to some bodies and minds than others" (Minich, 2016, p. 7). Thus, when seeking to challenge traditional understandings of the body and the self, recognising the complex and often contradictory nature of embodiment is central. Crip methodology is a resource to explore athlete embodiment in elite disability sport; to "take us out of our bodies and into others" (Couser & Mairs, 1997, p. 294), fostering a deeper understanding of how identities and selves are shaped and conditioned by our bodies, particularly in the context of disability. In approaching this research, it is important to acknowledge my subject position in relation to disability and how this influenced the research process.

Crip Positionality

I am acutely aware that respondents have entrusted me with their intimate and private lived experiences, with the understanding that these – and my own - experiences will be shared publicly. As Denzin (2017) stated, researchers receive these stories under a promise:

> [T]hat promise being that we will protect those who have shared with us. And in return the sharing will allow us to write life documents that speak to the human dignity, the suffering, the hopes, the dreams, the lives gained, and the lives lost (p. 15).

Honouring this promise, the narratives woven through the thesis celebrate the disabled sporting community and allow me to engage in a politics of representation that challenges traditional research practices. By centring the experiences of highly impaired bodies in high performance sport, I reclaim disabled bodies from 'medical colonisation', to reinvest the real and messy experiences of body dysfunction with meaning, countering the 'meaninglessness' that Couser and Mairs (1997) identified as the most profound threat posed by disability.

Living with impairment means entering a world that is created around myths and misunderstandings which can be damaging as disability itself. One's life becomes a world of "hidden negotiations" (Mitchell & Snyder, 2000, p. x) that can be brought to light with the right methodological approach. I recognise that the phenomena that I am studying is complicated and uncertain but it is meaningful, significant, and valuable work (Avner et al., 2014; Bochner, 2000). I have lived disability since 2013, and much of that time has been spent learning to manage my new body and new life. I now find myself able to function without the burden of conscious effort. This newfound freedom allows me to expand my horizons beyond survival and explore the complexities of this largely hidden world I now inhabit. Initially, the prospect of this research felt overwhelming and discouraging. I questioned its value. Yet, the global surge in focus on athlete welfare provides a timely context for understanding the significance of care for highly impaired high performance athletes. Thus, welfare and care is a powerful lens through which to expose the pervasive ableism that permeates the disability sporting world.

This research emerged from managing to meaning-making, from surviving to questioning. As I moved beyond the immediacy of care routines and daily negotiations, I began to recognise the deeper structures that shape, restrict, and define disabled life. These are not just practical or medical, but epistemic and political. My time as a high-performance athlete — representing Aotearoa internationally as a swimmer in the Paralympics development squad and a member of the Wheelblacks (our national wheelchair rugby team), illuminated the ways in which high-performance sport is not exempt from, but deeply complicit in, the reproduction of ableist logics and disciplinary power.

My lived experience in a disabled body has given me a visceral understanding of how ableism is pervasive and normalised. Living in an ableist world is like “living in the colonisers’ house” (Ross, 2020, p. 32), where disabled people are forced to use the words and images of the coloniser. This echoes Ahmed’s (2013) assertion, when difference is framed as a form of commonality it becomes a way of demanding conformity to a dominant norm. Thus, a paradox operates when researching disability, because the voice *I find*, which *becomes mine* in the research, is already entangled in the very structures of oppression and discrimination which *I oppose* (Denzin, 1997).

Thus, in centering disability there is an opportunity to develop new ways of “moving in and around research methodologies” (Kerschbaum & Price, 2017, p. 100). This thesis responds to that call, developing methodological tools that are centred on crip subjectivities; that is, starting with exploring what it is to be disabled (Hickman & Serlin, 2019; Kafer, 2013; McRuer, 2006; Minich, 2016; Schalk, 2013). Through this crip lens, *being othered* becomes a political tool to generate disability narratives that are written *by us* and not *for us*. Thus, by centring the embodied experiences of highly impaired athletes, this work aims to shift the ‘nondisabled’ to the margins, allowing *them* to see the world “from the inside out” (Linton, 1998, p. 13), exposing the perspectives and expertise that are often silenced. Embodied recognition, a cornerstone of cripistemology, generates greater understanding of the athletes involved in high performance disability in sport.

Reflexivity and Insider Research

Situating my insider status within cripistemology, my embodied experience becomes a legitimate methodological asset, shaping both the research process and the insights generated (Johnson & McRuer, 2014; Karlsson et al., 2023). There are unique opportunities afforded by insider research, where "bodily knowing and remembering is rooted in the physical experience" of doing, rather than a "grasping of abstract terms and concepts" (Ellingson, 1998, p. 496). Accordingly, as a participant in disability sport, the epistemological 'gap' between the myself and the athletes, carers and coaches, in the research is minimal, generating opportunity for reliable interpretation, authenticity, transferability, meaningfulness, and depth (Kacen & Chaitin, 2006; Padgett, 2008; Smith & McGannon, 2018). My experience as a researcher-athlete fostered a strong connection with participants. Rather than a one-sided narrative, the interviews with athletes became a lively conversation between friends, exploring our shared embodied experiences of sport and care. Athletes felt comfortable sharing personal or sensitive information, knowing they were understood and accepted (Berger, 2015; Lindlof & Taylor, 2019; Rubin & Rubin, 2012).

This approach, however, is not without its challenges, as research cannot and should not be value free. I had to consider the ways in which 'who I am' both assisted and hindered the process of constructing meaning (Lietz et al., 2006). Research has shown, that the insider's 'dual identity' can blur boundaries where the researcher may impose their own values, perceptions, and bias into the research (Drake, 2010). Berger (2015) suggests that "researchers must continually ask themselves…at any given moment" during the study, "what are the potential ramifications" of their position on the research (p. 231). To address this question there is an expectation that the researcher reveals themselves on the page; acknowledging limitations, ambivalences, contradictory feelings, and layered subjectivities, so that the readers gain insight into the social world being examined and the researcher's construction of knowledge (Bochner, 2000; Clarke & Braun, 2021; Pillow, 2003; Sparkes, 2020). Bochner and Ellis (2016) believed the researcher listens in a different way when they are embedded in the world they are observing – there is no way to compartmentalise and distance oneself – bringing greater reflexivity challenges. Acknowledging my role in the research, I employed Sage's (2012) approach to 'self reflexivity', using a research journal for 'self-supervision' that detailed ideas, reasoning, and emotional reactions, as well as peer support and review (Berger, 2015). The following is an excerpt from my journal:

> I like the stuff about reflexivity, thinking about where you stand, who you are and how you see the world, and how this impacts on what you write – on the things that you see as important. I have such a critical lens, that perhaps I never see the good… Or I have to look harder for it. I like that there has been a shift in my thinking, that I feel more positive about my work – that I know it is going to make a difference. I think reading some of the autoethnographic writers like Bochner and Ellis has helped me know how I want to write. I want to be present in the text, not in self-absorbed/narcissistic/masturbatory kind of a way – but I want the reader to be able to use me as a vehicle to understand what is like to inhabit the disability space. To feel what it feels like – to understand the level of organisation, logistics, management just to get our arses on the court or in the pool. I think if I make it too academic, it won't reach the people that I want it to reach – it becomes text that is only useful to academics. I want it to be real and messy and evocative and disturbing and hopeful. I want to do justice to all the people who have contributed, to highlight what they do – to show how amazing they are! (Amanda, PhD journal, 5 March 2020)

Throughout, I asked myself questions such as: how might my personal experiences influence my understanding of other athletes' stories; and, what might I do to minimise my influence? Despite this effort, I was not an effective interviewer. While my interview style fostered rapport, I tended to fill in the gaps, as I might do in everyday conversation and not ask follow-up questions or expand on points. When reflecting on why this happened, I realised I enjoyed asking people about their lives, and watching them light up as they talked about their passion for their sport and the opportunity involvement has bought to their lives. I came to understand that my love of this kind of conversation is deeply intertwined with the politics of emotion, specifically a complex paradoxical alignment with the 'supercrip' ideal and the narrative of triumph over disability through sport. It was only in retrospect, during analysis, that I recognised the sense of belonging I felt with other high performance athletes was predicated on a troubling dynamic. Adding to crip methodology, intersectional feminist, Ahmed (2013), spoke to this point:

> Love becomes a way of bonding with others in relation to an ideal, which takes shape as an effect of such bonding. Love is crucial to how individuals become aligned with collectives through their identification with an ideal, an alignment that relies on the existence of others who have failed that idea. (p. 124)

Thus, this paradox extends beyond a simple binary opposition. While highly impaired athletes push the limits of performance and success, our bodies do not align with ableist ideals underpinning the supercrip (Lowry et al., 2022). The very sense of inclusion we experience is entangled with exclusion, so that our alignment with the ideal relies on a structure that simultaneously positions ourselves and others as failing it.

Throughout this process, my supervisors became more than just academic mentors, rather they were a vital anchor. When my critical voice threatened to tip into fury or despair, they held the space for all of it - the anger, the grief, the sadness - and helped me find a way to honour those emotions without letting them consume the work. Their belief in the importance of what I was trying to do gave me the courage to stay with the discomfort, to sharpen the politics, and to keep telling the stories that needed to be heard.

To maximise the opportunity for social justice embedded within cripistemology requires a commitment to crip methodology, which is outlined in the following section.

Cripping Methodology

Crip methodology destabilises normative able-bodied knowledge making and pedagogy within the social sciences (Hickman & Serlin, 2019; McRuer, 2006). A project, like this thesis, lends itself to emerging methods of research, with authors such as Hickman and Serlin (2019), Linton (1998), Kafer (2013), Johnson and McRuer (2014), and Baril (2016), emphasising that the intimate, experiential, and sensorial contributions of the disabled experience and disabled subjectivity underpin the creation of a crip methodology. But, so far, crip methodology remains "complex, messy and undefined", raising questions about developing methodological tools to capture "what it means to be a disabled subject in the first place" (Hickman & Serlin, 2019, p. 135). This complexity stems from the diverse and fluid nature of crip subjectivities, where experiences vary and are constantly evolving – we are all in a state of becoming (Schalk, 2016). As Hickman and Serlin (2019), Kafer (2013) and Linton (1998) suggest, fostering a crip methodology requires understanding embodiment within a temporal framework.

Recognising the central role of identity and embodiment in research (Hickman & Serlin, 2019; Johnson & McRuer, 2014; Kafer, 2013), my disability is not something I must compensate for; rather, becomes an important source of knowledge (Kerschbaum & Price, 2017). By exploring diverse 'ways of knowing', this research aims to identify and articulate the unstable, decentred crip positions of highly impaired athletes; thereby informing anti-ableist theory by which to know disability differently (Hickman & Serlin, 2019; Johnson & McRuer, 2014; Kafer, 2013; McRuer, 2006). In order to deliver, the researcher must adopt a new methodological language, one that embraces "risky truth telling" (Kuntz, 2015, p. 142).

While existing disability sport research has offered valuable critiques of high performance structures and systems (Howe & Silva, 2018; Peers, 2012b; Townsend, Huntley, et al., 2018), and explore multiple aspects of athlete experience (Crossen et al., 2023; Howe, 2009; Lowry et al., 2022; Powis, 2018; Sparkes & Smith, 2016) it has only recently acknowledged the importance of centring research on the lived experience of impairment (Allan et al., 2019; Lowry et al., 2022; Powis, 2020 ; Sparkes & Smith, 2016). Ultimately, this work calls for a critical awareness of the power dynamics inherent in research relationships (Goodley, 2017; Howe, 2023; Kafer, 2013; Peers, 2012a; Townsend & Cushion, 2020). Embodying the tenets of critical disability studies, the research itself becomes a political tool, transforming into a moral discourse that connects the reader to the lived experiences of oppression and marginalisation, opening opportunities for social justice to be realised (Goodley, 2014; Powis et al., 2023).

Pūrākau

Like many critical disability scholars, Indigenous researchers have examined the social construction of knowledge and the politics of research (e.g., Tuhiwai Smith, 2021). A key contribution to bringing change is pūrākau. To fully explore the embodied experiences of disabled athletes and their supporters, coaches, and carers in high performance sporting spaces, requires a flexible methodological mechanism. As part of my crip methodology, I drew on concepts from Te Ao Māori to inform the research design. Te Ao Māori – the literal translation is a Māori world view - emphasising the interconnectedness between people, the environment, and spirituality, celebrating who we are as people. Lee's (2008) vision of pūrākau was predetermined by the goal of constructing textual knowledge inspired by Indigenous story work. Drawing from Cavino (2019), the translation of pūrākau focuses on the concepts of te pū (the origin or foundation, the roots) and rākau (the word, branches, and leaves). Pūrākau is used in Māori research as a story that relates to whakapapa (lineage and connection). The belief is that this method has the power to “allow the relationship tree, and us, to grow – to heal our whakapapa, our histories and our present” (Cavino, 2019, p. 96). Thus, pūrākau, with its focus on power, identity, and belonging, provides a powerful counter narrative, resonating with cripistemology. Employing a creation narrative as a methodological tool provides a platform for amplifying disabled voices on their own terms, challenging normative ideas about ability, success, and time. This approach emphasises the relational and collective dimensions of disability sport by highlighting ‘sporting actors’’ lived experiences of community and shared experience, while resisting individualistic, ableist frameworks.

My vision is that this work will manifest as raranga (traditional Māori weaving), where the pūrākau — narrative strands from the athletes, carers and coaches, and organisational representatives — are both descriptive and woven through analysis. Those strands continue throughout the work, discussing intimate geographies and the physicality of space, crip time, and the structures of care and the structures of sport. Cripistemology is the glue that will weave those stories together. Stories in the form of autoethnography are another key element of this thesis, embracing subjectivity and the insight of living research as inquiry (Ellis, 2003).

Autoethnography

In this thesis I use autoethnography as an entry point into the topic of welfare and care. An autoethnographic approach is a powerful mechanism to tap into my lived and embodied experiences as a highly impaired high performance athlete. By examining how I prepare, train, and compete; and how I care for myself and am cared for; this approach, guided by pūrākau, centres on my personal experiences and reflections within disability sport. As noted earlier, when disabled people share their personal experiences, their words can challenge ableist, oppressive structures and understandings (Taylor et al., 2015; Thomas, 2004). Ellis and Bochner (2006) celebrated autobiography as a “gift of living testimony” (p. 431); a dangerous, rebellious, creative, and messy form of expression that opens up multiple perspectives, unsettles meanings, and provides valuable insight into how disabled sports people live (Ellis & Bochner, 2003; Ellis & Bochner, 2006; Holman Jones, 2011; Holman Jones & Harris, 2019; Sparkes, 2020).

The overarching aim of this method was to use my personal experiences as a starting point for the research. My experiences grounded the research, allowing me to develop questions that could uncover experiences of other participants to promote change in the provision and understandings of disability sport. By compelling sporting organisations, academics, and readers to think about the world in a different way (Bochner & Ellis, 2016; Holman Jones et al., 2013; Sparkes, 1996, 2020), this autoethnographic approach, from a crip methodological perspective, becomes a useful mechanism to 'break the silence' by addressing, understudied complex and/or sensitive topics (Holman Jones et al., 2013). Gannon (2013) deftly articulate how we "write ourselves into being" as we write autoethnographically, but not in a naïve or innocence manner"; "instead, we write ourselves into particular subject positions, within the texts we write and, in unpredictable ways, we call others into relation – both inside the text and in their readings of our texts" (p. 230).

Autoethnography is designed to be dangerous, rebellious, creative, and messy; it is a "gift of living testimony" (Ellis & Bochner, 2006, p. 431) opening up multiple perspectives, unsettled meanings, and conversations that give insight into how people live (Denzin, 2003; Ellis & Bochner, 2003; Ellis & Bochner, 2006; Holman Jones, 2011; Sparkes, 2020), 2020). As Adams and Herrmann (2020) outline:

> Autoethnography is comprised of three interrelated components: 'auto,' 'ethno,' and 'graphy.' Thus, autoethnographic projects use selfhood, subjectivity, and personal experience ('auto') to describe, interpret, and represent ('graphy') beliefs, practices, and identities of a group or culture ('ethno'). (pp. 2-3)

As I tell my story, the text must not foreclose on meaning as it moves nearer to the details of things. It must move the reader, as well as the writer, effectively, emotionally, and rationally "by striving to keep the text – including the text of the self – open to multiple possible readings" (Holman Jones et al., 2013, p. 230). The raw and honest account of my experiences, do not bury passion, they centralise the subjective and invite the reader to see themselves in, and with, my story (Ellis, 2004; Holman Jones et al., 2013; Sparkes, 1996). The autoethnographic element of this work provides a written account of the intimate details of my daily embodied life experiences.

As I interrogated my own experience to illustrate the unique dimensions of care (c.f., Lowry et al., 2022), I began to consider how my experiences resonated with other athletes' and sporting participants'. Importantly, autoethnography allows me to be both subject and object, entwining my life with the lives of the other athletes (Kafer, 2013), exploring how bodies and meanings are created in, and through, engagement in high performance sport, not to reject them "but in order to build meanings and bodies that have a chance for life" (Haraway, 1988, p. 580). Our collective narratives reveal how the ableist foundations of sporting organisations and broader national structures not only shape, but fundamentally constrain, the embodied experiences of highly impaired athletes in high performance sport. Autoethnography is paired with visual ethnography to strengthen my storytelling.

Seeing Through My Eyes: Visual Ethnography

As outlined previously, scholarly activity, particularly in sport, often adheres to conventional methodologies. A crip lens, however, allows for different approaches. This research utilises a qualitative, visually-bolstered, multi-method framework to explore the intricacies of welfare and care in disability sport. This section sets out an argument for the combination of visual and textual contributions which are used as an explorative tool. The contribution of visual ethnography responds to the first three objectives of my research, highlighting the lived experience of the athlete as they prepare, train, and compete in sport, and the experiences of carers and coaches.

The photographic element aims to awaken critical imaginations, demonstrating different ways of knowing and understanding the world. This approach aligns with cripistemology by extending ethnographic methods to include and celebrate disability on our own terms (Kafer, 2013; Pink, 2015). Photographs capture the intimacy of human contact and interdependence within daily and sporting lives, revealing insights into the creation of self and the lived experience of power relations (Pink, 2015).

Ethnography is corporeal process. Since my injury, the senses I have left are hearing, smell, taste, and vision. As a high-level tetraplegic, without the ability to touch and feel and locate my physical self, vision and sound are vital for my proprioception. They are what ground me in physical space. When I close my eyes, I am nowhere. In the early days I would fall over. I cannot feel the chair beneath me or the firmness of the ground. I only know I am here when I open my eyes. Therefore, photographs offer a powerful way for the reader to relate to me and give insight into my bodily experience of disability. What the reader sees in the photos is *all* I have to locate myself in a physical space. The visual contributions are directly linked to situated knowledge – the materiality of life – those elusive qualities of lived experience that will be difficult to capture in text alone (Haraway, 1988).

In this method, the photographer, Jason Egnew, took a fly-on-the-wall approach, capturing images of a typical training morning. He documented my partner moving me out of my sleeping position, undertaking passive stretches, and putting on my swimming costume. He documented the hands-on care provided by support workers at the pool, and my personal care routine at home, including commode chair transfer, showering, toileting, and dressing.

Visual ethnography creates synergies between the images and text, providing context, insight, and learning (Pink, 2011). The photographs offer the reader an opportunity to experience my world and the space and time that I inhabit. In this work, the photographer acts as an extension of my body, capturing the intimate and necessary aspects of my life that I cannot document myself. The experience is emotional – I am vulnerable and I am exposed. This approach exposes the embodied nature of crip interdependence and contributes to cripistemology by providing a powerful visceral dimension to strengthen written analysis.

As Collier and Collier (1986) suggest, this visual approach creates “a cultural inventory” (p. 47) of my disabled life, offering an opportunity to compare specific material aspects to process, activity, equipment, and support required by highly impaired bodies. This photographic diary, a self-reflective chronicle of my experiences in disability sport, provides a situated perspective rather than an objective truth (Pink, 2013; Prosser & Schwartz, 1998). By making my approach explicit, I aim to enhance readers’ understandings of the research findings. Ultimately, visual ethnography, as an addition to autoethnography, is an attempt to raise critical consciousness, using photographs to understand and expose power relationships. In so doing, my hope is that researchers might embrace the Other’s gaze, to dismantle the ableist world (Kafer, 2013; McRuer, 2006; Schalk, 2016).

While this section establishes the broader rationale for my methodological choices, the reflexive turn deepens in Chapter Four, where I draw more explicitly on autoethnography to examine the ethical, emotional, and political stakes of insider research as a disabled scholar and athlete.

Participants and Sampling

My personal involvement in disability sport since 2013 provided me with valuable connections which I utilised to recruit participants. Initially, I purposefully selected athletes from wheelchair rugby and swimming across Aotearoa drawing on my own networks and connections in these sports. Some participants were enthusiastic about the research and suggested other athletes with whom I could connect. However, this initially provided me with a limited view—primarily a sample of athletes with impairments similar to my own. While this shared embodied experience offered depth and resonance, it also risked narrowing the scope of the study. To more fully capture the diversity of the highly impaired athlete population, and to avoid overrepresenting spinal cord injury, I used snowball sampling to reach athletes across different sports and impairments (Sparkes & Smith, 2014).

Potential participants were initially contacted via email or social media to ascertain their interest in the research. Upon expressing interest, they received an information sheet (see Appendix A), and consent forms (see Appendix B), informing them about the study and their rights within the research. After receiving the signed consent forms, interview dates and times were scheduled as convenient to the participants. While face-to-face interviews (Appendix C, D, and E) were initially planned, COVID-19 restrictions necessitated conducting most of the interviews on Zoom: “a remote interview is better than no interview at all” (de Villiers et al., 2022, p. 1774). Although I prefer face-to-face interactions, online interviewing greatly supports accessibility and the complexities of ‘crip time’ for the athletes that are the focus of this study. Positively, research found that there is little difference between the “nature and character of the interviews by mode” (Krouwel et al., 2019, p. 6) and even rapport between interviewee and interview remained high. In keeping with my experience, de Villiers et al., (2022) note that where research includes diverse interviewees in different geographical locations video interviews are ideal.

Furthermore, the live video recordings became an invaluable resource. Being able to review the recordings multiple times provided an opportunity to connect with the data on a deeper level, allowing for a more nuanced analysis. Additionally, utilising Zoom significantly reduced research costs, eliminating the need for extensive travel across the country.

The Participants

The athlete participants represented a range of impairments: five had spinal cord injuries; three degenerative conditions; and, two congenital impairments. Sports represented included wheelchair rugby (n=5), sailing (n=2), shooting (n=2), swimming (n=1), boccia (n=1), and athletics (n=1). Two of the participants are represented in two sports, one swimming and wheelchair rugby, the other boccia and wheelchair rugby. Participant ages ranged from 29 to 73 years. All athletes were Paralympians, with eight still participating. Participants' ethnic origins included: two Māori; eight Pākehā; and, one New Zealand born Fijian Indian. Of the 10 athletes, only three participants were women. The participants represented a range of journeys through para sport pathways, with some athletes' careers being overseen by PNZ as part of their remit for para sport, while others train and compete within their governing body as part of the broader mainstreaming or integration agenda in New Zealand. As such, the sample provided a rich temporal and spatial perspective on the changing nature and understandings of welfare and care in para sport.

Organisational representatives were drawn from HPSNZ, SNZ, Swimming New Zealand, and New Zealand Wheelchair Rugby (NZWR). Coaches represented wheelchair rugby and swimming.

Four wheelchair rugby participants are members of Aotearoa's national team, the Wheelblacks. One of these participants is also a Paralympic medallist in swimming, reflecting the common practice of talent transfer between sports in para sport. Another participant, a Paralympian boccia player was selected for the New Zealand Wheelchair Rugby Development squad. Both shooters are Paralympians. Both sailors are Paralympians, and the oldest participant is a multiple Paralympic medallist in athletics. The swimming coaches supported my own journey in high performance sport, while the wheelchair rugby coaches worked with the Wheelblacks in their preparation for the Tokyo 2020 Paralympics.

The following three tables give more information about the participants. Table 1 is an overview of the athletes and Table 2 is an overview of the officials and coaches and carers. Table 3 provides details of the classification system.

Table 1 - Study Participants: Athletes

Name	Age (years)	Sport and Classification	International Competition(s)	Impairment	Support
Zac	34	Swimming/wheelchair rugby Sport Class 2.0	Beijing 2008, London 2012, Sydney 2000, Rio 2016 Tokyo 2020, Paris 2024 Paralympics	Quadruple limb deficiency	Minimal home help, sport specific support
Ben	42	Wheelchair rugby Sport Class 0.5	Tokyo 2020 Paralympics	C5 tetraplegic	Personal cares, home help, sport specific support
Steve	67	Athletics Sport Class Javelin F52[7] Pentathlon P53	Barcelona 1992 Atlanta 1996, Sydney 2000 Athens 2004 Paralympics	C6/C7 tetraplegic	None
Rashmi	33	Shooting Sport Class SH1	Paris 2024 Paralympics	Spina bifida and rheumatoid arthritis	Personal cares, home help, sport specific support
Anne	73	Sailing Sport Class 7	London 2012 Paralympics	Syringomyelia	Home help
Hunter	52	Shooting Sport Class SH2C	Beijing 2008, London 2012, Rio 2016, Tokyo 2020 Paris 2024 Paralympics	C6/ T1 tetraplegic SH2C	Personal cares, home help, sport specific support
Jack	51	Sailing Sport Class 1	London 2012 Paralympics	Becker muscular dystrophy	Personal cares, home help, sport specific support
William	29	Wheelchair rugby Sport Class 1.0	Tokyo 2020 Paralympics	C5/C6 tetraplegic	Personal cares, home help, sport specific support

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[7] F51-57 (Limb deficiency, leg length difference, impaired muscle power or impaired range of movement). Pentathlon has been removed from Paralympics – but there is hope of revival.

Name	Age (years)	Sport and Classification	International Competition(s)	Impairment	Support
Marama	34	Wheelchair rugby Sport Class 2.0	Three World Wheelchair Rugby Championships Asia Oceania Championship Two Women's Cup Paris	Burns, and amputation, C8 spinal-cord injury	Personal cares, home help
Stella	47	Boccia Sport Class BC1-BC2	Sydney 2000 Paralympics	Cerebral Palsy	Personal cares, home help, sport specific support
Amanda	53	Swimming Sport Class S2/S3	International competition New Zealand representative	C6/C7 tetraplegic	personal cares, home help, sport specific support

Table 2 - Study Participants: Coaches, Carers and Organisational Representatives

Name	**Role**	**Organisation**
Max	Swimming coach	Evolution Aquatics
Sam	Swimming coach	Evolution Aquatics
Zane	Wheelchair rugby coach	Wheelblacks
Liam	Wheelchair rugby coach	Wheelblacks
Nikki	Wheelchair administrator	NZWR
Hannah	Diversity and Inclusion rep Wheelchair rugby official	SNZ NZWR
Anya	Athlete life advisor	HPSNZ
Suz	Wheelchair rugby carer	Wheelblacks
Layla	Wheelchair rugby carer	Wheelblacks

Classification

To provide a general understanding of the sport specific physical attributes of highly impaired athletes that are the focus of this thesis, the classification table below offers a simplified overview.

Table 3 - Disability Sport Classification

Sport	Classification System	Low Classification Athletes	Characteristics and Examples
Wheelchair Rugby	International Wheelchair Rugby Federation Classification System	0.5-1.5 for all events (based on the functional abilities of the athletes in four key areas: trunk movement, arm movement, hand function and grip)	Athletes with low classification have reduced hand and arm function, with limited grip strength that affects their ability to throw, bounce, or grasp a ball. They have limited or no trunk control. They typically play as defenders or blockers, using tactical awareness and positioning to stop the opposing team.
Swimming	World Para Swimming Classification System	S1-S3 for freestyle, backstroke and butterfly events; SB1-SB2 for breaststroke events; SM1-SM3 for individual medley events (for athletes with physical impairments)	Athletes with low classification have very limited trunk and limb function. They usually have tetraplegia, high-level paraplegia, or limb deficiencies. They rely primarily on their arms for propulsion or have minimal movement in the legs. Difficulty with head and neck control, which affects ability to breathe and maintain body position in the water.
Boccia	Boccia International Sports Federation Classification System	BC1-BC2 for individual, pair and team events (for athletes with physical impairments that affect the ability to throw a ball)	Athletes with low classification have impaired muscle control and coordination. They usually have Cerebral Palsy or other neurological conditions that cause spasticity, athetosis or ataxia which impacts ability to maintain a stable posture and execute controlled movements. BC1 athletes use a ramp to propel the ball and may have an assistant to help them.
Shooting	World Shooting Para Sport Classification System	SH1 for rifle and pistol events; SH2 for rifle events (for athletes who require a shooting stand)	Athletes with low classification usually have upper limb impairments or trunk instability that prevent them from supporting the weight of the firearm. They typically use a shooting stand to stabilize the firearm and may have an assistant to help them load or unload the firearm.
Sailing	World Sailing Functional Classification System	1-7 for all events (based on the functional abilities of the athletes in four key areas: stability, hand function, mobility and vision)	Athletes with low classification have impairments that limit their stability, hand function, mobility or vision. They may have limited upper limb function and reduced trunk and lower limb function. They typically sail in a crew and use adaptive equipment such as seats, straps, joysticks or voice-activated systems.

PNZ (2020)

Data Collection

The opening empirical chapter of this thesis is autoethnographic, focusing on my lived experience as a highly impaired athlete in high performance sport to articulate alternative ways of understanding sporting experiences. For me this was a powerful approach, as "in making sense of our experiences, we not only tell stories about our bodies, we also tell stories out of and through our bodies" (Sparkes & Smith, 2008, p. 688). As Kafer (2013) highlights, when the body is both an object and subject of study, it provides a powerful tool for enquiry.

To complement the autoethnographic component, this work incorporates a visual element. While image based research can be a distinct form of qualitative enquiry (Prosser, 1998), there is recognition of its value to disrupt the status quo, critically depicting and documenting the lives of individuals and groups, in keeping with the tenants of cripistemology (Langmann & Pick, 2018; Pink, 2011, 2013, 2015; Wagner, 2020). As such, I chose to adopt a visual approach to this study as the use of images allows us "to make statements which cannot be made by words" and these "images enlarge our consciousness" (Harper, 1998, p. 38). Photographs in this context become a powerful "instrument for change" because they are "harder 'facts'" (Carrington et al., 2007, p. 9) than written expressions, allowing an opportunity for transformation for both the researcher and the researched. The autoethnographic and visual approaches employed will be detailed later in this chapter.

Before embarking on my PhD thesis fieldwork, I reflexively engaged with my supervisors to understand how my disability and sporting background might impact my methodology, research questions, data collection and analysis. I thought deeply about the information that organisations and governing bodies need to know about highly impaired athletes' experiences of welfare and care, and this perspective shaped the interview approach. I chose to explore these stories with a semi-structured interview format as it provided flexibility to understand the world from the subject's point of view, and I was able to adjust and ask extra questions as they came up in discussion (Kvale, 2007).

Interview questions, initially informed by my personal experiences in high performance disability sport, were collaboratively developed with my supervisors. While my experiences of high performance disability sports are swimming and wheelchair rugby, the questions we designed were open enough to tap into the lived welfare and care experiences of those with different impairments, participating in different sports. The interview guide for athletes explored personal and intimate aspects of care are included in Appendix C. For carers, the interview questions shifted focus to the physical and logistical elements of care that they carried out to enable athlete participation (see Appendix D). At the coaching level, the questions centred on the participants' understanding of athlete care needs, and the tangible/measurable support provided to athletes (see Appendix E). The organisational representative questions were designed to explore how organisations understand, deliver, and prioritise care, welfare and support for highly impaired athletes (see Appendix F).

This research received ethical approval from the University of Waikato (see Appendix G). All potential participants were informed of the purpose and nature of the research via email accompanied by an Information Sheet and an Informed Consent Form (see Appendices A & B). An initial conversation was arranged to address any queries before potential participants decided to proceed. Upon confirmation, participants completed the Informed Consent Form prior to their interview. They were informed of their right to withdraw from the study up to three weeks after data collection.

This research carries a high risk of deductive disclosure, as outlined in the Participant Information Sheet. Participants were made aware of the potential for identification due to the close-knit nature of the disability sport community in Aotearoa. While every effort was made to ensure confidentiality, it was made to clear to the participants that anonymity could not be guaranteed. Existing research on deductive disclosure suggests that removing identifying factors can protect participants, but may also lead to the loss of valuable information (IRB, 2010). Although many participants were open to being identified, pseudonyms are used to protect their identities, given the personal nature of the shared information. Given the sensitive nature of the interview data, transparency was maintained regarding interview access, which was limited to myself, a transcriber, and my supervisors.

Building on the research commitments to crip methodology and pūrākau, semi-structured interviews were selected to empower participants' agency, allowing their experiences and understandings of welfare and care to shape the research narrative. As Seidman (2013) asserts, this form of open-ended qualitative interviewing offers flexibility and dynamism, creating opportunities for deeper understanding of the "lived experience of other people and the meaning they make of that experience" (p. 9). In this approach the researcher is not an impersonal data collector bound by a schedule or protocol, but the research instrument (Taylor, 2015).

I conducted semi-structured interviews with 19 participants: 10 athletes, 4 coaches, 2 carers, and 3 organisational representatives. Seventeen interviews were conducted via Zoom, and five were conducted in person. Interviews lasted between 40 minutes and 1-hour. For the participants that I did not know, the initial part of the interview focused on establishing rapport, clarifying the purpose of research, and addressing any questions before proceeding. While the first two athlete interviews began directly with the research questions, I realised after the second interview that a more informal approach would facilitate people to feel comfortable. I began the subsequent interviews with the question: “tell me about yourself and about why you love your chosen sport?” The reciprocity between the participant and myself created space to probe for clarity, meaning making and critical reflection, adding to the depth of my findings (Galletta, 2012; Taylor, 2015). To strengthen the reflexivity within my work, I documented personal reflections after each interview, using them to adjust and refine the interview process. Semi-structured interviewing was essential for my research project, allowing me to explore the unclear, uncertain and undefined elements (Ruslin, 2022) of welfare and care that currently lack definition and understanding in the literature.

One participant declined to be interviewed and requested that our email exchanges be excluded from the research. This refusal likely stemmed from my disclosure of negative personal experiences prior to the interview request, experiences that had influenced the interview questions. Additionally, as an official IPC representative, this individual was bound by a nondisclosure agreement. In retrospect, I recognise that my subjectivity overshadowed my research objectives in this instance. While the questions remained pertinent to the research, my emotional connection to the outcome prevented the interview from achieving its intended purpose. This experience highlighted the pitfall of ‘insider’ status, where I blurred boundaries, my emotional investment hindering critical inquiry (Drake, 2010), reinforcing the importance of reflexivity in the research process. Reflexivity, as Hertz (1997) states, is recognition of the “what I know” and “how I know it” requiring “an ongoing conversation about experience while simultaneously living in the moment” (p. viii) in order to produce better, less distorted research accounts.

To understand the impact of COVID-19 and the Paralympics on care provision, one wheelchair rugby athlete was interviewed twice, before and after the 2021 Tokyo Paralympics. As a result, his voice features prominently in this research. Similarly, one carer was interviewed twice for clarification. The interview period spanned 10-months. One athlete, who had not participated in high performance sport for over 20 years was ultimately excluded from the analysis due to the study's focus on current experiences. The 19 interviews were then transcribed. Given my physical limitations I transcribed six interviews myself and utilised professional transcription services for the remaining 15.

Data Analysis

As acknowledged earlier, the phenomena of disability sport is complicated, messy, and uncertain. Words like 'reliability', 'objectivity', and 'validity' only work to cage and limit the research scope. Choosing the right analysis for a multimethod approach is important because there are autoethnographic, visual, and ethnographic elements of the research. As such, I recognise that I am not only a cultural commentator, but a cultural member, and I had to find a way to step back from the data and critically question my own and my research participants' approach to life and knowledge. A crip-informed thematic analysis can foreground embodied experiences of disability, challenge dominant narratives, and highlight the intersectional power dynamics that shape disabled lives (Hickman & Serlin, 2019).

Reflexive thematic analysis, a recognised method in sport and exercise research, is well-suited to this study because it values researcher subjectivity and reflexivity (Clarke & Braun, 2021). Its flexibility allows for both inductive (data-driven) and deductive (theory-driven) analyses, and it is sensitive enough to capture both explicit and implicit, often underlying, meanings (Altheide & Johnson, 1998; Clarke & Braun, 2016; Denzin & Lincoln, 2000, 2003) embedded in experiences of welfare and care. With reflexive thematic analysis, my subjectivity was not a problem to be managed and controlled but a resource for doing analysis. Aligning with cripistemology, this approach prioritises understanding the nuances and complexities, and even contradictions, that exist within the data on disability sport rather than seeking nice, tidy explanations or a singular universal truth. In this approach my perspective as an insider is considered valuable, offering situated knowledge and insight integral to the analytical process (Clarke & Braun, 2016; Denzin, 2006, 2017; Denzin & Lincoln, 2003; Rubin & Rubin, 2012).

Guided by Clarke and Braun (2016) there are five stages to reflexive thematic analysis. Stage one involved data familiarisation through repeated readings of the transcribed interviews and, at times, re-watching the interview videos. This immersive process allowed me to experience the participants' contributions coming to life, recognising overlapping themes, patterns, and ideas within and between their lived experiences, understandings, and perspectives. The analysis followed an inductive approach, where analysis and coding themes were driven by the data content. Researchers that use thematic analysis outlined how inductive approaches are useful when exploring new terrain, as it provides an opportunity to use language and metaphors in a way that does not reinforce ableist assumptions and norms (Clarke & Braun, 2021; Denzin & Lincoln, 2000, 2003; Rubin & Rubin, 2012; Smith & Sparkes, 2006). While I sought clarification from participants regarding their contributions, a shortcoming of this project was the lack of participant involvement in data analysis.

For stage two, I initially utilised an online programme called ATLAS.ti to help me code the raw data into broad categories: athletes support each other, care, carers' experience, classification, coaches, family, gender, high performance sport, impairment effects, inclusion, organisational influence, and Paralympic experience. These broad categories had 32 subcategories, some of which overlapped. However, I found that this programme distanced me from the data, reducing my participants to mere words on a spreadsheet. To maintain a closer connection with their experiences, I returned to manual analysis, colour coding and creating thematic Word documents that brought together the athletes' narratives. Braun and Clarke (2019) stressed that "themes do not passively emerge from the data" (p. 591), but are produced by the researcher, highlighting the researcher's central role in knowledge production.

Stage three focused on collating examples of shared meaning across the data, seeking information relevant to the research questions. Stage four involved a more complex process of evaluating the viability of the analysis by comparing the identified themes to the full dataset. This phase also included reflection on the relationship between the emergent themes and existing scholarship. The themes identified were not hierarchical, nor mutually exclusive; their boundaries were often fluid and overlapping (Syed & Nelson, 2015).

Finally, stage five required further refinement of the analysis, focusing on defining and naming the themes to ensure their validity. In keeping with pūrākau, the strands of vivid and compelling data, with their overlaps and crossovers reflective of harakeke, provided a clear narrative to address my research questions (Clarke & Braun, 2016; Lee, 2008). I appreciated the flexibility of this approach because it allowed me to generate interesting and evocative ‘storytelling’, that surprises and shakes the readers from their common-sense assumptions (Denzin, 2017; Denzin & Lincoln, 2003; Ellis & Bochner, 2003; Ellis & Bochner, 2006; Tracy, 2010).

The analysis of disability sport does not occur in a vacuum. Analysis always has to be in relation to other scholarship. My story, the athletes’ stories, are not isolated stories; rather they are located in other fields of scholarship and part of a much bigger picture. Drawing on crip theory and cripistemology, this work moves beyond exposing the embodied experiences of highly impaired athletes in high performance sport to illuminate the complex power dynamics and nuanced ways in which impairment intersects with the broader social world.

As a part of my cripistemological approach I include pūrākau, Indigenous storytelling, a positive methodological approach that puts the power back into the hands of those who have been managed, controlled, and silenced. As Tuhiwai Smith (2021) asserts, “what makes ideas ‘real’ is the system of knowledge”, the formulations of culture, “and the relations of power in which these concepts are located” (p. 55).

Pūrākau: Athlete Creation Stories

Through pūrākau the narratives are written in a way so that the 10 athletes introduce themselves, recounting their origins of disability and their athletic achievements. Centering the experiences of disabled athletes in disability sport research is a political act and an opportunity for disruption (Budgeon, 2003; Shilling, 2003). Well-intentioned researchers and coaches have often spoken for and about disabled athletes, inadvertently silencing their voices (and the voices of disabled people more broadly) (e.g. Allan et al., 2019; Maher et al., 2022). Using pūrākau, the embodied accounts of the athletes’ journeys to disability sport, this chapter reclaims space for the voices of people whose bodies have been medicalised and classified (Peers, 2012b) within the sporting field that is routinely described as ‘empowering’ and liberating for disabled people (Goodwin & Peers, 2013; Hardin, 2007). Given my focus on welfare and care, it is important to centre athlete experiences, to ensure their voices are heard, prior to the ‘fleshy’ intimate analysis of their experiences of impairment effects and care detailed in the following chapters. All the athletes introduced in this chapter are either historically or currently embedded within the high performance structure, though their journeys to sport differ.

Ben

Ben got into playing wheelchair rugby two years after diving into a river in Australia in 2005. He was selected for the New Zealand Wheel Blacks team in 2009. He is recognised in the sport as one of the top players in the world for his point class (0.5). While working full-time in the health care profession Ben captained the team from 2013–2024.

When Ben first had his accident, the documentary *Murderball*[8] had just come out in Australia:

> That [documentary] gave me an insight into wheelchair rugby but also the lives of tetraplegics outside of sport. It was really helpful for me because I could see guys with my disability, and what they were doing… As soon as I saw that [documentary] I set my goals pretty high – of what I wanted to achieve with independence and with sport… I thought, 'holy shit', there's a group of guys travelling the world. They're playing a sport. They've got girlfriends, they're partying.
>
> You know what it's like when you first get into a chair, and your body shrinks away, and I've got funny little arms, and you're only a young fella, you are self-conscious… Because being active [was what I did] – fuck, before I was in a chair, I couldn't even sit down and watch a fuckin movie, I was so impatient and everything was a hundred miles an hour, surfing, snowboarding. I was always trying to do things to the extreme. I couldn't imagine that just because I'm in a chair I'd be sitting around at home doing fuck all.

His journey to disability sport was organic:

> While I was in Burwood hospital, an old low pointer[9] [wheelchair rugby player] from Canterbury would come in with a rugby ball and we'd do bunts for hours down at the

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[8] *Murderball* is a 2005 American documentary about wheelchair rugby centring on the rivalry between the Canadian and US teams building up to the 2000 for Paralympics. It was nominated for Best Documentary Feature for the Academy Awards.

[9] In wheelchair rugby, players are classified into seven classes: 0.5, 1.0, 1.5, 2.0, 2.5, 3.0, and 3.5 points. The lower the point level, the more significant the athlete's impairment and functional ability, while higher points indicate greater functional ability. Low pointers are players with 0.5, 1.0, and 1.5 classifications. For more information see: https://worldwheelchair.rugby/the-game-classifications/

> gym… then they took me down to one of the Canterbury trainings… That's how I got into the sport… I was like 'wow, I can really sink my teeth into this, and it'll get me out'. Rugby is my outlet… hopping in the chair and bashing around, is you just forget about whatever's going on, and enjoy it… I think getting involved with sports gives you that confidence to have a better-rounded life.

Zac

Zac is a Paralympic swimmer, a Wheelblack, and a husband and father of three. He is a world record holder and three-time Paralympic gold medallist in the men's individual medley 150m. He represented Aotearoa in swimming at the Beijing 2008, London 2012, Rio 2016, Tokyo 2020, and Paris 2024 Paralympics. In Tokyo he represented Aotearoa in both wheelchair rugby and swimming. He is classified S4, SB4, and SM4 as a swimmer; a 2.0 wheelchair rugby player.

Zac has quadruple limb deficiency. He started swimming when he was 11 years old and debuted for New Zealand in 2006 at the World Championships. He got involved in wheelchair rugby following a 'Have a Go Day' in 2007. He loved "the energy" of the sport and started training twice a week with the Auckland team before selection to the Wheel Blacks. Training across two sports adds to Zac's fitness and agility. While he is proud of his wins in swimming, he prefers the feeling of winning with the team – there are more people to share it with.

He shared his story:

> During mum's pregnancy no-one had a clue that I was going to turn out like I did… the social perception amongst the community towards them having a child with a disability changed massively. So, they lost friends because of me, essentially, which is a really shitty thing to have happened. But, that's a sign of the times. That's what it was like in 1990 when I was born. In 30 years, I'd like to think we've come a long way and the view of impairment is different. Growing up, for mum and dad there was no sort of booklet on how to raise a disabled child. It was a lot of trial and learning on their part. Very much just making it up as they went. I guess that creates my mentality. I try and live a very normal and active life.
>
> But the medical professionals were all very quick to dictate what my life would be like. In terms of – I would be confined to a wheelchair, I wouldn't be able to walk, and I

> wouldn’t have a meaningful life – that is the mindset that they were given from day dot around me.

Zac recounted that he ended up swimming because there were limited sporting options for him, yet, swimming provided far more than just physical activity: “In the water I had a sense of normality – of freedom and movement. When people saw me in the pool they didn’t see my disability – it was an escape”.

Fast forward a few decades and Zac has represented New Zealand at the highest level for both wheelchair rugby and swimming. Despite the successes Zac remains grounded:

> I am a strong believer that my sport does not define me. There’s a lot more to me than the swimmer or the wheelchair rugby player. But I guess I’m really big on sport because it has played a big part in shaping me – for sure, and in helping me gain self-confidence. As a little fella, having a disability and being 10-years-old and being in the pool around your peers and missing limbs and being overweight, is a really shitty experience. [But] it changed the way that I like to speak when I’m talking to younger kids, because I think we under-estimate how much that body image is so challenging for them… I acknowledge my disability and my impairment. I’m certainly not one of these people who tries to make out I’m able-bodied. I like to live as normal a life as I can, but I am disabled. I think you’re just putting your head in the sand if you say you don’t have a disability.

Zac uses sport as a political and social tool, bringing his lived experiences into coaching of other young disabled athletes, changing their perceptions, and public perceptions of what is possible in a differently abled body: “[B]ecause of the way society traditionally views people with disabilities, I went through life proving people wrong. I use that motivation now to bring change”.

Steve

Paralympian, Steve, represented Aotearoa at four Paralympic games in athletics: Barcelona 1992, Atlanta 1996, Sydney 2000, and Athens 2004, where he won a silver and a gold medal in Javelin, as well as a gold medal in Pentathlon. As well as coaching elite able-bodied basketball, he also established wheelchair rugby and basketball in Aotearoa.

Steve excels at athletics and basketball. He is a father and a grandfather and he passed on his love of sport as the Senior Sports Adviser for the Halberg Foundation[10] for more than 20 years. Prior to his injury he was a top Aotearoa basketballer who received a scholarship to play in the United States.

> I ended up going to California, on a basketball scholarship… A dream come true you know [until] I dove into the river, and the water level had changed and I bloody hit my head on the bottom.

The accident resulted in a C6/C7 spinal cord injury and tetraplegia.

> I was 21. So, yeah, no insurance, nothing. That was pretty scary shit. They were great in America. I got quite a bit of publicity because I was a Kiwi basketballer with no insurance and a broken neck and stuff. Anyway, so they looked after me really well. As I say because I was athletic, a trained athlete, I did every bit of physio, I did extra physios. I wheeled everywhere. I just pushed myself. You push yourself, and you're exhausted, and you stop – get your breath back – all your muscles sort of calm down from screaming at you, and then you go again, and then you stop and then you go again.

When he got to the spinal unit in Aotearoa, the staff wanted to help him toilet and dress, but he refused.

> I want to dress myself. I want to do it all myself. They said 'you can't… it would take me two hours to shower and dress… That's how determined I was… it was through that sort of singlemindedness that I was able to be independent… I hung out with paraplegics, and I tried to do everything they did. Someone described me as a paraplegic with quad hands… If I had wanted to, I could have been dependent. I could have lived that life but I've been strong… And so, that's how I build it up, years and years of pushing around. I played around with disability sport, threw the javelin and shotput. I did everything, you know, track and field. I sort of went hard in the coaching, and had good success.

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[10] The Halberg Foundation is a New Zealand charitable organisation dedicated to ensuring that physically disabled young people have equal opportunity to enjoy and benefit from sport and recreation. For more information see: halberg.co.nz.

Steve's unwavering determination to achieve independence, evident from his early struggles with disability, fuelled his journey to success in disability sport.

Rashmi

Rashmi was seven years old when she first learnt how to shoot while on a family camping holiday. She began shooting competitively at school when she was 15. She was born with lipomyelomeningocele, a degenerative form of spina bifida that affects her lower back and legs. She competes in the 10m Air Rifle Prone SH1[11] and the P2 Women's 10m Air Pistol SH1, representing Aotearoa in the 2024 Paris Paralympics in these events.

As her body changed in her youth, she was unable to engage in physically intensive sporting opportunities offered at school. She talked about her introduction to competitive shooting:

> I went and tried the school one [shooting team] where you do it in teams of three and the first year my team got top 20. I was like, 'Oh my gosh, I can actually do this'. It was very male dominated time back then. The mentality was, 'Oh girls can't shoot as good as guys'. And when I started shooting, they were like, 'Oh my gosh. How are you shooting that?' I'm like, 'I don't know'. And then we did a bit of competition and I was like, 'You know what, I can do this'.

Rashmi moved to Auckland to further her shooting:

> By mid-2012 I started shooting on a regular basis and started competing domestically in 2013, while I was still studying. By the end of 2014 I went to my first international competition… But because my shooting, this passion that I have for it, got so big, I was like… 'I need to see where this is going take me'.

While Rashmi was entering into the realm of high performance competitive shooting for Aotearoa, she was experiencing loss of function and increasing pain as her impairment progressed.

> For me it's a bit different because my disability I'd say is progressive. So, it's not in a stable state at the moment… My condition's changed quite a lot in the past 2, 3-years

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[11] Sport class SH1 (Pistol): Open to para-athletes with upper and/or lower limb impairment for competition in pistol events. Sport class SH1 (Rifle): Open to para-athletes with lower limb impairment for competition in rifle events. For more information see https://paralympics.org.nz/sport/para-sports/summer-games/shooting-para-sport/

> and because it’s still changing, there’s a lot of stuff that I’ve had to deal with, that I’ve never had to deal with before. Nobody at training would have known the amount of stress and pain I was dealing with… It was stressful as.

Rashmi puts her success down to the fact that “her mental game is 90% of her performance”. She talked about how shooting is an integral part of her life. She is committed and trains five to six days per week stating:

> At the end of the day, shooting is kind of like music. It’s a universal sport… I’ve been in the game for so long you think I’d get sick of it… [but] it puts me on a high. I would do this for the rest of my life! Because this is not just a little hobby, this is a passion.

Rashmi was the first female Kiwi Shooting Para sport representative for 40 years, and the first Aotearoa woman to represent her country in air pistol.

Ann

Ann has a degenerative spinal cord condition, syringomyelia, meaning she has lost the use of her legs. After 18 months of being in “shocking pain”, and sleeping on the floor to keep her back flat on a hard surface, her condition was diagnosed. She underwent several spinal surgeries to put a shunt in because the spinal fluid was leaking into a cyst that was pressing on nerves, causing loss of function and sensation on her right side. While she was in rehabilitation, she tried out a sailing simulator in order to regain upper body strength, and this sparked the beginning of Anne’s Paralympic journey.

> The course that you had to do was three minutes, I was still there 13 minutes later. I was sailing this boat through sand dunes, lighthouses, Sydney Harbour Bridge (laughter). I had no idea which way I was going or anything. I was so embarrassed.

She practised until she was able to navigate the course. From the simulator she went straight into a boat. “I had no idea that they wanted a female to sail with Jack, who was my co-sailor at the [London Paralympic] games”.

> In the boat that we were sailing, called a Skud, you had to have two females or one male, one female and you had to have someone who is most disabled and someone who is least disabled. Our classification was ranked one to seven. I was a seven and

> Jack was a one. He has Becker Muscular Dystrophy[12] and his arms don't have the strength to do the sails. I was at the front and they used to call us 'The Grunt in the Front.' When the women joined forces with men, we weren't called 'grunts' we were called the other word that rhymed.

After only three months of training, she was competing internationally:

> I was sitting in the boat the first time we went out and I thought, 'Here I am in the Netherlands, and I've never been here before, never been in a bloody regatta' and that movie was in the back of my mind, '*Cool Runnings*'.[13] I said to Jack, 'I hope we don't go back [looking like] a bunch of idiots'. He said, 'Just do what your body tells you to do and what your coach tells you to do, you'll be fine'.

Ann loves the opportunities that sport has given her saying; "Bugger it, I'm only going to be here once and all these wonderful opportunities, I might as well take advantage of it". Ann noted why sailing was good for her: "I'm in chronic pain but you're concentrating so much and if you're having a nice day out in the fresh air… because of the endorphins and the adrenaline rush, I don't feel any pain". The New Zealand team came sixth "by the skin of our teeth[14] and qualified for the 2012 London Paralympic games. They competed in the two-person keelboat event. Anne has also had national success in para archery and shooting.

Hunter

Hunter is passionate about shooting and is motivated by raising the profile of the sport and passing on his knowledge. He is a C6/T1 tetraplegic classified as SH2.[15] Injured in a motor accident when he was 22 years old, he started shooting in 2001.

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[12] Becker muscular dystrophy is a degenerative disease that results in progressive muscle weakening.

[13] *Cool Runnings*, is a 1993 comedy film loosely inspired by the Jamaican national bobsled team's remarkable debut in the 1988 Winter Olympics held in Calgary, Canada. Due to an absence of snow, the bobsled team trained downhill on the bobsled with wheels. See: https://en.wikipedia.org/wiki/Cool_Runnings

[14] 'Skin of our teeth' is used to describe a situation from which one has barely managed with gait or achieve something. See: https://en.wikipedia.org/wiki/Skin_of_my_teeth

[15] This Paralympic shooting sport class is for shooters with severe impairment in the upper limbs. These athletes use a shooting stand when they compete. Unlike the more functional SH1 class, SH2 participants shoot with a rifle only and not with pistols.

> I came across a brochure; I think it was at Parafed Auckland[16] for a shooting club in Ardmore. I went along there but things weren't accessible. The benches were really high and they didn't have ramps, they had steps and stuff. But they had a positive attitude. They were like, 'Oh yeah, you wanna shoot? We'll work it out'. And they basically stuck some bricks down and a big wooden board, lifted me on top and they grabbed the BBQ table and just said, 'Here, lean on this'. First, I was thinking, 'Wow, you're giving guns to disabled people? And I'm on this rickety, wobbly thing. This is nuts. Great!' And we started from there.
>
> I'd just been going along, plinking[17] away. And they said: 'Do you want to join this competition?' I was like, 'Yeah, why not?'… And it just sent me down this rabbit hole… I've tried to get better and better and better… But the great thing about shooting was that all the able-bodied shooters were really inclusive. So, you were competing against all the ABs[18] at the time as well, which was quite cool. And everyone just shot together and that's what I liked about the sport… There weren't many disabled shooters… And then in 2003 I went to my first international competition.

In the 2004 Athens Paralympics, Hunter won gold, and followed up with back-to-back bronze medals in Beijing 2008 and London 2012 Paralympic games. Hunter claimed world titles in 2006, 2010, 2014, and 2019. He competed his sixth Paralympic games in Paris 2024. What he loves about shooting is that it is one of the few sports in which disabled athletes compete with able-bodied athletes. While Hunter is still focused on competing, he also passes on his love of shooting through coaching: "I don't hide any secrets and pass on my knowledge freely".

Jack

Jack's passion has always been sailing. Throughout his life he competed in able-bodied competitions until his loss of strength brought on by Becker Muscular Dystrophy made sailing

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[16] Parafed organisations across Aotearoa are regional, not-for-profit entities dedicated to promoting and providing sport and recreation opportunities for individuals with physical disabilities. They offer programs ranging from grassroots participation to pathways leading to elite competition, including the Paralympics. Services typically include adaptive equipment provision, coaching, advocacy, and community sport initiatives.

[17] The sound that the air rifle pellet makes when it hits a metal target.

[18] The acronym AB stands for able-bodied participants.

at this level impossible. Fortunately, it was not the end of his sailing career, as his impairment made him eligible for para sailing.

> Six months out [from the World Champs in Holland] I didn’t even have a crew. We put feelers out everywhere looking for crew, and that’s when Anne stuck her hand up and came out for a sail… Anne was the first female in sailing. And we were the first two-person combo. The first time we went out it was like we were in 25 knots which is pretty windy… But we trained solidly for 4-months before we went.

Prior to the Campaign Jack’s disability worsened:

> The only positive thing about having a progressive condition is that I moved [classification] from a three to a two and later to a one, and I’d have been quite happy to stop at two.

While a lowered classification allows for stronger partners or players there is an unforeseen emotional toll. But Jack still loved sailing.

> Sailing is awesome because there’s nothing else on your mind. You’re not thinking about what’s happening at home. You don’t think about the bills you have to pay, or any of that stuff. Everything else goes out of your mind. And you’re just totally focused on that one goal of doing the best that you can, getting your boat going as fast as you can. I really enjoyed the two-person aspect of it, because you have to really tune into each other, you rely on each other the entire time. Both parts of the team are equally as important as the other part. It's just getting to know someone to that level… It can be quite an intense relationship.

Competitive sailing exemplifies remarkable teamwork between the sailors and their vessel. Every sail adjustment and weight shift is a synchronised dance, highlighting the profound understanding and synergy between Anne and Jack.

> After the Worlds in Holland, we ended up with a reputation of being heavy-weather sailors, because that’s what we got used to in New Zealand. The top six automatically qualified and we were kind of right on the sixth/seventh around that spot… Then on the second to last day, it just blew like nothing else; the wind came up… We managed to hold on and finish in second place… That cemented our qualification spot.

Paralympic sailing was dropped in 2020; however, conversations are ongoing about its reinstatement. Jack, while no longer competing, shares his family's passion for sailing and remains actively involved in the development of adaptive sailing initiatives across Aotearoa.

William

William was injured at 21-years-old in his second year of university in a "stunt gone wrong" diving off a roof into a pool, resulting in a C5/C6 spinal cord injury. It was a tough start for him as he spent 3-months in intensive care "on a ventilator because he got pneumonia in hospital".

> It was an incredibly dark time for me… By the time I got out [of hospital and into the spinal unit] all my friends had left Christchurch. They were all uni students. [Before they left for the uni break in October] my friends came and saw me, but I couldn't talk back to them because I had a ventilator in my throat… It was a dark summer. But I knew that the only way I would sort it was to have something I could work towards.

At the spinal unit one of the life coaches who had represented New Zealand in wheelchair rugby at four Paralympic games introduced William to the sport that would play a key part in shaping his future.

> He got Wheelblacks low pointer,[19] to bring along his rugby chair… So I jumped in. It was the coolest thing ever! It was so much more mobile than a manual chair – I was like oh my gosh I can actually move a chair.
>
> Soon as I started out, I felt like I was so slow and couldn't contribute to the game. [I] thought I was gonna be like that for ever. But I got lots of encouragement, and kept coming along and built up some of the strength that I'd lost. I ended up really enjoying the game and it's something that I've been pursuing with all of my energy three years solidly. I want to make the Wheelblacks team, travelling away and playing at a high level for the foreseeable future.
>
> Having the sport there as a motivator, is definitely a huge mental health pillar, as well as a physical one… I attribute a lot of my life balance and mental health to it. I know I would be a different person without it. But one of the most important things I think

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[19] Low functioning wheelchair rugby player.

> wheelchair rugby has helped me with is meeting all those people in similar situations who have been in through what I have been through and who pass on invaluable life skills that would have taken me 10+ years to figure out. But just hearing it directly from guys, like Ben, his level of injury is higher than me, so he is more disabled than me, but he is so independent and functional. I have learnt so much off him.

Three years after his accident, William was part of the Wheelblacks team that competed in the 2019 Asia Oceania Wheelchair Rugby Championships in which they placed third qualifying them for Paralympics. He made his Paralympic debut at the Tokyo 2020 Paralympic games – the first Wheelblacks side to reach Paralympics since 2008. He is a low pointer with a 1.0 functional classification.

Marama

“I was 18 months old I was severely burned in a car fire”. The severity of injuries caused major complications, including the amputation of one of her legs and a spinal infection which left her paralysed.

> I came from a really sporty family, but I lived in a really small town, I don’t think there were any other people in a wheelchair. At a Parafed ‘have a go day’ I tried wheelchair basketball, I really liked it and started playing for the Bay of Plenty. I used to travel [two or three hours] for trainings – then I made the New Zealand basketball team. I was only 13, and I was in the under 19 New Zealand basketball team.

To support her sport, Marama moved to Auckland. At the gym, wheelchair rugby was scheduled after basketball and Marama was spotted by the team: “we watched you play basketball and think you would qualify, would you be keen to give it a go? And I was like I don’t know. It looks pretty scary, and I haven’t seen any women”. But she gave them her details: “they kept emailing me every week telling me when the trainings were – asking me to come”. Although Marama struggled with self-doubt, she had the support of her caregiver and friend Tash who talked her into attending, “the boys were so happy that I finally made it there. It was really fun, and I liked it a lot, but I wouldn’t go without Tash. I made her come with me for 6-months, because I was too scared to go by myself”. After 6-months of training with the Auckland team:

> I got invited to one of the Wheel Black training camps and then that made me more nervous and scared again, because that's another level, and I'm just a newbie, it's too hard, I'm not fit, I'm not good enough – saying all of those things that I do… But my involvement in wheelchair rugby has been a way to grow my confidence. Now I'm just one of the boys… The boys never take it easy on me, and I don't take it easy on them… I love that they've never treated me differently because I'm a girl.

She wants more women to join wheelchair rugby: "Just give it a go. It's so much fun and [we] give the boys a serious run for their money. There were hardly any [women] when I started playing. Now there's another female on board now… and it's making our team stronger".

Marama has a (2) functional classification. She represented New Zealand in the 2019 Asia Oceania Wheelchair Rugby Championships qualifying them for Paralympics. But a severe infection in 2021 led to a hemipelvectomy, which meant the amputation of half of her pelvis and her whole right leg. This wahine toa (strong woman) is on the mend, and she was selected for the Wheelchair Rugby World Champs in October 2022 in Denmark, and has not looked back. "The Paralympics has been my goal since I started with the Wheel Blacks. And I still haven't made it, so I've got to carry on until I achieve my goal. I'm not stopping until I achieve my goal".

Stella

Stella, a Paralympic boccia player, and New Zealand Development wheelchair rugby was born with Cerebral Palsy (CP).

> When I was born doctors said to mum and dad that I would not walk, talk, or have any intelligence whatsoever. They recommended that I was sent to an institution, that way mum and dad could get on with the rest of their lives in peace. Thank God, my parents did not listen to them. To them, I was their baby girl – I was perfect and so loved.

She was denied entry into the local primary school on the basis of her impairment and her family had to fight for her enrolment. Stella's family were passionate about sport: "but it was still quite tricky to find a sport that I could participate in". Stella's dad heard about a sport called Boccia[20] and went to the world champs in Australia as a spectator. Stella recounted his experience at the competition:

> Dad thought it was only for rampies.[21] [Then] he saw someone who reminded him of me. And he thought, ‘oh Stella could play this’, and came home, and was like – ‘you need to get into this.’ And I did and I loved it, and I was good at it. It was finally, after years of coming last at everything at school, it was the first time I was sort of any good at sport. It was a really powerful experience because it taught me that I was – I did have ability, and I could compete at a high level.

In a world saturated with ableism, Stella discovered both enjoyment and proficiency in boccia – a significant boost to her self-confidence.

> I trained and worked hard and represented New Zealand at the Sydney Olympics. [Involvement in sport] changed the direction of life, my career, and my desire to reach my goals… you’ve gotta work hard to get to where you want to go, so that taught me don’t quit, don’t give up. I think as a disabled person that doesn’t get instilled in you in other areas. Because it’s well done, aren’t you a good person for turning up and tying your shoelaces. Where sport is like; nah nah if you are shit, get out!... I then carried that into my degree and then I went into a sport career.

Stella said she would do things differently if she had another chance:

> I’d get in people’s faces a bit more… and make people think that [boccia] isn’t just for ‘*those*’ people – we can play it too – anyone can play boccia… It’s a truly inclusive game (emphasis in the original).

Stella’s success in boccia blurred a lifetime of negative perceptions of her disability.

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[20] Boccia is a precision ball sport similar to pétanque or bowls played by people with severe impairments. Boccia demands a high level of muscle control, concentration, accuracy, precision, and tactical thinking. Played on a small indoor court, the objective is to propel leather balls as close as possible to a designated white target ball. All participants use wheelchairs and employ various techniques to deliver their balls.

[21] Some athletes utilise a ramp (rampies) and the assistance of a sport assistant, while others propel the balls independently.

Summary

This chapter has presented the methodological framework underpinning my research into the lived and embodied experiences of welfare and care of highly impaired athletes in high performance disability sport. Contributing to understandings of crip methodology, grounded in cripistemology, this research engages a powerful qualitative approach combining autoethnography, visual ethnography, pūrākau, and semi-structured interviews to explore and articulate the embodied experiences of highly impaired athletes and those who support them in high performance sport. When the athletes tell stories about their disabilities, they give voice to the body and they make the body familiar, not only to the reader, but to themselves (Frank, 2011). As Sparkes and Smith (2005) aptly summarised:

> [t]he stories we are told, and the stories we learn to tell about ourselves and our bodies, are important in terms of how we come to impose order on our embodied experiences and make sense of events and actions in our lives (p. 261).

Impairment is experienced not only in, on, and through the body, but its meaning and outcomes are grounded in personal and cultural narratives, and created in particular places (Frank, 2011; Hughes & Paterson, 1997; Peers, 2012b; Smith & Perrier, 2014). Thus, the intricate interplay between embodiment, identity, and disability sports underscores the importance of delving into athletes' real-life encounters and perspectives (McKay, 2022). As Peers (2012a) stated, stories are all that we are.

Cripistemology, with its focus on situated knowledge, methodological flexibility, and the disruption of normative assumptions, aligns with Clarke and Braun (2021)'s thematic analysis by offering a critical, reflexive approach to coding and interpretation. A crip-informed thematic analysis can foreground embodied experiences of disability, challenge dominant narratives, and highlight the intersectional power dynamics that shape disabled lives.

Thus, the use of crip methodology and cripistemology in this research is a political act, reclaiming the narrative and challenging knowledge production in disability sport. In centring the research on the lived experiences of highly impaired athletes, traditional ableist research paradigms are disrupted, highlighting the need for a more inclusive and empowering research processes. Embodying the famous catchphrase, "nothing about us without us", this crip intervention disrupts ableist norms, advocating for a shift in power dynamics and a more just representation of disability in sport (Charlton, 1998).

The following chapters detail the embodied experiences of welfare and care of athletes participating in high performance disability sport. The first chapter highlights my experiences of high performance sport. The second chapter exposes the messy, gritty embodied experiences of impairment effects, and the impact on athletes, carers, and coaches. The third chapter brings to light the cost of broader structural and institutional ideologies, approaches, and funding on highly impaired athlete’s performance pathways. The final chapter concludes with a summary of the research findings.

Chapter Four: Cripping Care in Disability Sport

This chapter marks the beginning of the thesis's spatial and analytical arc, grounding the research in my own embodied experience as a highly impaired athlete navigating the intensive, often invisible, labour of care required just to access the starting blocks of high-performance sport. In this chapter I offer a personal, self-reflexive autoethnography, in rich narrative form, in the hope that readers can connect with my embodied experience of training for the Paralympics. The autoethnographic account, taken from my training journals, is an embodied and lived account of the processes of care for elite, highly impaired athletes. The narrative is contextualised with data from interviews with my coaches, and other coaches of disability sport, as well as my training journal.

Throughout, I draw on Thomas's (1999) 'social relational' definition of disability as an analytical tool, allowing me to tease out and examine the gritty emotional, physical, messy lived experiences between myself and my family carers and coaches (Smith & Perrier, 2014). While physical impairment effects are unique to each disabled athlete and directly impact how that person engages in the world, often unnoticed are the psycho-emotional effects of disability. Importantly, the disabled body is more than just hat one may become" (Smith & Perrier, 2014, p. 102). Thus, with cripistemology as my lens, I examine the 'realness' of having an impaired body in sport. To that end, what follows are three autoethnographic narratives: two are drawn from my journal, and one is presented through a raw visual ethnography, storying a 'day in the life' of a high performance, highly impaired athlete. These contributions are reflexively considered in relation to the existing gaps in disability sport literature to provide insight into high performance sport and the enactment of both physical care and coaches' responsibility to engender a duty of care. As detailed by Cronin and Armour (2019b) and Rhind et al. (2015) a duty of care is considered a fundamental aspect of coaching practice where coaches deliver athlete development in a safe, supportive, and respectful environment that prioritises athlete physical and emotional well-being/welfare. Extending understandings embedded in 'duty of care', the coaching data serve to 'locate' the narratives in the real world, bringing to light the social relational barriers that highly impaired athletes must contend with to compete in high performance disability sport. Grounded on personal experience, I offer my story as a purposeful critique of normative culture practices and offer a powerful contribution to existing research. The photographs capture me at my most vulnerable, intentionally crafted to deepen the reach of autoethnography and foster a reciprocal connection with the reader (Holman Jones et al., 2013; Pink, 2015). Drawing inspiration from other disability sport scholars, such as Peers (2012), Berger (2009), Howe (2009), I weave personal narrative with critical theory, articulating lived experience, which I then explore, explain, and interrogate. This approach allows reflections from my standpoint to be intertwined with relevant literature in order to interrogate how care practices are theorised, understood, and enacted in the context of disability sport.

This chapter is divided into six sections. Section one Cripping Care situates the chapter. Section two introduces the first vignette, 'The Illusion of Time', which documents and visually captures my experiences of crip time. Section three explores my experiences with coaches in Cripping Care and Coaching. The section leads into the second two vignettes, 'Tokyo Looming' and 'Now or Never', that provide insight to my preparations as a member of the New Zealand Paralympic Development Squad, aiming for Tokyo 2021. With these vignettes, I tease out the tensions of what it takes to get highly impaired body to a high performance space, and what it feels like to be there with regard to the emotional and physical labour. This section draws primarily from Duffy et al. (2013), Stacey et al. (2015), and Hochschild (1983, 2012), bringing a critical perspective on labour, emotion, and embodiment in caregiving professions into the sporting arena. This section includes a visual narrative that lays bare the intimate, embodied experience of care. The chapter finishes with a brief Summary outlining implications and conclusions.

Cripping Care

Before turning to the vignettes, it is important to situate this discussion within the broader cultural and institutional narratives that frame high performance disability sport—particularly the ways in which dominant ideals of independence, resilience, and able-bodiedness obscure the realities of care for highly impaired athletes. As (Lowry et al., 2022) have argued, in high performance disability sport, "the provision and arrangement of care is often based on a view of the disabled athlete as high functioning [read able bodied]" (p. 2), in contexts that are outcome-driven, highly-pressured and built on often masculine ideals and expectations of athlete independence, resilience and autonomy. This is reflected in the proliferation of 'supercrip' narratives; stereotypical representations of disability that focus on the idea that it is possible to 'fight' disability – through determination and willpower – to overcome and achieve unlikely success in ways that are ‘inspiring’ to a non-disabled audience (Schalk, 2016; Silva & Howe, 2012). As such, high performance disability sport can reinforce the distinction between ‘supercrip’ bodies versus highly impaired bodies (Apelmo, 2012). For highly impaired athletes, little is known about the types and patterns of support required to compete and perform at this level. This raises questions about the visibility and representation of disabled people in research, as well as the extent to which organisations, coaches, and practitioners are well-placed to enact care and protect athlete welfare in high performance disability sport. Thus, heightened awareness of the need for care is complicated by the lack of insight into the interpersonal relations and structural conditions that shape care practices in the context of disability sport.

The Illusion of Time Through Story and Imagery

> I open my eyes. I lie on my side. I hear my partner Gemma stir as she wakes behind me. She removes the bolster that keeps me in the same position overnight, and the pillow between my knees and rolls me on my back. My body protests, my muscles all tight, it shakes and spasms, sometimes my knees bounce to my chest. It is hard to breathe. When I am still, she lies in the crook of my arm for a moment. It’s our only moment during the night when I know we touch. It is hard to connect when you can’t feel. We are body to body, but I can only feel her on my shoulder. We rest and cuddle for a moment. She looks at the clock. It is 7.05; I’ve got to be at the pool to meet the support worker at 7.30. She jumps off the bed, and disconnects my night bag[22] on the way to grabbing my togs and morning drugs.
>
> She pulls off the covers and begins my stretching regime (see Fig. 3). A short series of yoga postures that make sure that my hamstrings don’t shorten over time, my ankles and achilles still have a range of motion required to sit flat on the footplate and so my hips don’t atrophy. She removes my pyjama bottoms and begins to inch the togs up my body. She rolls me a couple of times to get them to my waist. She puts me into cross-legged position, and hauls my upper body forward so I am lying on my legs. The stretch feels lovely and I could stay here all day. It is over too fast as she removes my

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[22] I have a suprapubic catheter – a hollow flexible tube that goes directly into my bladder to drain urine. It is inserted into the bladder through a cut in my belly just below the navel. Overnight the urine collects in a large bag or bottle. During the day the urine collects into a leg bag that is emptied regularly.

sleeping t-shirt. She pulls the togs up and over my boobs and shoulders. She puts the binder behind my back – I lie back on it – she does it up tight around my belly. I feel my breath strengthen, my blood pressure rising with the pressure from the tight elastic – I'm ready to go. She brings the wheelchair over to the edge of the bed while swinging my legs over the edge. I push myself up into sitting position, placing one hand on the seat of the wheelchair while she gets a handful of my togs. On three, I 'pop' into the chair. My left hip is down; she puts pressure on my right hip while pulling up on my left so that I am balanced. I choose a t-shirt from the chair – she slips it over my head.

Figure 3 - Stretching Routine Begins. Posture One- 7 a.m.

Figure 4 - Posture Two Glute Stretch

Figure 5 – Forward Bend

Figure 6 - Feet Articulation

Figure 7 - Swimming Costume On

Figure 8 - Attaching Binder

Figure 9 - Transferring to Wheelchair 7.15 a.m.

Gemma's moving quickly around our house. I head into the bathroom to adjust my bed hair while she opens the van and puts my swim bag in. I roll to the table as she gathers my vitamins and gives them to me with a shot of lemon juice and hot water. I

> knock them back. I roll over to her and reach up for a hug, tell her to have a good day, and to cuddle the kids from me. When I'm training, I don't see them in the morning – every day I have to choose.

This account and images provide insight into the everyday, domestic reality of life in a highly impaired body, revealing the emotional and logistical complexity rarely visible in sporting narratives. It brings to light the deeply embodied and relational work of familial care: the tenderness of shared touch, the coordination of medication, continence, discomfort, mobility, and love. These intimate acts unfold under the never-ending demands of care time (Stevens, 2018), as nonnormative bodies resist the tyranny of the clock (Kafer, 2013). This is the emotional labour of disability (Bondi, 2008): the grief of disconnection, the quiet intimacy of touch without sensation, the unspoken intensity of beginning each day negotiating bodily resistance.

> It is 7:22. I'm late. I hurry to the van. The hoist platform whirrs as I slowly get lifted into the car – I wish it went faster. I push forward into the driver's position and my chair locks into a metal bracket bolted to the floor. I lean forward and hold two buttons on the dashboard that close the door and bring the backrest into place. The door shudders and closes slowly with a clunk. I clumsily search for the two Velcro straps hanging off the side of the backrest, wrapping them tightly around my belly to hold me upright when I drive. I click the seatbelt into place; finally ready to move – start the car and head off to the pool.
>
> I meet my support worker Cherie in the car park at 7:28. She grabs my swim bag while I exit the car. While I put on my push mitts, she closes the van. We roll down to the pool and I zoom ahead down the steep path and into the door at the bottom to open it. The lifeguards greet us with a smile. We head to the far side of the pool to the hoist. We don't need to talk; the transfer is like a well-timed dance. In this moment, my

support workers[23] are an extension of my body; a necessary evil for me to live the kind of life I want to live. My independence is dependent on them.

Cherie puts the hoist seat in place ready for me to transfer. I park my wheelchair beside it and she removes my t-shirt and jewellery. She crouches down in front of me holding my chair firmly as I inch myself as far forward on my seat as possible, till my head rests on her shoulder for balance and support. She pushes my shoulders back so I can sit upright. I am perched on the edge of my seat, putting her feet between my feet – I lean all my weight forward so that my shoulder rests on her thigh. Putting her hands under my sit bones. On three we pivot to the hoist seat. I catch another swimmer's eye, they are staring, mouth slightly open – I know that they have never seen anyone like me get into a pool before. They quickly look away.

Figure 10 - Transferring to Pool Hoist 7.35 a.m

Cherie assists me to put on my cap, goggles, and nose clip. I push the button on the hoist controller and raise into the air over the edge of the pool. She spins the chair

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[23] In the 12-years since my injury, my support workers have all been women aged between 30 and 50 years, with limited exposure to formal training. Support work is precarious; there is no job security and care agencies generally provide no training. On my team I have three support workers and my partner Gemma.

around, and lifts my legs over the edge so I am facing the water and lowers it down. It is 7:45, I tell her to come back in an hour. I flop in face first. No one is touching me! There is no wheelchair. No one can tell how busted I am – in the water I am strong and free. I warm up my body, stretching out, doing slow double arm backstroke down the pool. Concentrating on my breath, feeling the spasm and noise in my body turning down. I swim about 10 lengths until I see my coach standing near the edge of the pool. I stop swimming – pulling myself up onto the edge. While my coach and I have a chat, I get him to tighten my goggles. He hands them back and gives me direction for the session.

Figure 11 - Swimming Cap On

Figure 12 - Hoisting into the Pool

Even though carers are an integral part of many disabled peoples' lives, care work is stigmatised by society because of the association with the feminine attributes of nurturance and emotion in contrast to the capitalist masculine values of competition, individualism, and rationality (Duffy et al., 2013; England & Dyck, 2011). As such, there is little recognition of a job that is emotionally and physically demanding and offers few material rewards (Wolkowitz, 2006). Boddy et al. (2006) extend this argument when they discuss how care work is understood as work to which women are best suited on the basis of domestic skills and innate qualities that women 'naturally' know how to do. While care work is highly skilled as highlighted in Hochschild's (1983, 2012) research on emotional labour, what is missing in these investigations is the recognition of the relational nature of care work from the perspective of disabled athletes and their support networks (Katzman et al., 2020). As detailed in the narrative, emotional labour is undertaken by both parties in the caring relationship. It is multidimensional and requires the ability to think holistically, be prepared for complexity, to listen, communicate, reflect, and make appropriate judgements (Hochschild, 1983, 2012).

Figure 13 - Finally Free 7.45 a.m.

Cherie arrives back at 8.45. We repeat the process getting out of the pool and into my wheelchair. She dries my body and my hair, puts on my binder and my t-shirt. And we roll out of the pool.

Figure 14 - Hoisting out of the Pool 8.45 a.m.

Figure 15 - Drying Off

Figure 16 - Adding Layers 8.55 a.m.

She pushes me up the steep hill and we head to the van. I open up and roll in and we both head home. I roll through my front door. Thankfully, it is not a toilet and shower day (which would be another hour of hands-on care), so I park next to the bed and she peels down my togs and we dress my upper body.

Figure 17 - Dressing Begins 9.15 a.m

Figure 18 - Reapplying Binder

While she is doing this, we chat about meal prep and my schedule for the day. I transfer to the bed, and she washes, dries, and dresses my lower body.

Figure 19 - Shoelaces Tied 9.40 a.m.

> After, she helps me transfer back to the chair and hook up my drainage bag that is hidden under my chair. I clean my teeth and tidy up my hair. 10 a.m. Now it's time for breakfast.

The narrative and photographic diary together highlight the mundane and monotonous nature of daily care, revealing a nuanced and critical consideration of time. It illustrates exactly how long things can take, the touch points, the barriers, the invasion of the personal self and other boundaries. From waking and getting dressed through, to training at the pool, time is a commodity that rapidly diminishes through the everyday 'care' routines that I require. While 'clock time' is fundamental to the organisation of disability sport environments, these data are illustrative of the concept of 'crip time' (c.f., Kafer, 2013). Crip time is a relational phenomenon that only occurs because non-normative bodies are interacting with social worlds built on a particular version of normalcy (Kafer, 2013). If we think about time, we begin to understand able-bodied privilege as an "energy saving device" it becomes a useful tool for thinking about impairment effects; "we are saved from knowing what we are saved from doing" (Ahmed, 2017, p. 182). Crip time requires a rethinking of our understandings about what can and should happen in time, and recognising how “expectations of ‘how long things take’ are based on very particular minds and bodies” (Kafer, 2013, p. 27).

Kafer (2013) highlighted how the flexibility of crip time accommodates those who need more time but challenges normative assumptions of pace and scheduling. Katzman et al., (2020), added to this understanding outlining how crip time reflects lived experience in bodies that are unpredictable and at times defiant, illuminating the “added layer of unpredictability that is a reality of many ‘crip’ lives” (p. 522). In a crip world ‘the time that things take’ is dependent on many different factors that do not need consideration in an ‘abled body’. Crip bodies are impacted and mediated not only by body rhythms, but physical and social environments, people and technology. It is these factors that determine the pace of everyday life (Katzman et al., 2020). Indeed, as Kafer (2013) argues, “rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (p. 27).

Building on the idea of crip time, in competitive swimming, those with more severe impairments may take more time and space for participation, therefore, are seen as challenging to accommodate and potentially disruptive to other participants (Hammond et al., 2019). Highly impaired athletes disrupt the normative narratives of what bodies are supposed to be able to do and how they are expected to behave, challenging definitions of high performance athlete (Jonsson, 2017) and the knowledge-practices/routines inherent in such structures.

Cripping Care and Coaches

As one of the main participants throughout para-athletes’ career trajectories, parasport coaches are pivotal to athlete well-being, shaping their experiences throughout their careers. Coaches, therefore, bear a particular responsibility for athlete welfare (Cottrell, 2018; Lang, 2020). The swimming coaches interviewed for this project primarily worked with able-bodied athletes, and the shift to coaching highly impaired athletes was not easy, “as all the ground rules… the basic fundamentals don’t apply” (Max). My first swimming coach noted the difficulties that he had trying to coach an S2 swimmer, which I was able to capture through my training diary:

> Our first training made him the most experienced S2 coach in Aotearoa, not because he knows what he’s doing, because there are no others. He finished our third session suggesting that I work on getting myself out of the pool, ‘by lifting my butt up onto the edge’. He has no concept of my impairment. Why has he not done any homework? (Amanda)

As an attempt to help him understand so that he would be able to work effectively with me I sent him the following email to explain my physical reality.

> **From:** Amanda
>
> **Date:** 11 February 2018 at 4:59:31 PM NZDT
>
> **To:** Coach
>
> **Subject: Tetraplegic function c6/7**
>
> Hey Max,
>
> I think you need to have a good understanding of my level of function. The image below shows you exactly what a C6/7 injury entails. 86% of me does not work. The 14% I do have is from armpit to armpit and those few muscles are all I have. I have an upper band of chest muscle; my lats are only functional from the top (effectively they are cut in 1/2). Triceps are C8... which is below my level of injury therefore my triceps are only partially functional. I breathe only with my diaphragm. I cannot lift myself out of the pool... nor rotate myself to sit... as I have no stomach or back muscles. I cannot cough or sneeze. If I take on water, I will need manual assistance to expel... effectively a Heimlich manoeuvre. I hope this gives you more insight into my reality. I realise I look capable and strong but being in this body is pretty tough, and I have worked really hard to be as functional as I am. I need to make sure we are all on the same page. Let me know when we are catching up again.
>
> Thanks Amanda.

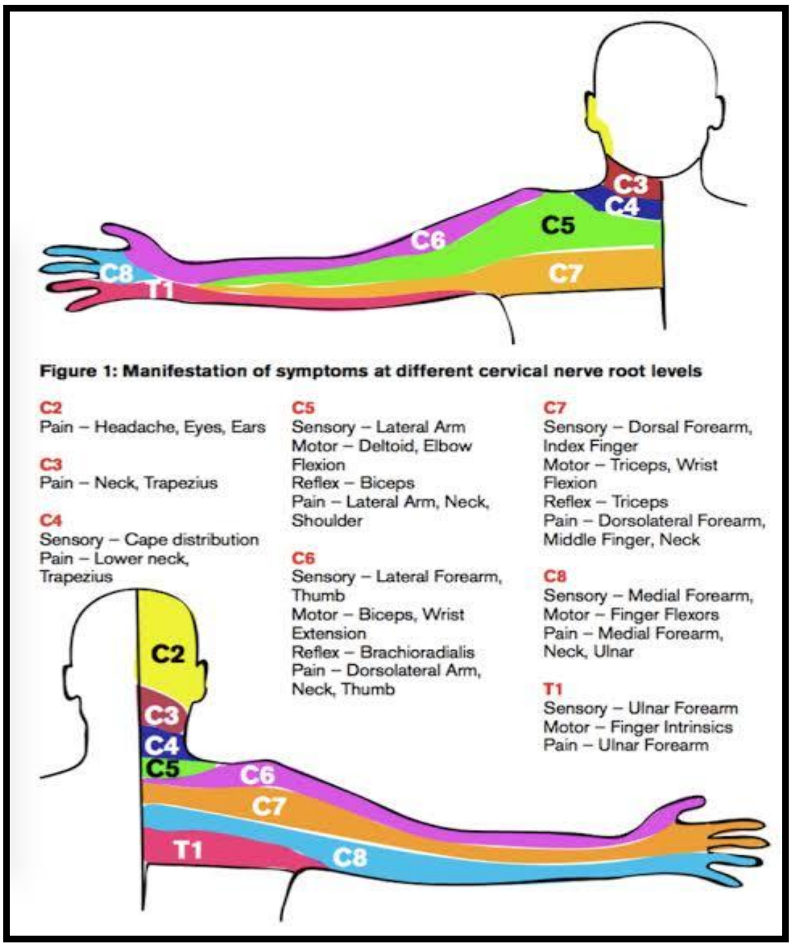

Figure 20 - Cervical Radiculopathy

Source: Kobayashi et al. (2016)

In sport, the notion of care often sits outside the remit of coaching, despite the centrality of coaches to high performance disability sport, and is further complicated by the presence of disability. The normative ideologies underpinning disability sport (Goodley & Runswick-Cole, 2013; Townsend, Huntley, et al., 2018) were brought to light when my coach, Max, reached out to PNZ for support. The response from a PNZ swimming coach was, “I have no idea, I’ve never coached anyone like that, good luck!” (Max). The coach’s response illuminates the stereotypes and misconceptions about the abilities of disabled athletes, and how coaches lack the training and expertise to effectively include these athletes in their programmes (Hammond et al., 2019). Max details the difficulty he faces coaching a minority in a minority group, “there are so few S2, S3 swimmers… Resource wise, there’s no manual to go to, I can’t just go and read. That was a major difficulty, a lack of resources for me as a coach and no one in New Zealand has any idea… We’re forging new ground, no one’s done it before, coaches are learning, PNZ are learning, everybody is learning”.

After a year and half of coaching me, Max only came to understand the breadth and depth of care I required to participate when we went on a Paralympic development camp in Christchurch. In the camp we tried to do two sessions a day. I asked him:

> Do you have any idea of what it takes for me to get into the pool in the morning?
>
> Max: You spend all of your focusing either getting ready or getting unready afterwards and there’s no real recovery time afterwards. Why would you choose to be a swimmer? It is just so difficult compared to most other sports. You should go play wheelchair rugby – it’s shit loads easier. (Max)

This quote can be analysed in two ways. Perhaps Max identified the physical and systemic barriers I face as a highly impaired swimmer attempting to navigate a sport designed for abled bodies. Consequently, it made sense for him to suggest wheelchair rugby – a sport designed for tetraplegics. Alternatively, it might allude to the difficulty he encountered trying to coach a swimmer with my level of impairment, or even a combination of both. However, it must be noted that wearing a blindfold to “experience blindness” (Kafer, 2013, p. 4) does little to teach someone about ableism.

Despite being with my swimming club for three years. I asked my second coach if he understood the level of care required to get me into the pool.

> Not really. No, I, what I see is you roll in, in a wheelchair. You have your carer with you. They get you set up onto the hoist and into the pool and away we go. I can see that getting in and out is hard, and doing, say two sessions a day would be really tough on you just because of the getting in and getting out. Um, but as to why it’s tough or how it’s tough, No I don't know. (Sam)

He articulated that he thought he could probably do more to help me get in and out of the pool, but he was “a bit scared of those things.… As they [the carers] have the expertise” (Sam). He felt like he could trust them to look after that and he could just focus on “what’s happening in the water” (Sam). In contrast to Max, Sam recognised that there was a need for a different lens to fully understand how to work with para-athletes: “This is a completely different sphere. And I think it does a disservice to you guys [para-athletes] to try and put them [able-bodied athletes] in the same bubble". Sam recognised that every, every athlete is different, and that training has to be individually focused. He said if he had the opportunity to coach other disabled swimmers, he would ask himself before each session, "what is best for this athlete and how do we modify the stroke for them?" (Sam)

Thus, while there was recognition by both coaches that a "unique tailor-made Amanda centred approach" was the only way it would work, "where everything was important, down to every bloody last centimetre" (Max), I was still positioned as a problem or a challenge to overcome, thus underscoring the functional and normative framework underpinning coaching (Townsend & Cushion, 2018). My second coach extended my first coach's observation:

> With an able-bodied swimmer I know where you are today and where you'll be tomorrow, and where you'll be the next day... if there's anything I'm not sure about it's quite easy to jump on other people's knowledge or just go look something up. [With you] who do I ask? [With able-bodied athletes] there's quite a mechanical process that makes it easy to answer questions. Whereas coaching you… I think it's a lot more of an organic process where it's going to be trial and error and try something out and if it doesn't work, try something else. (Sam)

Thus, despite a vocal commitment to inclusion at a broad level, the fragmented and siloed nature of disability sport undermines opportunities for coach education (Thomas & Guett, 2014; Townsend, Cushion, et al., 2018). My second coach's observations about coaching me are in keeping with Taylor et al.'s (2015) findings, where many inexperienced disability sport coaches draw on knowledge outside the disability sport context, relying on a self-reflective process of 'trial and error'.

> Max has finally been doing some reading on tetra swimming. He has suggested that if I turn my head from 11 to 1 each stroke, that will prevent me doing the little extra flick at my hip required to keep my body level. For some strange reason this seems to work. But I was having such a hard time doing it, [and] the bastard had the audacity to ask me if I was a slow walker when I was a kid. That is such an insult. He doesn't understand how hard it is to be in this body. (Amanda)

In opposition to duty of care understandings, Max's approach demonstrated a lack of empathy and dismissal of my embodied experiences. Instead of creating an environment where I felt safe, supported, valued, and respected (Cronin & Armour, 2019a) a disempowering framework was imposed on me, reinforcing the powerful hierarchy in the coach-athlete relationship (Townsend et al., 2018). While he playfully referred to me as ‘Bubbles’, in reference to the amount of time I spend underwater while swimming, or ‘Girly’, it was a subversive way to assert authority in our relationship. As a member of more than one subordinated group, his name-calling reinforced sexist and ableist societal norms that deepened my experiences of systemic oppression. As Ahmed (2016) argues: survival “becomes a project when your existence is the object of a rebuttal. You have to survive a system that is constantly chipping away at your being” (p. 31). These engagements bring to light the social relational aspect of disability sport coaching where I am both enabled and disabled as I engage with coaching practice (Townsend & Cushion, 2018). Consequently, in opposition to duty of care understandings, in all of my coaching engagement I had to undertake emotional labour in an effort to resist psycho-emotional disablism (Reeve, 2020). Not only is this problematic, but it is detrimental to the maintenance of para sport systems and pathways for highly impaired athletes. Unsurprisingly, research shows that some talented disabled athletes quit sports to avoid the ongoing psycho-emotional discomfort of discussing their limitations and difficulties with unsympathetic coaches while striving to enhance their skills (Bredahl, 2010).

Despite coaching me for more than two years, my coach continued to train me like an able-bodied swimmer detailing how, “sameness practices for inclusion reinforce an ableist view of disability” (Lyons, 2013, p. 247). Though well-meaning, his powerful embodied identity as an older, white, able bodied, cisgendered man meant he was unable/unwilling to acknowledge the barriers and the struggle for representation I experienced as a highly impaired athlete. Resultingly, his language and coaching approach highlighting his belief that highly impaired athletes were ‘less than’ their able-bodied counterparts.

> I still have mental issues over performance sides – nothing personal, but I go, how the fuck is 45 or 48 seconds for 25 metres high performance sport? I can relate to that because of your injuries, that it is high performance. But I’m thinking because I have Josh (able-bodied international swimmer) who swims at able-bodied pace and I see that as high performance. But I struggle to categorise para swimming at the same level. I know I shouldn’t, because I’ve seen so many para swimmers in the 30 years

> I’ve been coaching, and they’re outstanding. The number of gold medals we have in para swimming in New Zealand is just outstanding – totally brilliant… I watched Jesse [Paralympian S9 classification – single leg amputee] swim, and I read an article on him the other day and it was kind of wow… But the little negative sitting in the back of my head is that there’s only seven S2’s in the world versus 70 bloody million able bodies, so how was that high performance? So yes, I guess I do have a bit of an issue there. (Max)

Undermining a focus on athlete care, compulsory able-bodiedness is embedded in the very fabric of how sports are conceived, structured, delivered, and celebrated (McRuer, 2006). My coach’s perspective reinforced the ableist viewpoint that, despite Jesse and I both being high performance athletes, only high-performing supercrips like Jesse are considered elite, while highly impaired athletes like me are not. While not meaning harm, he drew on normative ideas that underpin the wider coaching culture to construct my identity (Cushion et al., 2021), unable to see how the social relations between coach and athlete “produce, institutionalise, enact, and perform disability” (Smith & Perrier, 2014, p. 12). In opposition to the ‘athlete first’ or ‘athlete-centred’ discourses common in coaching, my coach focused solely on my impairment rather than my potential as a high performance athlete (Cushion et al., 2021; Townsend & Cushion, 2018). Thus, while recognition of para-athletes' outstanding achievements may reduce the Otherness of a few individuals with disabilities, it ultimately increases the Otherness of the majority who cannot meet this ideal (Wendell, 2006). With these experiences underpinning my training, I prepared myself to compete.

Tokyo Looming

> This weekend’s competition is fast approaching. Gemma looks worried, “Do you think it would be worth going over the day before to check out the pool?” She’s right. I haven’t swum for a year and I need to get some new qualifying times on the clock. The Paralympics is bubbling away in the back of my mind. Will I make the squad? My body has been misbehaving too; uncontrollable leg spasms have made driving interesting.
>
> “Do you think we should do cares the night before the race so that your body isn’t too tired?” She’s looking at me intently, concern etched in her face. I decide that I’ll be okay – that we’ll have time – we can do cares the next morning. My support worker

Julie arrives, and straps my feet to the chair – we are ready to go. Gemma gives me a squeeze, and wishes me good luck.

We arrive at the venue and find an accessible carpark. The lifeguards are lovely, and point me toward the competition pool. Julie helps me undress and put on my goggles, cap, and nose clip, disconnects my leg bag and transfers me onto the hoist wet wheelchair. In the wet chair I awkwardly roll over to the hoist platform – at the last-minute she reminds me to remove my binder and I feel my blood pressure drop – I hope I can get into the pool fast – I feel like death. The lifeguard makes sure I am secure and slowly lowers the platform into the pool. As we are going down, I yell out to Julie, "there is some cash in my wallet, go grab yourself a coffee". I flop forward into the water – holding my breath, face down. My body spasms, legs tight and shaking, toes pointed. I roll onto my back as my body equalises and swim a couple of lengths to find my bearings – looking to find some markers or lines on the roof to guide my path for tomorrow's race.

I swim for about 40 minutes, confident that I will remember the space and then head to the hoist to get out of the pool – they lower it into the pool and I swing my butt around onto the seat, it moves slowly out of the water and then jams. I am stuck; my feet about half a metre out of the water, not yet on the edge where I can transfer to my wheelchair. I just sit there slumped forward in my togs, trying to prop my upper body, suspended above the water, I feel so exposed and vulnerable. The lifeguards are flustered but can't fix it. The only way to free myself is to put my hands above my head and lean forward – crumpling into the pool. It is quite high and my hands and elbows hit the bottom (which is frightening given my history). Luckily there are some coaches who have worked with me before; who know how to lift me out manually. The coach pulls my upper body back to the edge of the pool with my tog straps to prevent me from face planting in the pool. They then grip underneath my armpits and squat lift my full weight to get my butt onto the edge of the pool, trying not to scrape my back up the pool edge. Julie goes under my knees, and spins me around. They reset their grip and count to three before lifting me into my chair. I get tired of being touched.

> An hour later than planned Julie gets me dressed, joking with me that if she'd known it was going to this long, she would have told me to get stuffed. I like her because she doesn't mother me. We load into the car and head back home. Our time together began at 7:30a.m. and we arrive home at 4.30p.m. Nine hours of paid support, and 300km for a 40-minute swim.

The narratives reveal the level of 'interdependence' required for the highly impaired athlete to perform independently, producing an interesting and subtle tension that has implications for the arrangement of care practices and active support for disabled athletes. Impairment itself does not necessarily create dependency and a lower quality of life – it is rather a lack of control over the physical help required which diminishes people's independence (Morris, 1997). Mitchell and Snyder (2001) summarised how "the interdependency of disability living" (xii) is an important factor in achieving independence and autonomy. For the able-bodied, independence is framed as being capable of doing things by oneself; whereas for the disabled, independence is defined as the ability to choose and control the assistance needed (Morris, 1995; Morris, 1997). As detailed in the narratives, highly impaired athletes rely on extensive patterns and practices of care delivered by employed support workers, family, and friends. The support that they receive is not just relational, as outlined in the sporting literature, but emotional and physical. Support workers are resources, 'vital and valuable human commodities' (Katzman et al., 2020); and the formal arrangements of dependency enable highly impaired athletes to participate, achieve and reach their goals in sport and in life.

Now or Never

> It's Sunday morning – competition day. We have chosen not to have a support worker because Gemma wants to come – she knows I am a bit nervous about racing again and wants to be there for me. At 7a.m. we do stretches – I transfer onto the commode chair, shower, and then she does cares.
>
> Gemma puts me in my togs, with my clothes on top by 8:30a.m. (9-hours before my race), because it would be too tiring and rushed to get changed at the pool. We drive to Hamilton and drop the kids off at friends and head to the pool at 4p.m. for warmup.

During the week I emailed event coordinators to let them know that I am competing. They need to understand the limitations of my impairment and what might make it easier for them and me. With some discussion, they agreed to put me in lane one for all my races. I would get lifted in at the finish of the last race and move the short distance to my lane. I asked that they advise officials to wait until my body stopped spasming before they called the other competitors to the blocks. I just have to hope that this is what happens today.

I take a few deep breaths and get lifted into the pool for my warmup by Gemma and a lovely swimming coach. They joke about me having eaten too many pies. Once in the water my body calms down a wee bit– I feel so grateful to be away from the noise and the people – just doing my own thing – I try to find my rhythm and not to think about the hundreds of people watching.

My first race is 50m freestyle. When I propel away from the wall – every part of my body is yelling at me – high-grade pins and needles and intense spasm, one knee bounces up to my chest, my hands are tight fists and won't open.

I can hardly breathe. The harder I try the worse it gets.

My body is a traitor.

When I finish, people are standing and clapping and cheering. The coach and Gemma lift me out of the pool and back into my wheelchair. Gemma dries me off, hooks up my leg bag, and puts the tight elastic binder back around my belly (I feel my blood pressure rise). She then helps me put on a sweatshirt, a beanie, and wraps my legs in a towel. There is an hour until my next race, and we have to make sure that I don't get cold. From behind she wraps her arms around my shoulders and gives me a squeeze; she can see I am struggling.

People come up telling me how inspirational I am. Gemma stands behind them, rolling her eyes with a grin. I smile and say thank you. A woman asks me "why you do it when it must be so hard?" I reply; "I swim so that younger disabled people will see me and say to themselves; if she can do it, I can do it! I want it to be easier for them than it is for me! I want them to come knock ‘the old bitch’ off her perch”.

The emotional responses of everybody else are exhausting. I know they mean well, but the fact that this happens every time I swim, reinforces just how different I am; bodies like mine are not the norm in competitive spaces.

My next race is 100m freestyle. Gemma helps me roll quickly down the side of the pool as the last race finishes. As the other swimmers exit the pool, the coach and Gemma lift me out of my wheelchair, and I flop back into the pool. This race is better, my body is less annoyed, and I am pleased with my swim.

Luckily the pool has an accessible changing room with a height adjustable bed which means I don’t have to drive home in wet togs. Gemma helps me transfer onto the high, hard, narrow plinth. Getting me changed in the stifling hot room takes 40 minutes. By the time I am dressed Gemma and I are both shattered. I stop her before we leave the room, and get her to bend down for a hug; holding her tight I whisper, “thank you”.

Our eyes fill with tears. I am absolutely broken; every part of my body is tired. A different kind of tired – there is sadness and darkness attached to it. Despite my independence, I am lifted, I am constantly touched, handled and hustled; sometimes it hurts. There is a massive cost for Gemma too, she is my partner and she gets paid, but the work is emotionally and physically heavy, hard and relentless. She takes care of all my material and physical needs while supporting me emotionally – creating a buffer between me and the social world. I really don’t know if it’s worth it – for both of us.

Figure 21 - Emptying Leg Bag (Catheter) 9 a.m.

Figure 22 - Removing Swimming Costume

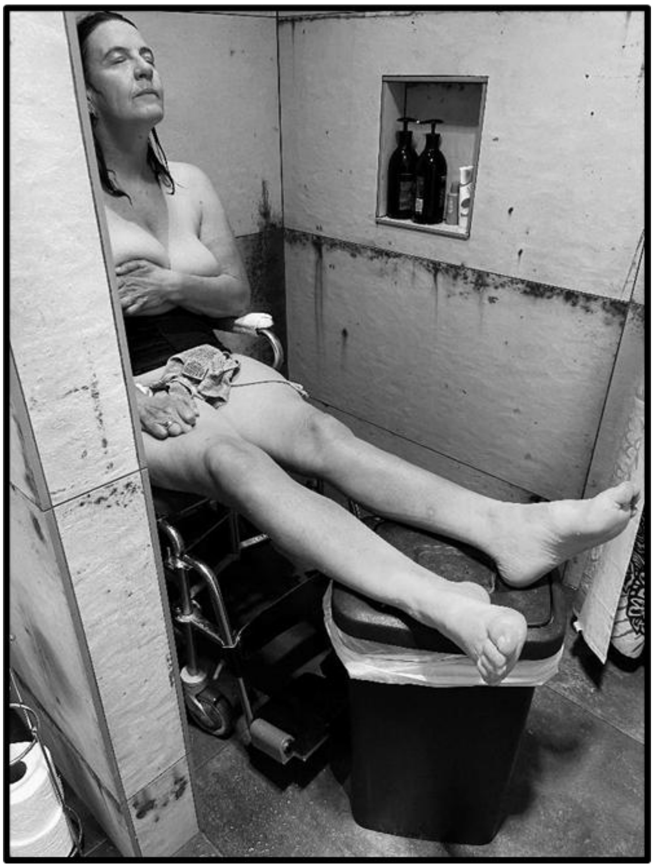

Figure 23 - World Goes Grey: Blood Pressure Drop Requiring Leg Elevation and Binder

Figure 24 - Drying

Figure 25 - Upper Body Dressing

Figure 26 - Getting Ready for 'Cares'

Figure-27 - Positioning the Commode

Figure 28 - Doing the Dirty Work: Assisted Bowel Care

Figure 29 – Messy, Gritty, Abject Dirty Work

Figure 30 - Transfer from Commode to Bed 9.30/45 a.m.

Figure 31 - "Is my Arse Intact?"

Figure 32 - Checking 'Day Bag'

Figure 33 - Pants Up

Figure 34 - Finally Shoes

Figure 35 - Back into My Chair 10 a.m.

As the vignettes and photographs show, dealing with impairment effects alone can be debilitating and demoralising. Many disabled athletes have family, friends and formal support structures. This narrative exemplifying how the boundaries between the two can be blurred and the emotional toll this can take. Furthermore, the narrative illustrates how support work creates a space where family and market collide. Hochschild (1983, 2012) exposes the tensions embedded in work norms and expectations when the home becomes a site of work; when private life becomes marketised. Family caregivers are in a particularly precarious position as their ‘paid’ work violates social norms associated with caregiving which is generally viewed as an act of altruism (Stacey & Ayers, 2019), blurring the lines between formal and informal labour (Stacey, 2005).

In the large body of work around care, scholars have shaped the definition to recognise that care is a unique form of labour, not simply an economic transaction, but embedded in relationships and emotional connections (Duffy et al., 2013; England & Dyck, 2011; Wolkowitz, 2006). In a sporting context, for a highly impaired athlete, personal ‘cares’ is an undocumented impairment effect that is largely absent from the disability sport literature, suggesting a certain squeamishness around care practices and care knowledge. The personal ‘cares’ described in my narratives refer to the assisted process of toileting and showering that I require. Both of these processes cause a drop in my blood pressure, and every morning I take a drug that raises my blood pressure to make the process a little less taxing. Sometimes the support workers have to lift my feet to prevent me from passing out. This process often takes between one and two hours to complete. It is fatiguing and, at times, unpredictable. It has significant physiological effects on my body. For others, the practice of ‘cares’ is undertaken alone or with support depending on the individual’s level of impairment. A highly medicalised discourse embedded within rehabilitation, cares is not an innate practice; rather, it is learned over time for both the support worker and the disabled person. Understandably, for athletes to perform their best, ‘cares’ need to be managed. Yet the visceral, embodied realities of care—especially when it involves bodily fluids, dependency, and intimacy—can evoke discomfort, even disgust, from outsiders (Grosz, 1994, 2020; Kristeva, 1982), positioning the disabled body as abject within elite sport. Furthermore, for the highly impaired athlete the need for care extends beyond the bathroom and bedroom, as such care can be an intense form of physical and emotional labour for both parties. As the narratives illustrate, the degree of independence is not determined by what or how much assistance a disabled person needs but hinges on the quality of life gained with the assistance.

Managing these care practices is psychologically taxing, where the psycho-emotional dimensions of impairment meld with physical restrictions of activity (Thomas, 1999). This is intensified by the ongoing emotional cost of being ‘out’ in public, where our ‘physical difference makes our bodies public property’ (Morris, 1997). As such, the data further illustrate the politicised, visible, and felt limits of the impaired body within high-performance sport contexts.

> [Athletes] with severe disabilities cannot keep their bodily issues private, they cannot keep their bodies privates. Not only are they forced back into their bodies, but they are also forced to have the private parts of our bodies exposed and handled on a daily basis (Rohrer, 2005, p. 52).

Thus, the role of care is difficult to reconcile in a high performance, ableist disability sport culture that celebrates independence and disassociation from notions of disability. In this context, many equate receiving care to dependency – incompatible with the ‘supercrip’ narratives that permeate disability sport. High performance disabled athletes' lived realities embody the 'interdependence' of disability living (Mitchell & Snyder, 2001).

Summary

As athlete welfare continues to gain prominence in sports discourse, disability sporting researchers and practitioners need to consider the lived realities of impairment and the associated care practices and knowledge required to facilitate inclusion. This chapter is one perspective, one voice, but the rich personal stories of these "absent subjects" (Morris, 1997, p. 68) play a crucial role in raising critical questions around the formal support structures in high performance disability sport. In presenting these autoethnographic narratives and visual diary of my experiences of care, cares, training and competing, I shine a light on four interrelated factors shaping the lives of highly impaired athletes in high performance sport.

Firstly, crip time emerges as a defining feature of athlete life. It captures how care routines, bodily unpredictability, and environmental inaccessibility stretch, fragment, and reshape time itself. As the narratives and photographs reveal, the complex logistics of daily care, from waking to dressing transferring continence management, medication, and spasm fragment time, placing athletes in conflict with the rigid, regulated, normative schedules of elite sport. As evidenced through the narratives and photographs, the everyday logistics of care, medication, dressing, continence management, transferring, and preparing to train fragment time, diminishing both time and energy available for athletic participation. In this context, time cannot be understood as a neutral or objective measure; rather, it becomes a contested terrain where the rigid, regulated temporal structures of elite sport collide with the fluid, relational, and often unpredictable temporalities of highly impaired athletes' lives.

Second, interdependence is as a defining condition of highly impaired athletes' lives. Far from being limiting, these relationships with carers enable access, mobility, and performance – they enable freedom. Carers, whether paid, familial, or both, are integral to every training session, every competition, every day. And yet, the relational depth of these caring practices sits uncomfortably within a high-performance culture that valorises autonomy, self-discipline, and control. In the space where public meets private, that the affective dimensions of care are laid bare. The photographs and vignettes expose the friction generated when bodies that defy normative scripts move through spaces not built for them—laying bare the relentless, largely invisible physical and emotional labour required as athletes and carers as they juggle care-time and crip-time.

Thirdly, cares is an undocumented impairment effect that is absent from the disability sport literature, highlighting the squeamishness around care practices and care knowledge. Specifically, I highlight how impairment, and its fleshy, messy realities can have direct and unavoidable impacts on the provision of care and coaching in the ableist environment of high performance disability sport. These intimate bodily practices—often involving waste, fluids, and vulnerability—can render the disabled athlete's body abject within sporting spaces that prize control, autonomy, and containment (Douglas, 1966; Grosz, 1989; Kristeva, 1982). Understanding the physiological impact, time requirements and logistics of personal care on athletes with higher levels of impairment is vital for performance success.

Finally, the chapter highlights the systemic ableist roadblocks brought to light in my experiences with my coaches. As detailed in the data, there was fear and hesitance about how to coach and care for me – I was just too different. My coach's resistance and ensuing practice grounded on ableist norms compounding my experiences of psychoemotional disablism, undermining my welfare (Reeve, 2002). Furthermore, the absence of resources to support the development of highly impaired athletes reflects a broader structural and institutional failure, exposing the lack of investment, value, and long-term commitment to highly impaired athletes participating at the highest level. For coaches, "the production of knowledge about disability comes not only from being disabled but from being with and near disability – thinking through disabled sensations and situations" (Johnson & McRuer, 2014, p. 141) whether these experiences are one's own or those of others. Coaching through this lens becomes an act of social justice—one that fosters inclusion, challenges ableist assumptions, and centres the humanity of the athlete. In doing so, they rise to DePauw's (1997) enduring challenge: "where all bodies belong and are valued as sporting bodies" (Wheeler & Peers, 2023, p. 111).

This chapter issues a call to crip disability sport – a call for researchers and practitioners to actively subvert the 'taken for granted' able-bodied norms (Kafer, 2013; McRuer, 2006), so that all athletes experience a profound sense of belonging and inclusion as they train and compete. I believe that change brought on by organisational awareness of the ‘care’ factors will allow disabled athletes and practitioners to navigate care in ways that facilitate high performance outcomes while effectively safeguarding the welfare of the athlete. At a broader level this knowledge could help to address the underrepresentation of highly impaired athletes in all sporting spaces.

Importantly, these issues are not just confined to me and my body but are echoed to various degrees by other athletes situated temporally within high performance sport systems. It is to these my attention turns in the next chapter, The Embodied Experiences of Highly Impaired Athletes in High Performance Sport.

Chapter Five: The Embodied Experiences of Highly Impaired Athletes

This chapter builds on the findings from chapter four to explore the embodied experiences of care for highly impaired athletes. As I have started to show through critical examination of my own experiences, highly impaired athletes require a range of support and care in order to function in everyday life, and these needs are amplified when engaging in high performance sport (Lowry et al., 2022). However, existing disability sport discourse theorises *about* the body, rather than *from* it, and as a result there has been little attention to disabled athletes' impairment effects, nor the way in which these are managed (Lowry et al., 2022).

Thomas (1999) in her social relational conception of disability argues that impairment effects are a part of all disabled people's lives, and as I have shown in Chapter Four, these shape and frame the experiences of athletes in high performance disability sport. Current research centring on disability sport emphasises the construction, language, and discourse of disability in their analysis, overlooking the real, felt, and direct impact of impairment (c.f., Morrison et al., 2020; Peers, 2012a). Through this approach, the body is overlooked or tidied away, which is arguably a form of academic ableism (Campbell, 2009; Schalk, 2013) that I wish to disrupt. My research sets the challenge, encouraging disability sport scholars to explore the meaning of impairment as critically as they do disability. Doing so involves espousing a view of impairment that extends beyond the bodily foundation upon which disability is built (Powis, 2020). Impairments are not static and their effects often vary depending on context or situation. While having an impairment can be understood as a corporeal experience, the influence of discourse and social interaction in shaping it must also be acknowledged (Powis, 2020; Thomas, 1999). Thus, this chapter brings the embodied experiences of impairment effects to the foreground, as well as recognising the discursive construction of impairment effects.

Linking to the main objective of my thesis – to examine high performance, highly impaired athletes' experiences of care – this chapter addresses and focuses on the lived reality of impairment effects during training and competition. As I have begun to illustrate, managing impairment effects is a complex bodily practice that requires external support, a range of care mechanisms and knowledges, planning, embodied knowledge, and a disruption to ableist conceptions of time (Kafer, 2013; Katzman et al., 2020; Lowry et al., 2022). This complexity, however, receives little attention in disability sporting literature and, as a result, is arguably invisible in organisational policy responses to disability in sport. Consequently, there is a collective and systemic failure to acknowledge the impact of impairment effects and the level of interdependence required by highly impaired athletes to participate.

In order to build on and further excavate the bodily dimensions of welfare, care, and disability in high-performance sport, I began by reflexively examining my own embodied experiences as a highly impaired athlete. This provided an initial grounding in the intimate, daily negotiations of impairment that often remain obscured within performance-focused sporting narratives. I then extended this exploration through interviews with other disabled athletes, deliberately designed to elicit discussion about their bodies, the specific impairment effects they navigate, and the care and support required for them to perform in their respective sporting codes. Rather than abstracting impairment into classification categories or functional labels, this chapter foregrounds the lived, fleshy, and affective realities of disabled athletes—across different sports, impairment types, and performance contexts.

In an attempt to understand the demands of training and competing in high performance disability sport, in this chapter six athletes and two support workers discussed, sometimes in intimate detail, topics that are usually taboo, such as getting to the toilet, 'shitting', catheters, assistant care, and commodes. These topics and people are absent from the disability sporting literature where emphasis has been on what goes into the body (i.e., nutrition) and not what comes out of the body, perhaps an attempt to disassociate disability sport from its medical and rehabilitation of roots (Peers, 2012b). Two athletes and two carers are involved in wheelchair rugby, two athletes are shooters, one a swimmer, one a sailor.

As mainstream sports organisations are increasingly called upon to support disability sport pathways, their lack of engagement with crip knowledge risks reinforcing superficial inclusion. This chapter aims to be "a revenge of the real" (Bratton, 2022, p. 3) that will upend the comfortable illusions on which high performance sport is usually based. As Introna (2023) suggests, the enduring legacy "might be the appreciation of how staying with the uncomfortableness that the crip lived experience brings" (p. 90) allows us to explore the myriad alternative realities it encompasses. Rejecting stigmatised assumptions, the redeployment of disabled bodies becomes more than a tool for integration; it becomes an instrument for transformation – reclaiming that which has been historically viewed as dysfunctional (Snyder & Mitchell, 2001).

Theoretically, this chapter is guided by Thomas's (1999) social relational model. The intention is to engage and challenge readers to deconstruct the social, cultural, and political constructs of disability, emphasising the lived experiences and agency of disabled individuals while advocating for social justice and inclusivity. To further this aspiration, this chapter draws from crip theory (Garland-Thomson, 1996; Kafer, 2013; Linton, 2006; McRuer, 2006); abjection (Kristeva, 1982; Longhurst, 2001; Tyler, 2021); neoliberal ableism (Goodley, 2014; Goodley & Lawthom, 2019; Wolbring, 2012); and embodiment theories (Ahmed, 2017; Campbell & Brown, 2021; Peers, 2012a). The aim is to expose the embodied experience of impairment effects, including the intimate bodywork and care needs (or 'cares' as we refer to it) for highly impaired athletes' as they prepare for, and compete, in high performance sport.

There are four sections in this chapter that encompass many elements of impairment effects. This chapter draws on the social relational model of disability to examine how impairment effects are not just experienced in the body, but are produced, lived, and negotiated in ableist high performance sporting structures (Thomas, 1999). The first section, Body Management and Ableism, discusses the complexities of managing a highly impaired body in an ableist high performance sporting space. This section includes two subsections that highlight the training experiences of athletes in "One Fall Will Screw It Up" and the complexities of managing messy bodies in, "No Matter How Well You Know Your Body, When You Can't Feel, Things Can Go Wrong". The second section, "It's Something That Can Kill You. We Can Have a Stroke or Heart Attack", details the life-and-death experiences of impairment effects. The third section, centres on the athlete support worker relationships in Invisible Labour and Interdependence. The following subsection, highlight the complexity that support workers face delivering care in inaccessible environments in, "There's Always Something That is in Our Way to Deliver Care". Section four, "Just Get Off the Toilet and Start Living Your Life", delves into the relational dynamics of athletes learning to manage their impairment effects. The chapter concludes with a brief Summary.

Body Management and Ableism

The physiological, emotional, and psychological experiences of living in a highly impaired body can be as varied as impairment itself. For the highly impaired, the embodied symptoms of impairment effects are all-encompassing, impacting on every aspect of life. In reclaiming a focus on impairment effects, I build on the crip notion of ‘cares’ (Bourke et al., 2015; Goodwin et al., 2009; Lowry et al., 2022), which, as described in Chapter Four, remains an undocumented impairment effect within high performance disability sport research. In doing so, I highlight athletes’ personal experiences of care practices.

As a highly medicalised discourse embedded within rehabilitation, ‘cares’ is not an innate practice, rather, it is learned over time for both the support worker and the disabled person. For example, as I have shown elsewhere (see Chapter Four), managing cares takes time, and for the most impaired, often requires attendant support. For those with acquired injuries managing bladder and bowel is an integral aspect of life in a newly impaired body, often taking years to perfect. Chapter 4 highlighted how managing these care practices is emotionally taxing, where the psycho-emotional dimensions of impairment meld with physical restrictions of activity (Thomas 1999). Yet, there is little sporting research about the physiology of impairment effects and how to get the best out of highly impaired bodies (Sparkes & Brighton, 2020). Across the interviews, a number of participants described the various ways that they manage their cares, pain, and fatigue, while at the same time describing how they navigated a lack of understanding from key personnel around them such as coaches, administrators and disability sporting organisations. Wheelchair rugby player, Ben, articulates this point, highlighting the lack of understanding of the impairment effects of tetraplegia; even from the players themselves:

> The support that we get is generally around nutrition, hydration, and sleep. It’s not really around the understanding of our bodies… If we’re playing high performance, how do we get bodies feeling [really good] in the morning? I think there needs to be more research done [so that athletes and organisations have] greater understanding about how to get the best out of our bodies.

High performance disability sport is not inclusive, nor does it purport to be. It does, however, order and classify bodies reinforcing a body politic that requires critical examination particularly in reference to athlete welfare and care. The athletes are given support around standard (read able-bodied) performance driven topics, completely overlooking their physiological differences. Ben describes how the time-consuming process of managing personal cares while competing impacts on team performance.

> We’ve got people in our team that they’re getting up at five in the morning to get their cares done, to get ready in time to get to let’s say a 9am game, but you’d think what’s the best thing for recovery is sleep… but they haven’t gone to bed at 9 at night to make sure they get an 8-hour sleep. They’re still up at 11 o’clock at night. All of that stuff impacts hugely on the way that we perform on court… it’s like a 2-hour process just to have a shower and a shit. We’re not going to be at our best… And maybe you should be looking at other times, because your blood pressures so up and down, and sometimes you take a big shit and then… if I have a big feed – I [feel like] I’m dying. But I thought if I’d had a meal that I’d start feeling better, but my body’s trying to take it all on, and you know it’s working overtime to try and metabolise it and do everything else.

This narrative gives insight to some of the complexities highly impaired athletes face, highlighting the intersections of crip time, body knowledge, body management, and performance expectations. Driven by neoliberal politics, high performance disability sport is commodified, time driven, and rationalistic, and embodied knowledges are not recognised. As a result, the status quo is maintained. High performance disability sport continues to privilege the productive autonomous disabled bodies that approximate normality, closing it to the complexities of highly impaired athlete bodies and their lived realities (Goodley & Lawthom, 2019; Lowry et al., 2022; Powis, 2020). As a result, the responsibility for generating strategies to manage care while maximising performance is often devolved to the athletes.

> At the end of the day, it's their responsibility as athletes to understand how their bodies work and make sure they're ready to perform. Everyone in the squad has different needs — it’s up to them to figure out what works for them. (Liam)

My experience with food mirrors Ben’s, yet when I reached out for help from high-performance sport, I was given an able-bodied athlete food training guide:

> I eat carbs and my body crashes, so I take a pill before every meal that is like pseudoephedrine – that raises my blood pressure – that gives me a boost, so that I don’t pass out. For half an hour after a meal my vision is blurry, and I feel like death. To help manage these symptoms, I wear a tight elastic binder around my stomach that helps to raise my blood pressure, gives me voice projection. But the minute I take it

> off, before a race, I can feel myself going – everything goes grey. My heart rate is usually in the 60s, so raising it up is really difficult when so little of me works. (Amanda)

Paralympic sailor, Jack, with Becker Muscular Dystrophy, speaks about the increasing loss of energy while competing at Paralympic qualifying regattas. Here, Jack illustrates the intense form of physical and emotional labour required to perform, and the lack of support mechanisms:

> After regattas, when I came home, it would be two or three weeks before I would feel like my energy levels were back up to where they were beforehand. It was just a constant physical drain. I can remember getting my sailing gear on and it was just so labour intensive. Everything was feeling tired. The more the competition week went on the worse I got. I don't think there was anyone [in the sailing community] had a higher-level disability than I did… It was hard to get that message [that I needed help] across to yachting New Zealand.

Jack's experience brings to light who has voice and who does not in high performance disability sport (Townsend et al., 2018). Jack had to find resilience to overcome physical and emotional barriers that made his involvement in high performance sport even more challenging. For athletes, the politics of knowledge underpinning high performance sport promote and sustain 'felt' dimensions of psycho-emotional disablism (Reeve, 2004; Thomas, 2004).

This point is further demonstrated by Paralympic shooter, Hunter, who details his first experience of high performance sport. At this World Series event, Hunter was the only para competitor travelling with a team of able-bodied shooters. He was not allowed to bring his support worker.

> We had this team manager and, honestly, he was so bad. The bathroom was not accessible. There was a step to get down, so I had to get down onto a step. The toilet was dead in front of me, and I'd have to transfer forward,[24] to get onto my commode. Then do my cares. Drag that into the shower, have a shower, and then try and get

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[24] A front or forward transfer (moving from wheelchair to commode) is difficult for tetraplegics. In this transfer the person has to have the strength to hold their entire body weight, and rotate 180° while moving between two seats, with no core and limited arm function.

> out. And everyone else is asleep. I remember saying to [the team manager]: ‘This is what I’m struggling with’. And he was like, ‘What are you complaining about? Why don’t you just shit in a bucket?’ You know, it was pretty bad. I remember one day being in the dining hall, we’re having breakfast, and I must have been just so exhausted and so over it, I was just crying. I wasn’t like sobbing, tears were coming down my eyes; I’m just eating my breakfast, and I’d just had enough. Just from the whole frickin’ – the competitive stress, your cares, and nobody helping. Oh my God it was terrible! But I actually got my first lot of qualifying scores for the Athens Paralympic Games. I don’t know how I managed it.

Contrasting Hunter’s data with more recent athlete data throws into stark relief a historical pattern of institutional neglect and ableist disregard for care needs in high performance contexts, which despite recent improvements in athlete wellbeing practices do not necessarily translate into recognition of the welfare and care needs of highly impaired athletes.

As Ahmed (2013) states, “[b]odies take shape of the very contact they have with objects and others” (p. 1). Hunter was acutely aware that he was a ‘body out of place’ when trying to care for himself in an inaccessible able-bodied environment (Ahmed, 2000); his stressful experience moving him to tears. The manager’s unsympathetic response was reflective of psycho emotional disablism, invalidating Hunter’s lived experience, undermining his emotional well-being and self-worth (Reeve, 2002, 2006). Emotion is political (Ahmed, 2013). Hunter’s abject body and abject emotions revealing the fault lines in the ableist doctrines of what a body should be and should do (Donaldson & Prendergast, 2011). Highly impaired athletes disturb the “identity system and order”; they are “that which does not respect boundaries positions rules: the in between the ambiguous the composite” (Kristeva, 1982, p. 4). The abject embodies a challenge to the symbolic order, which means that disabled athletes who “cannot deny or escape their excrementality, their liquidity, their humanity” (Longhurst, 2001, p. 89) are forced to manage their coaches and support staff – with significant emotional cost. Thus, while Hunter and Jack are included ‘publicly’ as a para competitors, the structures and institutions that underpin their involvement do not support their ‘private’ embodied experiences. Their experiences exemplify the paradox of the simultaneous ‘inclusion and exclusion’ of disabled athletes.

Building on the psycho-emotional element of impairment effects, Zac described the difficulty that he faced dealing with structural and social barriers while training for his fourth Paralympics.

> A lot of it is just around understanding that sometimes the wheels will fall off. Like, this week I fell over going down a very simple ramp and caked it into the garden. Smoked myself on the edge of the ramp. It hurt. So, it's just understanding that when I turn up to training, I might not be ready to go fast. If my prosthetics are playing up, it's just understanding that I might be a little bit late, or a little bit less inclined to be normal, or I might have a few more things going on mentally in terms of concentration. I might be preoccupied with other stuff, whether it be prosthetics or having fallen over or being injured from a fall.

Despite Zac's ongoing positive relationship with his able-bodied coach, his experience sheds light on the lack of recognition of the lived realities of impairment. As Sherry (2016) notes, the body is "central to social, emotional economic and physical life" (p. 731). As such, tiny aspects of daily life that might seem inconsequential to able-bodied individuals can have profound impacts on those with impairments. Consequently, for Zac, the coach's failure to recognise the subtle psycho-emotional effects of impairment undermine his experience of training and competing (Reeve, 2020).

The psycho-emotional dimensions of impairment featured prominently across the athletes' stories. For example, Rashmi spoke about the impact of managing fatigue, an intensifying effect of her progressive spina bifida, and the internalised oppression she experienced as a child. She spent her childhood with able-bodied people and could not talk to them about "the stuff I've been going through, because they would never understand". It was only when she began to compete that Rashmi had the opportunity to share her experiences with other disabled athletes. The support provided by others with lived experience was important as her family carers often undermined her assertions of pain and fatigue. Rashmi describes how despite the fact her mum and are aunty are both nurses "they've seen it, day in, day out – but they don't know the real feeling of it – because they never had to do it". Rashmi elaborates how they were not willing to sit with the uncomfortableness of her disability embodied effects:

> There's just certain things, like I'd say, 'Oh my legs aren't up to it today'. They're like, 'No, no you can do it, you did it before'. And I'm like, 'No, today my legs are really bad, I can't do it'. They think they're encouraging but it's not, it's patronising. It's like, if I'm telling you that I'm not okay, you need to hear me say I'm not okay!

Rashmi emphasises her need for genuine connection in order to feel truly seen and accepted. While Rashmi attempted to express the lived experiences of her disability, her family appear emotionally unable or unprepared to accept the progression of her impairment. Similar to Zac's experience with his well-meaning coach, Rashmi's aunt and mum are nurses, their beliefs and expectations grounded in the medical model, and they are the "unwitting oppressors" (Reeve, 2004, p. 8) or agents of psycho-emotional disablism. The lack of recognition for her impairment effects left Rashmi feeling angry, ashamed, vulnerable, and invalidated (Reeve, 2004; Thomas, 2004). The body is a "cultural body and the physical act of violence is felt and interpreted through our relationships with others" (Goodley & Runswick-Cole, 2011, p. 606). Her need to have her impairment effects recognised broke the unwritten rule of social exchange that requires disabled people anticipate and manage the emotional needs of others and avoid certain 'upsetting' aspects of their lives (Watermeyer & Swartz, 2008). Those who are unable to "sink into spaces, whose bodies are registered as not fitting, often have to work to make others comfortable" (Ahmed, 2013, p. 224), undertaking emotional labour to manage others' fears and prejudices (Reeve, 2006).

Rashmi has a tetraplegic shooting coach with whom she is able to connect. Although their disabilities differ, their shared experience of negotiating impairment effects fosters a form of crip kinship. It is through this embodied commonality, Mike is able to support Rashmi's mental and physical preparation for the competitive environment in ways that traditional, ableist coaching frameworks cannot accommodate.

> Being able to talk about what's happening with my body, it is nice, so that's one of the things, that support network – Hunter's been a big part of that for me. Because having someone to talk to about it and them [having] experienced it, is so different. (Rashmi)

These narratives highlighting the social relational nature of impairment effects which are exacerbated through engagement with others (Thomas, 1999). Although impairment remains under-theorised (Campbell, 2009; Thomas, 1999), its material effects become visible within socio-cultural practices, such as sport. In high performance disability sport, highly impaired athletes face the dual challenge of managing the complexities of their impairment, and “how others experience and respond to their bodies” (Goodley & Runswick-Cole, 2013, p. 1).

These athlete experiences highlight how disablism is felt and experienced in person-to-person interactions as well as at the level of institutions (Campbell, 2009; Sherry, 2016; Thomas, 2010). Disappointingly, the real-world implications of this disablism undermine the provision of appropriate resources and services for highly impaired athletes. These athletes are the drivers of change; their participation defies and disrupts ableist assumptions within high performance sport, opening up opportunities for agency and resistance.

Yet this agency is rarely individual. It is sustained through interdependence, through the daily, often invisible collaborations between athletes and their support networks. This interdependence between athletes and their support networks becomes even more critical in the demanding context of high performance training, where physical assistance and time management are paramount.

“One Fall Will Screw It Up”

The interdependence between athletes and support workers extends beyond the bathroom. For example, some of my participants do not have hand function; therefore, trainers and support workers must carabiner tetraplegic athletes, or those with limb deficiencies, to gym machines to do weight resistance training. This is labour-intensive and time-consuming. Ben explains:

> ‘Cause I can’t train to the best of my ability by myself. You need someone holding you, you need someone setting you up. [A]n abled-body guy can go and workout by themselves, and there’s no issues. Firstly, I have to find a trainer [who is willing to work with a disabled athlete], and secondly, [I have got to] work with him and to what times he’s available, and work around my routines and schedules, and then make it happen. When you think of an able body, I could go to a gym session before work. It’s literally jump out of bed, go to a gym session, but [when you are disabled] if you’ve got a cares morning, and you’ve got to get to work, that 2-hours that you would have spent at the gym is 2-hours spent in a bathroom. I think that’s a massive hurdle.

There is a stark difference between the ease with which able-bodied athletes access training resources when compared to para-athletes (Campbell & Brown, 2021). Zac details the complexity:

> Sometimes I'll go straight from work to home, to training, to bowel cares and into bed – and that'll be an entire evening. So, I have carers in the mornings and evenings. Same on the weekends. To help get me up and I need help with my training all the time, I can't quite get set up in my rugby chair by myself, I need help to transfer, put my equipment on my chest, strap on my gloves and I need help to get out, and if I am setting up with battle ropes [and] weights. Most of the time I need assistance getting things the way I want them.

Zac is also dependent on others for training. Zac has a quadruple limb deficiency and, in many situations, remains capable and independent. Yet, he, too, discussed the extra time required to manage his impairment effects, and the risk he takes when he aims to be 'too independent'. In Zac's upbringing, his family encouraged him to be as independent as possible, which sometimes means he chooses to take risks rather than ask for help or extra time. As Zac describes, overlooking impairment effects may have a costly outcome:

> I can [do it by myself], but it takes me probably three times as long. Something as simple as unclipping carabiners not having hands, it makes a big difference to have someone to clip-on and clip-off. That sort of stuff, but also setting up a weight. So, if you're doing chin-ups for example, and you've got a weight strapped around your waist; and I guess I become a fall-risk when I try and be too independent… one fall will screw it up.

Zac's reflection illustrates how internalised ableism operates, particularly as it intersects with normative masculinities that valorise independence, control, and self-sufficiency (Campbell, 2009). His language articulating how efficiency, risk, and resistance are weighed against the perceived 'burden' of asking for help. Dependence is a compromise, and crip time incompatible with elite sport norms.

While Zac's account foregrounds the embodied risks of internalised independence, Stella's experience reveals how structural underinvestment in care and support can quietly undermine athletic potential—particularly when needs fall outside tightly defined funding categories. Despite being on the Paralympic pathway, Stella speaks about the difficulty she experiences accessing the support needed to excel in the high performance space. Stella's funding covered support for self-care and household maintenance activities but did not stretch to meet her leisure and social needs.

Stella:	When I was training for the Paralympics, I didn't get a lot of support… I didn't really benefit that much from being a carded[25] athlete. It was kind of tokenistic kind of a thing. In terms of what I needed back then, I just needed people to pick up my balls 'cause I trained by myself. Cause I just had to throw balls – that was my training. And picking up the boccia balls was the longest and tedious thing that I [had to do]. Picking up the balls, took me longer than throwing the balls.
Amanda:	So, who ended up helping? Family friends?
Stella:	There were university friends I used to try and talk into, but mainly myself really. It was really boring and really long and really tiring but that's what you do when you want to be the best.

Care provision, as outlined by Slasberg and Beresford (2017), is framed by a neoliberal understanding, that "a 'need' is only a need if there is the resource there to meet it" (p. 1263). As highlighted in the examples above, there is a constant tension for athletes who must balance the extra time and support required to manage basic bodily functions and the assistance required for training. The following quote from Ben reinforces the tension between the societal ideal of autonomy and the practical need for support:

> Most of our two pointers and above, they don't need any help. You know, they're all fucking pretty much [independent], they do their own thing… I suppose there has been a mentality of independence and if someone can't do something, you know, you give them shit and or you try to help them to be able to be as independent as possible. So, while independence is a good thing, [as an athlete with low function] you have also got to think, sometimes I don't want to waste all my energy on those things too.

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[25] In many countries, high performance sports organisations support elite athletes through a system of 'carding'. In New Zealand, carding has been replaced with TAPS (Tailored Athlete Pathway Support). In this system athletes who are top six in the world receive funding and support from HPSNZ.

These requirements are magnified in a performance and training environment where time equals medals and is a (un)controllable commodity. Ben, Stella, and William's experiences of training are a vivid illustration of crip time, and Zac alludes to the danger as someone who strives to be 'too independent'. As such, managing the multidimensional physiological and psychological aspects of impairment effects requires constant effort and energy from athlete and support workers. The toll is multiplied for those who are in paid work, as expressed by both William and Ben. However, the ableism ingrained in national healthcare and sporting structures becomes increasingly intensified and restrictive as athletes navigate between these two fields. This constraint undermines the acknowledgement and support of the different care needs based on human variation (Campbell & Brown, 2021; Fraser, 1995; Loja et al., 2012). These dynamics underscore the psycho-emotional impacts of disablism and bring to light the complexity of the management of impairment effects in high performance disability sport. The following section details these complexities in practice, illustrating the abject, messy, and gritty lived realities that highly impaired athletes contend with on a daily basis.

"No Matter How Well You Know Your Body, When You Can't Feel, Things Can Go Wrong"

In overlooking the bio-social realities of disability sport, there is a danger that research is overly sanitised and able-washed, reflecting a politics of knowledge in which only *some* disabled bodies are considered acceptable and only *some* disabling experiences are worth socio-cultural analysis (Lowry et al., 2022). The stories in this research represent some of the intimate, private, and challenging aspects of non-normative bodies. Because such representations are often absent from disability sport research, my participants challenge norms and goals associated with high performance sport and the standards of 'what counts' as elite athletic bodies (Lowry et al., 2022). Such analyses and representations are important, as they reveal deeply held discourses about disabled athletes that require attention and response.

In examining the literature in high performance sport, for example, abject words such as "shitting", "urinating", and "faeces" do not appear, nor are these experiences acknowledged by para sports organisations. Drawing from Grosz (1994, 2020), there is an unspoken social and physical goal to "establish as great a separation as possible from the excremental"

(Longhurst, 2001, p. 207) which can be understood as a mechanism of governance through aversion (Butler, 2006).

> People shit themselves on a flight, I've shit myself before hopping on a flight, but that was my own fault… it's going to happen at the end of the day, if you haven't got feeling… everyone's got that understanding that that sort of stuff can happen. And you're trying to tell them that 'it's all good, bro'. But you can tell that they're absolutely devastated. (Ben)

Even though events like this are common, the athletes commented that there is a 'don't ask, don't tell' approach embedded in high performance which runs counter to the current narrative around athlete welfare (HPSNZ, 2024b). The social and personal taboos associated with managing body waste (Douglas, 1966, 2003; Grosz, 1994, 2020; Kristeva, 1982, Longhurst, 2001) continue to prevent organisational responsiveness, as exemplified by Layla, a support worker:

> I've had one guy have an accident on the plane, but I wasn't actually on the same flight. So, it wasn't till we met up in Sydney. And he was like, 'I've had an accident on the plane', I'm going to need help when we get to the room, can you help me?' [But the hotel had] double booked our rooms. We actually didn't have anywhere to go. I'm like, 'Oh, okay, do you want to try, go to the bathroom now? And I can do what I can'. And he's like, 'it is that bad that I need to get onto my commode'. But because he couldn't transfer [we were] just on and off the floor of the hotel bathroom and had to bring [one of the guys] in and out to do so many lifts. I think we had to do about 10 lifts.

The structure and timing of care exchanges are an important part of this experience. As the rugby player had to get up early for a flight, his daily bodily rhythm was disrupted which had devastating emotional consequences for himself and imposed acute physical demands on the carer and support crew. Layla stressed the intensity: "you're trying to protect them and their dignity and get the job done, but it wasn't until about 11:00 p.m. that I managed to get him in the shower". Crip time is vampire time, "of life schedules lived out of sync" from the everyday world (Samuels, 2017, para. 23). The athlete felt shame and embarrassment because he was unable to protect others from his disability experience, a result of the "affective cost of not following the scripts of normative existence" (Ahmed, 2013, p. 107). Douglas (1966) outlines how boundaries of bodies relate to social structures with clear lines and boundaries upon which identity is formed, but the highly impaired athlete's body is perceived as too messy, making sporting organisations uncomfortable – frozen in their abject reaction. They are "unlike one's co-citizens" (Watermeyer & Swartz, 2008, p. 608) with their runny, gaseous, flowing bodies with insecure boundaries with fluids that seep and leak (Longhurst, 2001); affronting high performance organisational aspirations of autonomy and independence (Lowry et al., 2022), the key elements of a positive athlete self-identity.

Support worker, Layla, describes the psychological and emotional cost on game day for the athletes when cares do not go to plan.

> I'd definitely say that there is an impact, especially because there's always that uncertainty. Like are they finished or not? You can tell that they are [questioning], 'I don't know if I'm done or not'. There's been situations where I've missed the bus with one of the guys, because we were still on and off the commode on and off the bed and over bucket... I was like 'I don't know [if you are done]'… You can tell that [if cares don't go well] it doesn't just affect them physically – after that they're just mentally drained and don't feel like themselves… Then they don't feel good on the court as well… They're just not in a good mindset to be out there… It really ruins their head space.

While these cases do not constitute overt oppression, the athletes' embodied experiences highlight how the biological realness of impairment impacts heavily on their physical and psycho-emotional welfare (Reeve, 2006; Smith & Perrier, 2014; Thomas, 2004). The fact that many highly impaired athletes need support in the toilet (for shitting, washing, and dressing) undermine ableist ideals of citizenship and identity founded on a closed 'sealed' body with a clear delineation between the self and objects or others in the world (Kristeva, 1982; Longhurst, 2001). Within this framework, support workers are "socially appointed agents of abjection" (McClintock, 1995, p. 75), dealing with abject objects (bodily fluids), from an abject population (Longhurst, 2001). Support workers' relationships with highly impaired athletes highlight the stark reality of the body as a physical entity with a spatial presence, embedded in an environment not fit for purpose (Apelmo, 2012, p. 45).

Despite having primary responsibility for athlete welfare and care, and having the authority to prevent or mitigate the issues, national sporting organisations and Paralympics distance themselves from the messy aspects of highly impaired athletes' lived realities. Impairment effects present a unique set of challenges that cannot be solved by a standardised approach to care. High performance disability sport organisations must enact athlete-centred policy changes to address and resolve these issues. In enacting athlete-centred organisational change, disability sporting organisations will not only support the welfare and care of highly impaired athletes, but generate an environment that enhances performance outcomes.

Thus, the challenges faced by disabled athletes extend beyond social and institutional barriers. The very nature of impairment introduces a range of dangers and risks that can affect bodies in profound ways. Turning the focus to the physical realities of living with a disability, it becomes evident that the effects of impairments can pose significant threats to health and well-being. The following section delves into the dangers of impairment effects, exploring what can go wrong in a disabled body and how these risks further complicate the already challenging landscape of high performance sport.

"It's Something That Can Kill You. We Can Have a Stroke or Heart Attack"

High performance sport brings highly impaired bodies into the public arena, and with it exposes the multiplicity of impairment experiences. As detailed in Chapter Four, high-level spinal cord injuries often have suprapubic catheters to expel urine from the body. Sometimes the catheters can block, which for many tetraplegics leads to dysreflexia. Dysreflexia occurs when the body, below the level of injury, reacts to stimulus or pain, producing a sudden increase in blood pressure. Coupled with low heart rate, it can lead to seizure, stroke, or cardiac arrest (Sparkes & Brighton, 2020). While not common, and banned by the IPC, there has been research into the use of autonomic dysreflexia to increase performance. In these instances, highly impaired athletes purposely block their suprapubic catheters to cause a spike in blood pressure, in a process known as 'boosting' (Sparkes & Brighton, 2020). However, for the most part, dysreflexia is something to be avoided. Ben speaks about getting a catheter block at the last training camp, and the impact on his body producing two days of headaches and fatigue. I wanted to understand how Ben dealt with a catheter blockage, when he was away from home, on the court, without his usual support:

Amanda: So, you’re at a training camp, do you get someone rush back to the room, get the syringes and stuff you need. Or do you try and sort it out while you’re there? What’s the procedure?

Ben: So, I just change my catheter while I’m in the rugby chair. I just have to slump my bum forward and pull it out. I’ve usually always got a spare catheter change kit on me, but I didn’t that day. Luckily someone did, so I just grabbed theirs. Just went into the bathroom at the stadium… Both Suz and Layla [support workers] gave me a hand, which was good because I needed it, because with these things you can’t fuck around, man. You start with a headache and you start getting really irritated and it turns into a bit of an emergency.

Amanda: Would you go to A and E [Accident and Emergency Services]?

Ben: I would never even bother doing that. Fuck that. We have to know our bodies well enough to know how to manage that kind of stuff. I know if I’ve got a blocked catheter coming on, but it takes a while to learn. I start getting a bit of a shiver down the back of my spine and then I start getting a bit hot. And then, the headache starts coming on.

Amanda: But like you said, the cost for you that, that’s like almost a day and a half, 2-days of recovery?

Ben: Yeah, but I carry on, but feel like shit.

Amanda: So, does it impact on your performance, or can you push through it?

Ben: I mean I can push through it, but I’m sure over time that it’s not great for the body. You get a spike in your blood pressure, and you stretch your bladder, which is fucking painful, and while you can’t feel it, your body’s feeling it in other ways… It definitely effects performance.

There is tension between the conservative medical approach to body management conveyed by physicians and the participants’ experiences (Goodwin et al., 2009). Ben reiterated the gravity of the situation, and how, post-impairment one has to take “health with a new seriousness” (Smith, 2013, p. 113).

> You have got to know your body. I know how a catheter works and I know I can talk anyone through how to change it… I'm not going to wait for a fucking ambulance to turn up, to take me to hospital… It's something that can kill you. We can have a stroke or heart attack. (Ben)

Ben talks about some of the things he and his teammates do about blocked catheters when they are without support workers. They have gotten hotel cleaners and strangers to change the catheters for them, and in the worst-case scenario: "I've had to suck my catheter until I got a mouth full of piss to unblock it! I was at home alone and I went 'oh yeah, fuck it!' – I'm a fucking mongrel, I'm a mongrel' [laughter]" (Ben). "But you're alive my friend – you're alive!" (Amanda)

While not all tetraplegics who play sport experience what Ben has described, organisations that govern disability sport need to understand the gravity of the situation, and ensure that teams are resourced with the equipment and skills to support their players in potentially life-threatening situations. Rashmi discusses the intensifying impairment effects of her spina bifida and the psycho-emotional adjustment required to manage an ever-changing body:

> My bladder started giving out a couple of years ago and there was back pain I'd never had before. Because I was getting incontinence and things, I was like, 'What is happening to my body right now?' I had no idea. I ended up going into retention[26] and I had to go to hospital a few times. And it was scary, I was [thinking], 'what's my life going to turn into now? I don't know what this means'. I was only 25 at the time. You know this shouldn't be happening. Then you have like the doctors going, 'Oh this is going to happen, this was bound to happen'. But I didn't know that. I shouldn't be preparing myself for the worst every day. So, it was something I had to adapt to and then had to get Botox and learn how to catheterise, which was a bit of nightmare.

As Rashmi's impairment progressed, so too did her need for 'self-care time' (Stevens, 2018). Crip time became her new lived reality as her everyday body care and daily life experiences

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[26] Urinary retention means problems completely emptying the bladder. It may occur suddenly (acute urinary retention) or it may develop over a longer period of time (chronic urinary retention). Acute retention: A sudden inability to empty the bladder. It can be very uncomfortable and may require immediate medical attention. Chronic retention: A long-term issue where the bladder is unable to empty properly over an extended period. It can lead to a variety of complications if not treated.

took longer, required more energy. It was a constant battle to manage the unpredictability of her deteriorating body (Kafer, 2013). Samuels (2017) and Stevens (2018) discuss how for those with degenerative impairment, "crip time is *grief time"* (Samuels, 2017, para.7) [emphasis in original]; "a never-ending process of grieving each new symptom and mourning lost potential" (Stevens, 2018, para.3). It is *broken time* that requires disabled people and the people who support us to:

> [B]reak in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds so closely, so attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honouring their words. (Samuels, 2017, para. 9)

Support workers are vital resources, enabling athletes to navigate the temporal and embodied demands of crip time; however, they are also directly affected by its pressures. The expectations compounded by the severity of some impairment effects such as dysreflexia, which is life-threatening and demands immediate, skilled intervention. Layla, who has supported the Wheelblacks for over five years and accompanied them to the Tokyo 2021 Paralympics, reflects on the personal cost and weight of responsibility she carries caring for the team:

> Layla: But even sleeping, you can't sleep because you get to in your head that someone could be calling out for you. If I hear a knock on it, I'm like, 'Oh, was it the door? Someone needed me?'
>
> Amanda: So, you're just on call that whole time. Do you get called in the middle of the night?
>
> Layla: Oh, every time I go away I, get called in the middle of the night, at least every second night.
>
> Amanda: Really, for what kind of stuff?
>
> Layla: Mainly catheter block, blocked catheters.

Amanda: So, what's the process then?

Layla: They tend to try and fix it themselves until they get stuck. They don't want to wake me up cause it's, you know, 1:00a.m. But then it gets to the point where they're like full on dysreflexic, and so then I'm kind of like panic mode and the adrenaline is through the roof. Usually it's just trying to, make sure all that the tubing is clear. Otherwise, I'll do a wash out. I've had to do a lot of emergency changes as well.

Amanda: Can you tell me because I've never had to do it, I don't get dysreflexic.

Layla: I disconnect the day bag… and then you get the big, huge syringes, and you just push it in.

Amanda: So, you just push water through the catheter tube into the bladder?

Layla: Yeah. And you push some [saline] in and then you draw it out and when you draw it out and you can see a lot of the debris in there you can see what's blocked it up.

Amanda: Bloody hell. That's huge. And so, does usually flushing work?

Layla: Some people it does. One of them I can just, instead of putting water in, I just have to get the big syringe and just start just trying to draw [urine] out because they have really, really gritty, gritty residue.

Amanda: So, so if it doesn't unblock with the syringing or anything, then you have to do like a change?

Layla: Yeah. I did my first change… for someone who had completely, soiled the bed and I had to just try and do a quick change then we were late for all the team meetings — it was full on.

Amanda: So, hang on. So, go back to that again. So, this was in the day?

Layla: First thing in the morning after I'd been up all night clearing it, that it re blocked again and then had to change it. We've had cases where some people haven't packed exactly what they need and then I've been in a situation where they're totally dysreflexic and then I'm running

> around trying to find syringes. So, I'm actually ringing Suz [the other support worker], and I'm like can you come help me like find syringes I'm doing a catheter change right now. And then she's in panic mode trying to find equipment.

Both athlete and support worker were up all-night managing life-threatening impairment effects. This is an excellent example to demonstrate how crip time challenges conventional notions of time; how disability shapes and reshapes experiences of temporality. It emphasises the non-linear, unpredictable, and often slower pace of life, where the demands of impairment and accessibility impact heavily on both athletes and support workers. Kafer (2013) explained how 'crip time' is viscerally understood by people who experience it. Support workers through peripheral experiences and intimate knowledge gain 'crip affiliation', leading to an in-depth understanding of disability embodiment (Kafer, 2021).

Support workers are the able-bodied hands managing the impact of unpredictable bodies in often inaccessible environments or conditions. They carry the physical and emotional burden of supporting athletes to manage their impairment effects. Suz stresses: "I feel sometimes exhausted and I go to bed and I can't sleep, because I feel like my adrenaline is so high". Ironically, failing to acknowledge the degree of responsibility carried by support workers, some of the athletes' hand over the "authorship of caring" (Rivas, 2011, p. 79) which may well be the most caring gesture of all. Rivas (2011) continues, "how could something unseen be completely valued" (p. 80)?

> Some people are just too easy breezy. They're like just do it how you want. But no! I want to do it how you want it. I need you to be comfortable. Obviously, every single person has their own routine and maybe a different setup, with how they like everything. So, I'm like, no! Tell me what you want and I'll do what you want. (Layla)

Despite these experiences, many national disability sport organisations do not recognise the importance and value of care. Leading up to the Paralympics, the consequences of neglecting care for an elite Wheelblacks member became tragically clear. Her teammate, Ben, describes the situation:

> Marama had sepsis and she had her leg amputated… She was pretty much dead... She's been sitting on it for years, and we've all known about it. Pressure areas are

> serious and we’re traveling around the world. There should be someone [in our organisation] doing a bill of health and making sure that players haven’t got fucking health issues going on… the team are a unit and when things go wrong for one it has an impact on all of us.

Bringing to light the power of ableism, Marama did not speak out about her health issues for fear that she would no longer be seen as ‘one of the team ’and further marginalised:

> I knew that it was there. I was just ignoring it because we had things coming up and I didn’t want to miss training because people might say stuff about me. But my body was hurting, just everything was hurting.

Ahmed (2013) suggests that sometimes “it is difficult to talk about the experience of pain”, as “pain is not only a bodily trauma, it also resists or even ‘shatters’ language and communication” (p. 22). Marama’s silence highlights the double-bind often faced by women in sport, where expressing vulnerability or need for care is perceived as weakness (DePauw, 2023a). Thus, the disconnect between the organisational stated aims of “equal opportunity” (NZWR, 2010, p. 8) and practice led to ‘organisational trauma at the level of the body’, where Marama ignored and suppressed her pain in service of the team.

> Cause I always felt so much pressure. I would think that I’ll have to be good and I have to be well, even if I wasn’t… I don't like letting people down and I knew they needed me and were relying on me, so I just put them first. (Marama)

Internalising societal and organisational pressures to perform (Ahmed, 2012a), able-bodied and disabled elite sport athletes (regardless of gender) are socialised to accept a ‘culture of risk’ (Charlesworth & Young, 2006), and accept injury and pain as a career norm (Agnew & Drummond, 2018). Yet, as a result of an untreated pressure sore, Marama spent 6-months in hospital and had half her pelvis and one leg amputated. Marama’s experience tragically highlights a critical gap in the organisational policy, research, and practice. For highly impaired athletes there is a disproportionately higher cost of “playing hurt” (Liston et al., 2018, p. 668).

While ableism is embedded in everyday life (DePauw, 2023b), Marama’s example shows how high performance disability sports’ powerful disciplinary and normalising techniques produce subjects, who willingly, yet often unconsciously, imitate able-bodied norms, leading them to monitor, discipline, and subjugate themselves and others into conforming to ableist standards (Avner et al., 2014; Campbell, 2009; McRuer, 2006; Silva, 2023). Marama's injury occurred while the Wheelblacks were competing to qualify for Tokyo; therefore, under the care of HPSNZ. While there are no formal duty of care policies embedded in NZWR's constitution, there is currently a commitment by HPSNZ (2024a), in their 'Well-Being Framework and Guidelines' to "lead well-being assessment and accountability in the sector". Thus, there is a strategic commitment by HPSNZ to ensure athlete welfare is prioritised, it becomes clear that the ableism underpinning high performance sport means that commitment to well-being should be reframed as 'able-bodied athlete well-being'. When governing organisations espouse well-being without understanding its application for high performance para-athletes, it amounts to nothing more than lip service. As Ahmed (2012a) suggests, "even commitment can become tick the box… [The] approach to diversity in which institutions go through or along with the process but are not behind it. Even a commitment can involve going through the motions" (p. 118).

A senior official occupying leadership and governance roles in both a national sporting organisation and para-sport Hannah, notes:

> It's a lack of awareness, lack of understanding, and looking down on [highly impaired athletes]. I honestly think it's a massive lack of understanding of what is actually involved in a low point athlete going from here – sitting in an airport lounge, to participating on the court – on the field. Because the typical able-bodied pathway is dominant, everything [from that perspective] is seen as the norm, and unless you are completely immersed – that is completely immersed, not just coaching here and there, or administrating, even boards and governance… Unless you've travelled, been immersed, lived with [highly impaired athletes] or been in situations, you just won't have that insight.

This section vividly demonstrates how the complexities of care, lived realities of interdependence, and crip time, challenge conventional notions of 'high performance athlete'. The management of life-threatening impairment effects is complex, requiring constant vigilance and quick, skilled responses, in often unpredictable and demanding situations, underscoring the challenges faced by support workers and highly impaired athletes of navigating high performance sport. Recognising the invaluable insight and dedication of support workers presents disability sporting organisations with a crucial opportunity to grasp the essence of crip time and foster a deeper understanding of athletes' lived realities. This approach would create multiple benefits. It would engender an environment where support workers' contributions are recognised and rewarded. Furthermore, it would generate a positive sporting environment where athletes thrive and perform at a high level.

Despite the intense physical and emotional burden placed on support workers, their crucial role is often overlooked. It is imperative for disability sporting organisations to recognise and address these challenges, ensuring that teams are adequately resourced and supported to manage impairment effects successfully. The complexities of care, lived realities of interdependence, and support workers' invisible labour are explored in the following section.

Invisible Labour and Interdependence

As outlined above, the support worker's role in the team is integral, yet unrecognised and unrewarded in high performance disability sport. In Chapter Two I argue that care, 'dirty work' (Rakovski & Price-Glynn, 2010; Wolkowitz, 2006), relational labour (Kelly, 2016), and emotional labour (Hochschild, 1983, 2012), do not capture the breadth and depth of the role that support workers play in helping the athletes manage the material, physical, and psycho-emotional impact of impairment effects in the high performance arena. One of the more care intensive para sports is wheelchair rugby, as it is a sport that requires players to have a significant impairment in at least three limbs. Wheelchair rugby athletes typically have functional impairments such as spinal cord injuries, limb deficiencies, or neuromuscular disorders (World Wheelchair Rugby, 2022). Developed in the 1970s, wheelchair rugby is well-established in the para sporting arena, whereas the inclusion of highly impaired athletes in other sporting programmes varies from country to country due to differences in cultural attitudes, funding availability, and the accessibility of facilities and resources. This section is based on data from the team and their support workers.

New Zealand's wheelchair rugby team of eight players travel internationally with only two support workers. Four of the team's players require support in the bathroom. Support worker Layla spoke about how often they end up with one accessible bathroom for the whole team, and the issues that the athletes and support workers sometimes face scheduling and managing cares. She notes how "[t]here's been times where people are going at the exact same time… where, you know, we've got one accessible bathroom for the four guys that need help" (Layla). While not everybody needs help, they still must "work out a schedule with like six, seven people for one bathroom" (Layla). As noted, highly impaired bodies do not always respond to the clock; at times functioning unpredictably or at slower pace than the norm, making crip time a key consideration of this scheduling (Kafer, 2013; Katzman et al., 2020).

The process of cares does not happen alone for athletes with the highest levels of impairment. Interdependence with support workers is a vital aspect of athletes' everyday lives and sporting lives (Lowry et al., 2022). Support worker Suz discusses how the team manage and schedule their own cares when on tournament:

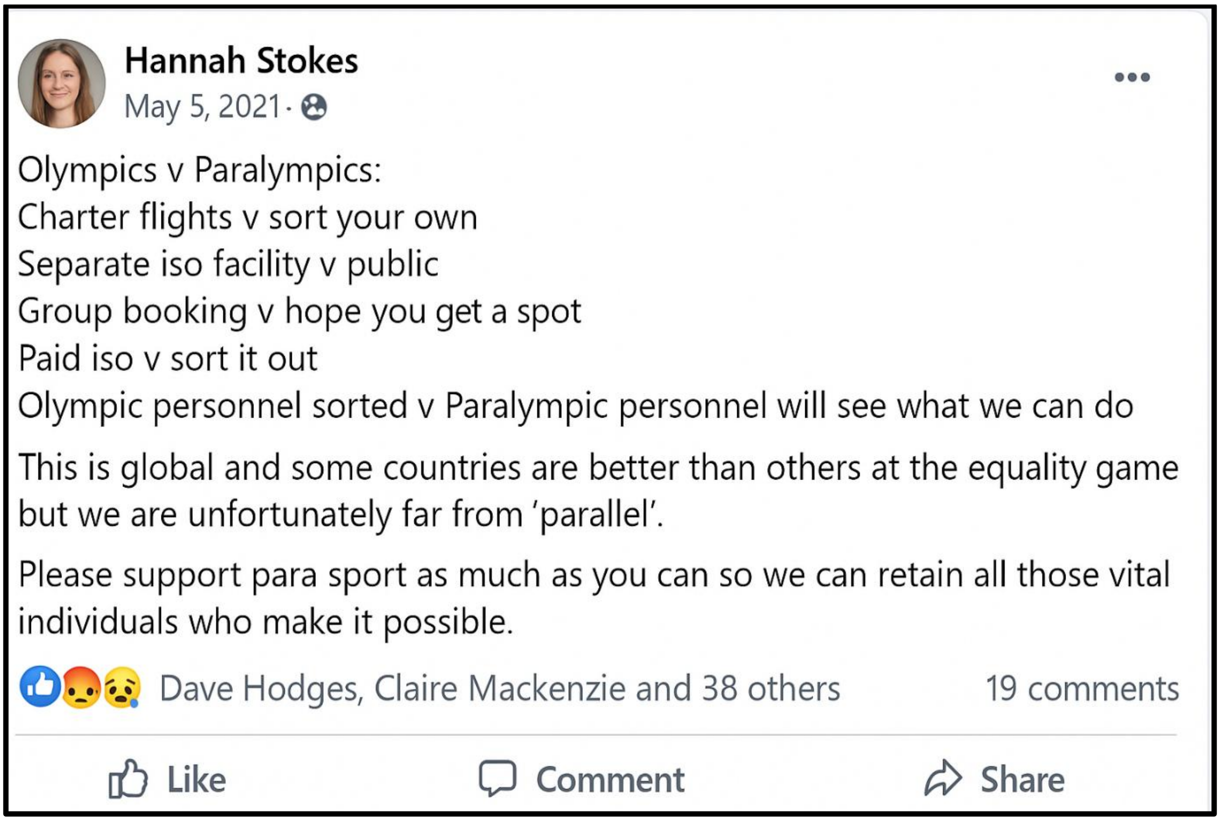
> The guys who do need my help they would already work it out... depending on the schedule, when they want to do toilet routines. Say we're on a tournament for, you know, a week, or even 4-days they will tell me, if they will need me that night or the next morning… Again, that's very individual.

The team support workers acknowledge how important it is for their labour to remain invisible so that the athletes can experience a sense of sovereignty and autonomy over their bodies, and their lives (Wolkowitz, 2006):

> A lot of people do find that really good balance… For instance, one of the guys, he dresses himself every day, but when it comes to game time and tournament – so he's not using up all his energy dressing himself, he asks for assistance. So, I think they can find that good balance themselves. You just kind of have to wait to be told what to do, or like asked what to do. Cause you don't want to interfere. (Layla)

Despite an incredibly demanding workload, the support workers that travel with the NZWR team are unpaid volunteers, which in and of itself is illustrative of the value attached to the role at the structural and institutional level of disability sport provision. Indicative of enlightened ableism (Lyons, 2013), the commitment to inclusion from organisations responsible for disability sport only reaches those who are viewed as competent, self-sufficient and autonomous (Goodley, 2014; Goodley & Lawthom, 2019), and for whom minimal adjustments to the broader power structures are required. Highlighting this point, Figure 36 is a Facebook post from a national senior sport leader and para-sport governance official. She was angry about the discrepancy between the support that Olympic athletes and

Paralympic athletes received managing COVID restrictions while attending Tokyo Paralympics in 2021:



Hannah Stokes
May 5, 2021 ·

Olympics v Paralympics:
Charter flights v sort your own
Separate iso facility v public
Group booking v hope you get a spot
Paid iso v sort it out
Olympic personnel sorted v Paralympic personnel will see what we can do

This is global and some countries are better than others at the equality game but we are unfortunately far from 'parallel'.

Please support para sport as much as you can so we can retain all those vital individuals who make it possible.

Figure 36 - Facebook Post: National Sport Leader and Para-Sport Governance Official

While organisations in disability sports are pledging inclusion, they are *failing to back* duty of care promises with tangible actions, rendering their approach 'non-performative' (Ahmed, 2012b), further reinforcing the inclusion/exclusion paradox of para-athletes. Institutions that deliver disability sport determine 'who gets what', without the in-depth understanding to interpret what people actually need (Fraser et al., 2004). As Campbell and Brown (2021) assert, personal care assistants for disabled athletes are viewed as a luxury rather than a necessity for optimal performance, further undermining disabled athlete sporting parity. These injustices generated by organisational 'lip service' require independent remedies of recognition (grounded in athlete lived experience) and redistribution (of carers and resources) to facilitate inclusion (Fraser, 2007; Shakespeare, 2014).

Given the culture and lack of recognition in some high performance disability sports, the small support crew of "donated talent" (Campbell & Brown, 2021, p. 128) puts pressure on the whole team. Wheelchair rugby representative, Ben, asserts:

> I think we definitely need more people around us to be the best we can be… We're pretty low on stock… We've got two carers at the moment – Layla and Suz. That's not enough. What happens if one of them gets sick, or injures themselves?

Ben's stark and dehumanising reference to support workers as 'stock' highlights the pervasive nature of neoliberal ableist thinking that strips away qualities of "humanness, mutuality, vulnerability and dependence" (Goodley & Lawthom, 2019, p. 236). In effect, support workers through this lens become mere tools and commodities that enable autonomy through interdependence (Meziani et al., 2017). Interdependence is in opposition to the autonomous, self-sufficient, and self-contained subjects of the neoliberal world, and disabled people inherently know they are perceived as the damaged Other (Campbell, 2009; Campbell & Brown, 2021; Goodley & Lawthom, 2019; Wolbring, 2012). Thus, to negatively frame support workers who enable independence as "stock", is the emulation of ableist norms – an expression of internalised ableism (Goodley, 2014). However, while this subconscious negative connotation was articulated, in every other conversation or exchange about support workers the athletes showed nothing but respect and care. William summarises the team sentiment:

> We are lucky that they are great at what they do… They definitely spend some days, just under the pump. I feel really sorry for them… Suz has been doing it for a long time, I certainly couldn't take my carer along to do that job, she wouldn't cope.

Ben spoke about their experiences at Tokyo 2020 which had even more restrictive policies around numbers of support staff allowed for athletes.

> It definitely could have been better… It's stressful, you can see that they were stressed and it came across to us. There were tears. It definitely could be better. I feel they've got the hardest job, first up in the morning, last to bed, fucking everything else they had to do [wiping everything down because of COVID requirements]. If you had an extra person, you might be able to give one caregiver a sleep in one morning 'cause you've got someone else that's going to go up and get that person up.

Being a support worker in a sporting context is not just the physical ‘arms and legs tasks’ that enable the athletes to compete (Kelly, 2016; Rakovski & Price-Glynn, 2010), but involves emotional and personal exchanges, which build enduring relationships (England, 2005; Himmelweit, 1999).

> I definitely love it… I so look forward to it. You get there, and even though you’re working really hard, and some parts are quite exhausting, especially the 1:00 a.m. call outs. But otherwise, the whole time… it’s just such an enjoyable environment to be around… You just become part of their life, don’t you? If you see someone ‘24/7’ you definitely get very close. (Suz)

Aotearoa’s national wheelchair rugby team volunteer support workers care very much about the players despite the intensity of the work. They are not remunerated for their work but continue to sign up and travel with the team. Support workers have constant pressure and responsibility in this environment, as Layla articulates: “the volunteer position is way more physically and mentally draining than my actual usual workload when I come home”. Despite the workload, the team support workers are committed. Suz discusses how she has been putting an important ‘life goal’ on hold: “I've been wanting to have a baby and I’ve been postponing, postponing, for bloody Paralympics. I do want to go to the Paralympics!” Fortunately, their hard work does not go unnoticed by the team, and the athletes openly show empathy, affection, affirmation, and compassion toward the carers that support them (Katzman et al., 2020):

> They’ve probably got one of the hardest jobs, maybe not in terms of mental stress but they are responsible for the team’s well-being, like if a player gets hurt or injured… When you’re out of your environment things go wrong. You might get burnt or turn up with a pressure area, and the carers have to manage that as well. They’ve got to monitor it. And they work the longest hours… because they’re looking after more than one person. (Ben)

Interdependence is not limited to the relationship between support workers and players. The wheelchair rugby team takes responsibility for each other when travelling and playing away from home by pairing low functioning players with a higher functioning player. This approach serves two purposes. First, it builds autonomy and self-determination among the athletes; second, it alleviates responsibility from the small team of support workers:

> Sometimes I room with Zac, and he'll help me grab something, or do something. So sometimes they'll put you with someone that's a little bit more able, if something was happening and you couldn't get up in the night, there's someone there that can help you grab something, or call a carer. Who knows, your catheter could be blocked, or something like that. (Ben)

This approach eases some of the pressure off support workers who can then rest knowing that the least functional players are supported by their more able-bodied teammates. Suz comments, "When there is emergency at night or something – the more able-bodied player can actually help or even contact me if there is an issue".

These experiences highlight how care does not always reflect paternalistic notions of dependency (Oliver, 1996; Shakespeare, 2014; Tronto, 1993); rather, embedded within it are opportunities for freedom and independence (Milligan & Wiles, 2010; Morris, 1997). Care in this context embodies a more relational, transactive approach, where it is constantly negotiated, reviewed, and adapted in response to circumstance and environment.

On game day, Suz discusses the integral role that support workers play:

> Lots of them need a lift from chair to chair, usually us with one of the men, then [some of the low pointers need help] strapping up, and then just making sure we grab their drink bottles, we ask them what they want – like an electrolyte drink. We mix that for them… So, when we get to the court it's all ready to go. Every athlete has a tray, which we put snacks and tubes and spare axles – so we know whose is whose. And before they get to the main court, everyone goes to the toilet. To make sure they have empty bags. It's not just low pointers who need a hand… If someone needs to go during the game, we have to try and get to the 'one' disabled toilet and it's usually busy – so you're spending your time waiting – losing time not being on the court. To make it faster we [usually] empty it into a bottle. We need to have organised a couple of bottles, like big milk bottles or Powerade bottles. There is always a couple in our bags which we carry all the time. If we do to go to the toilet you have to unstrap them and

> all that sort of stuff, and that takes too long – so to make it as quick as possible we just do it in the bottles.
>
> Amanda: So, the team see you as part of the team.
>
> Suz: Yeah, they always say, thank you. Because they know, they wouldn't be there or ready without our help. So that's nice, and that's why I think I'm still there.

As the Wheelblack support workers care for the team, they occupy a liminal position between the worlds of crip time and abled time in a complex and unpredictable dance. Stevens (2018) described how carers straddle both worlds, simultaneously a vital part of the team and an outsider. As detailed in the athlete and support worker interviews, while crip time bends time (Kafer, 2013), care time means living with the constant uncertainty as the need for care is not always linear, predictable, or organised (Stevens, 2018). Carers must become "adept at 'code switching' between the time zones" – between crip time and abled time (Stevens, 2018, para. 6): "Care time, like crip time, means every plan [they] make has an unspoken asterisk after it, because every plan is subject to cancellation. Care time means unpredictability" (Stevens, 2018, para. 6). Suz explained the commitment that they feel and the difficulty of getting a proper break:

> Liam or Brad will try to help us, they say, 'you guys just sit down and have your dinners', but there is always the feeling that our guys need a hand… [It is difficult because of] the amount of people we have. There are times that you get… [frustrated]. I guess you try to think of everything… But I'm just a carer – I feel we do a lot, you know, we do everything, we are always there… We try to do our best and do whatever the guys ask us to.

Care time means no time for oneself. Thus, for support workers there is constant tension when trying to find balance between care time and self-care when fewer of their personal needs are being met. Being a carer requires them to step away from everyday self-care and tune into the unpredictable reality of crip time. I asked support worker Suz how they looked after themselves in this intense environment:

Suz: The guys are generally really good. They always say, ‘you guys go have a rest. We’ll be okay for a while, cause you need to recharge as well’. Yeah since we’ve both realised the last few times we’ve gone away – we just need a bit of time for ourselves, and it is possible.

Amanda: So how do you take care of yourself? How does it work?

Suz: I guess… when I know there is a window in the day where I have few hours off, I either just hang out with other support staff, see what their plans are. You know, I might just sit down, have a cup of coffee together, or just go in your room and relax… whatever people feel like doing. Usually I lie on a bed for an hour and close my eyes, or when we went to hot countries, like in Korea… We’ll meet up for a quiet beer and just, and just chat about everything and anything that is *not to do* with rugby. So, we’re getting like a nice mental break.

While all of the data demonstrates the essential role that support workers play, Suz highlighted how their effort and commitment are, at times, taken for granted.

Suz: There were people in the past who may not have been that appreciative—sometimes demanding, or expecting things to be done without asking.

Amanda: You mean the guys were demanding?

Suz: More like the players expected us to do more, and sometimes they weren’t that nice about it. They acted like we were just there for them. They didn’t ask nicely. I get that emotions run high during games – I understand that, but there were definitely players who had higher expectations about what we should be doing.

Amanda: Were they respectful?

Suz: No, the respect was definitely missing.

The dynamic between support workers and players showcases a complex interplay of dependency and independence, revealing inherent tensions and challenges. Support workers must navigate the demanding nature of crip time, often sacrificing their personal needs to maintain the athletes' autonomy and performance. This relational, transactive approach to care emphasises mutual recognition and appreciation, showing that caregiving is far from a one-sided dependency but more a relationship in which both partners contribute (Wolkowitz, 2006).

While this relational, transactive approach to care fosters an environment where freedom and autonomy are actively negotiated and supported, it can obscure the significant physical and emotional toll on caregivers. The constant balancing act required to meet both their caring responsibilities and self-care needs highlights a systemic issue where the current support structures rely heavily on the dedication and selflessness of these workers. Thus, while their commitment undeniably contributes to the athletes' success, it also raises critical questions about the sustainability and fairness of such caregiving models. This situation calls for recognition and a more equitable distribution of resources to ensure that caregivers are not unduly burdened, and their well-being is prioritised alongside that of the players. The complexities of being a caregiver in inaccessible environments is examined in the following subsection.

"There's Always Something That is in Our Way to Deliver Care"

Not only are athletes and support workers negotiating impairment effects, but their ability to deal with them is exacerbated by inaccessibility (Campbell & Brown, 2021). Layla says: "There's always something that is in our way to deliver care to someone, whether it's non-accessible bathrooms or doorways that are too small so people can't get in anywhere, even during tournaments, sometimes they block off toilets". Ben expands on some of the physical barriers that they face when they travel and compete:

> You gotta improvise, you gotta be prepared to shit in a bucket or you might have to get lifted into a shower. I remember I had to have a bath once because, there was just no way to shower… When we went to Japan last time I couldn't even get into the toilet in my day chair[27] cause the door was too small. You can't even get in there to brush your teeth or do anything.

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[27] A day chair is a lightweight wheelchair that is manually propelled by pushing the large rear wheels.

Layla reiterates Ben’s point, but from a carer’s perspective:

> [I]n Japan… because of all the bidets and stuff, the commodes didn’t fit over the toilet. So, everyone was having to go over a bucket. I had two guys side by side in a bathroom over a bucket at the same time only because one of them was like, ‘Oh yeah, chuck me in there too’. And I was like, ‘I don’t think you’ll want that’, and they were like smiling, and saying, ‘we don’t care – come on in’. So that was quite easy. Cause I was just going back and forth [between the two of them], but anything that could’ve gone wrong, went wrong. So, we had blown haemorrhoids and blood everywhere. We had everything happening. And it was just me jumping between two people – we were lucky we made it to the game on time.

Intimate acts required by disabled bodies ‘to shit’ blur the conventional boundaries between private and public spaces, between inside and outside, providing an alarming embodied confrontation with the abject – their messy, untrustworthy, leaky bodies (Douglas, 2003; Grosz, 1966; Kristeva, 1982; Longhurst, 2001). Athlete identity is constructed on compulsory able bodiedness (McRuer, 2006). Highly impaired athletes in sport spaces designed for more abled bodies are crossing borders and disrupting the conceptions of athlete identity. Longhurst (2001) asserted that bathrooms, and what goes on in them, have not been excluded “because they are unimportant (they are as political as any other space)”; they have been excluded because they are threatening to those who construct “what counts as legitimate knowledge” in sport “and who can bear that knowledge” (p. 89). The athletes in this study proudly talk about the “weighty, messy materiality of flesh” and the “fluids that cross bodily boundaries on a daily basis” (Longhurst, 2001, p. 89). The finding is in keeping with Longhurst’s (2001) exploration:

> In this conversation vulnerability becomes (re)constructed as its binary opposite, powerfulness… Feelings of impotence, forcelessness and emasculation over broken corporeal boundaries and bodily residue are recast as an attempt to appear powerful, forceful and robust. In this instance ‘shit’ is turned into a positive signifier. (p. 89)

These intimate; embodied negotiations of bathroom care are not only spatially marginalised but temporally disruptive—demanding time, flexibility, and attention that high-performance sport rarely accommodates.

As Layla's lived experience exposes*, "crip time is time travel",* (Samuels, 2017, para. 3), [emphasis in original] and a forced departure from the linear, able-bodied timeline, where highly impaired athletes and their carers navigate a 'wormhole 'of fractured and unpredictable temporalities.

Rashmi talks about the difficulties that her and her mum (who was her carer) faced when competing internationally:

> Because they only had limited disability rooms, we had to have an able bod room [with a] massive glass wall in the shower area and I couldn't walk all the way down… So, I was [asking myself], 'how am I going to shower? I've got no idea how I'm going to manage'. Mum had to grab the actual shower nozzle, pull it to the end and we had to get like a picnic chair and do all those little things that nobody really thinks of. Mum had to hold my chair while I tried to transfer, because on a normal basis, I've got a bar [in my bathroom] to hold on to.

Despite these challenges, highly impaired athletes are expected to perform at the same level as their able-bodied counterparts, when they often compete and stay in spaces that are not accessible, without extra support readily available. Disabled athletes must purposefully plan, acknowledging the extra time required waiting for access or support, and the opportunity for very real bodily harms (Bailey, 2021). From an able-bodied perspective, it is often assumed that the barriers of living with impairment can be overcome by individual effort alone, ignoring the complexity of disability experiences (Bredahl, 2010; Silva & Howe, 2012). While carers face systemic barriers, athletes too must navigate these gaps. The following section details how athletes turn to each other, sharing knowledge and strategies for quality of life in a nonnormative body.

"Just Get Off the Toilet and Start Living Your Life!"

As shown thus far, organisational support is often not available to help athletes navigate training and competition demands. However, as I highlighted earlier through the notion of crip kinship, those involved in disability sport commonly share their knowledge and expertise with new athletes about a range of topics related to inhabiting a nonnormative form. Forming an embodied learning community, the athletes often discuss transferring; skin, bowel, and bladder care; and achieving daily tasks that bolster independence (Goodwin et al., 2009;

Lindemann & Cherney, 2008). Ben, who was one of the more experienced players in the Wheelblacks, describes his pride in sharing the ‘tricks of the trade’ with new players.

> I’ve learnt so much about independence from rugby, because [others have] been there showing me how they’ve done stuff, I feel it’s my duty to be showing that to the new guys. We had the new low pointer Ian along to camp on the weekend, and I showed him how I transferred, got dressed and stuff like that, and over the last week I’ve been sending him videos on stuff, so he can replicate stuff… I love doing it anyway, but someone’s taught me, so you know, I’ve got to show these fellas.

Ben highlights the interactive process of embodied knowledge sharing in disability sport, where the group’s collective knowledge is a key resource enabling athletes to integrate their own experiential learning with insights from others (Asare et al., 2023; Barbour, 2002). William clearly expresses this point:

> One of the most important things I think wheelchair rugby has helped me with is meeting all those people in similar situations who have been through what I have been through and who can pass on invaluable life skills that would have taken me 10+ years to figure out. But just hearing it directly from guys, like Ben, his level of injury is higher than me, so he is more disabled than me, but he is so independent and functional… I have learnt so much off him.

Four-time Paralympian, Hunter, who has been 22-years in a chair, discusses how he received support from an athlete in a different sport with a similar level of impairment.

> Even now, I’m still learning. ‘Cause your cares are such a headache right? It wasn’t ‘til I went to Athens in 2004… 8-years after my accident and, I was talking to one of the wheelchair rugby guys. I had like a revelation… I’d spend forever on the toilet and my attendant would always have to check to make sure everything was empty. I was always paranoid… And [the wheelchair rugby guy] was like, ‘You’ve got to get to a point where you just go – don’t worry about it, fuck it. Just get off the toilet and start living your life!’ Those sort of things [are invaluable].

As the solo disabled shooter for Aotearoa, at the Paralympics, Hunter had the opportunity to engage with other disabled athletes. The wheelchair rugby player that he spoke to was part of a community that shared their knowledge and experience ‘of being a quad’ to support new players. The culture of wheelchair rugby teaches participants empowering attitudes toward their body and how to get along in the ‘real’ world, challenging the conservative advice provided by medical practitioners (Lindemann & Cherney, 2008). They discuss how sharing knowledge of how to navigate the material body (particularly for those with acquired impairments) is an important rehabilitative element of disability sport (Asare et al., 2023; Lindemann & Cherney, 2008). As Asare et al. (2023) highlight, there has been limited research into the way athletes learn about disability and embodiment in sport. What their study found was access and engagement with “teammates and peers” created a “network of embodied skills and knowledge” (Asare et al., 2023, p. 9), which was considered crucial when learning to navigate a purposeful and meaningful ‘new life’. Layla notes that the biggest achievement for the team in 2021, was:

> Ben teaching Ian how to get in and out of bed. They spent probably 30-40 minutes over a lunch break transferring on and off their chairs onto a mattress in the gym. Jarne and I were both there spotting. But that ‘one thing’ means Ian can now have a life. He wants to go for that beer, he can put himself to bed and get up in the morning and save those care hours for when he needs them. While it takes longer, he said it’s changed his life completely, and you’d never learn that in another environment.

They openly share knowledge on how to do things better, to help each other gain greater independence and freedom. As Ben states, “sharing understandings of our bodies, that’s what gets the best out of what we do”.

In bringing to light the embodied experiences of impairment effects, this chapter demonstrates that impairment is more than biological or a relational socially constructed phenomenon, it is emotional and collective. In wheelchair rugby the whole team (including support workers) understand each other’s physiology in an intimate embodied way, on and off the court. They know different approaches to cares, who gets pressure sores, who bypasses, experiences blockages or dysreflexia, how each other dresses and transfers. Athletes’ and carers’ embodied experience of impairment effects underpin a collective, emotional, and visceral bodily knowing. The management of impairment effects generates a symbiosis that blurs bodily boundaries in and between athletes and their support workers. While a politics of knowledge has rendered leaky ‘messy’ bodies as inherently negative and untrustworthy, this research shows that they are reconstituted as the antithesis and generate a powerful sense of belonging identity and resistance. Impairment is not something you have – it is something that you are.

Summary

Drawing on crip theory, abjection, and critical disability research this chapter explored highly impaired athletes' 'everyday' embodied experiences in high performance disability sport, focusing specifically on the bio-social character of impairment effects. It highlighted the diversity, complexity, and levels of interdependence required for the management of (sometimes life-threatening) impairment effects. Dysreflexia is not just a biomedical fact but contingent on context; the emergency protocols, medical literacy among carers, and the allocation of care time within training. The chapter also explored how impairment effects underpin structural and psycho-emotional barriers that restrict disabled people's lives and intensify within elite sport—but which also generate crip resistance through collective knowledge and affirmative practices. As Thomas (1999; 2004) argues, ableist sport transforms impairment effects into avoidable disadvantages—where disability is not in the body, but in the structures that fail to meet it on the field, in the pool, and in every care routine we normalise or neglect.

While it is acknowledged in the literature that involvement in disability sport provides status, recognition, and a sense of belonging, the lack of acknowledgement of impairment effects and care requirements puts athletes at risk, and 'non-performative' organisations in breach of their duty of care (Ahmed, 2012b). In telling these stories, this chapter has exposed the politics of knowledge in disability sport that is closed to the taboo aspects of daily bodily functions, and the challenges highly impaired athletes face in managing them.

Crip time shapes the experiences of support workers and highly impaired athletes as they navigate the complexities of managing highly impaired bodies (Kafer, 2013). To illuminate the complex nature of support workers' role in highly impaired athletes sporting lives, the concept of 'care time' was introduced (Stevens, 2018). Care time highlighted the constant adaptation and 'code switching' between crip time and abled time required by support workers as they navigate the uncertainties inherent in caregiving. Notably, the empirical evidence shows the tensions faced by support workers as they strive to balance the demands of care time, encompassing emotional and relational labour, with their own needs, which are often overshadowed by the demanding caregiving responsibilities (Stevens, 2018). Crucially, the chapter emphasised the pivotal and vital role of interdependence, structure, and timing of care exchanges, and access that underpins highly impaired athletes’ sporting experiences (Lowry et al., 2022).

Building on ideas of ‘embodied knowledge’ (Asare et al., 2023; Howe, 2015; Powis, 2020) in high performance disability sport through the lens of wheelchair rugby, the research highlighting how shared experiences of impairment effects become a foundation for belonging, identity, and resistance. The athlete experiences powerfully reframing impairment as an integral and defining aspect of selfhood.

Despite the indispensable contribution of support workers to the welfare and success of highly impaired athletes, the care ecosystem underpinning such achievements remains largely unseen and unacknowledged in the realm of disability sporting literature. While highly impaired athletes’ embodied experiences challenge normative understandings of sport and athlete (DePauw, 1997; DePauw, 2023a; Howe, 2015), they are a powerful tool to push for the recognition of impairment effects, emphasise importance of care, and, most importantly, to bring change (Lowry et al., 2022). This chapter calls for a paradigm shift in policy and practice, advocating for greater recognition, visibility, and appreciation of both the lived realities of impairment effects and the critical role played by support workers in facilitating and sustaining the well-being of highly impaired athletes in the high performance sporting arena.

In extending my critical examination of care, the following chapter Athlete Care: An Uneven Playing Field, further widens the spatial scale to explore the experiences of highly impaired athletes and their relationships with organisational representatives, coaches, and athlete life advisors.

Chapter Six: Athlete Care - An Uneven Playing Field

In understanding highly-impaired athletes' experiences of being situated in high performance sport structures and institutions, this chapter necessarily takes a broader view to highlight how systemic arrangements—across health, sport, and funding, intersect to undermine equitable participation. This chapter analyses how healthcare provision, as a foundational element, alongside disability sporting institutions and regulations (within the broader context of government funding), shapes welfare and care practices for highly impaired high performance athletes. By examining the embodied experiences of highly impaired athletes at this macro-spatial scale, provides a unique opportunity to better understand the institutional and structural constraints that impact these athletes.

This chapter details the complexity of Aotearoa's disability health and sporting structures that highly impaired athletes must overcome to participate in high performance sport. Messy bodies with insecure boundaries tend not to be discussed when one is aiming for perfection in high performance disability sport, as they affront high performance organisations' ableist aspiration for athlete autonomy and perfection. Thus, the stories of highly impaired athletes, often marginalised and silenced, demand to be heard, for they hold the power to ignite change and push the global disability sport community towards a more equitable future.

Theoretically, this chapter is shaped and framed by Ahmed's (2012) theory of organisational non-performativity. The embodied experiences of highly impaired athletes provide a unique lens through which to expose the limitations of current systems and advocate for meaningful change. As Ahmed (2012) stressed, commitments to inclusion must be met with concrete action, "for a commitment to do something, you must do something 'with it'" (p. 120). Thus, non-performativity becomes a useful tool for highly impaired athletes as the utility of the universal commitment to inclusion in disability sports organisations generates principles those organisations are "meant to be acting upon" (Ahmed, 2012, p. 121). Those commitments become usable, as they allow athletes the opportunity make the global disability sports community subject to upholding those principles.

This chapter is grounded on interview material from fifteen participants, thirteen of whom have contributed to other chapters. Of the nine athletes four are wheelchair rugby players, two are sailors, two are shooters and one is a swimmer. There are two carers, two coaches and a HPSNZ performance life coach. Also included is a Senior National Sport and Para-Sport Governance Official. My insider status in the Paralympic development swimming squad and involvement in wheelchair rugby gave me access to the HPSNZ and SNZ officials who feature in this chapter.

This chapter is divided into six sections. The first details sport provision in Aotearoa in A Complex Sporting Landscape. The second section details the disability health landscape in Aotearoa in I Am Discriminated Because I Was Born Disabled. This section has one subsection access to Adaptive Equipment. The third section discusses the inequity in disability sport funding and resourcing in an Uneven Playing Field, with one subsection High-Performance Sport which details elite sport funding streams. The fourth section, the Illusion of Inclusion, brings to light the ableism and lack of understanding of highly impaired athlete care needs. This section has one subsection which discusses highly impaired athletes' experiences of Paralympics. The final section, Crip Change and Advocacy, brings to light the possibilities for organisational change with disabled athlete and coach advocacy. This chapter finishes with a brief summary.

A Complex Sporting Landscape

In Aotearoa, the government influences the sports sector through the distribution of public funding through its crown entity SNZ, and in the case of elite or pinnacle sporting success, HPSNZ. The SNZ Outcomes Framework and 2019 "Everybody Active" strategy outlines a holistic approach to promoting physical activity, focusing on inclusivity, cultural relevance, safety, and strong athlete support systems. Through this strategy, SNZ (2020) commits "to contribute to the wellbeing of everybody in Aotearoa New Zealand by leading an enriching and inspiring Play, Active Recreation and Sport system" (p. 14.). It includes a commitment to ensure that sporting infrastructure, policies, and programmes are accessible and cater to the needs of *all* participants. This entails recognising that equitable access and opportunity in sport requires a clear strategy across multiple sectors that acknowledge the issues, solutions, participants, aims, timelines, and responsibility for service provision delivery (SNZ, 2020).

Organisational oversight of disability and para sport in Aotearoa is complex and ever shifting. Strategically, HPSNZ works with NSOs to support high performance athletes. Some sports are 'integrated', such as swimming, athletics, and cycling, meaning that NSOs manage the para sport component. However, not all NSOs provide a dedicated para-specific pathway and often rely on broader structural support to deliver para sport campaigns. In contrast, some national disability sport organisations (NDSOs), such as NZWR, Blind Sport New Zealand, and Boccia New Zealand, focus exclusively on para sport (e.g. Figure 2, p. 11). While PNZ historically received funding from HPSNZ to develop and manage elements of the para sport pathway, a major shift occurred during the course of this PhD, with responsibility for several para sports transitioning to NSOs. Prior to integration para-athletes found themselves navigating at least two organisational systems—each with performance expectations and overlapping obligations toward athlete welfare and care. This transition in governance does not resolve the systemic issues identified in this thesis; rather, it raises further concern. While disability-specific organisations such as PNZ hold great experience in para sport, their support often privileges the most physically able athletes, leaving those with higher support needs marginalised. Integrated NSOs, meanwhile, lack the institutional understanding to recognise or meet the complex care and welfare requirements of highly impaired athletes. As Quinn et al. (2022) notes, while the integration of para sport looks good in theory, it often comes with a hefty price tag. The ableisation of para sport leads to the "growing exclusion of athletes with greater impairment from high performance spaces" (Quinn et al., 2022, p. 573). Thus, without clearly defined and adequately resourced duty of care provisions, integration risks deepening existing inequities and placing further strain on para-athlete welfare.

Because of the lack of clear para sport pathways from NSOs, many sports organisations rely on the talent identification and development efforts of regional disability sporting organisations (RDOs). While key players in the disability sporting landscape, RDOs face significant challenges, relying on ad hoc government funding, donations, and grants (McBean et al., 2022). While under-resourcing hinders many New Zealand sports, it disproportionately impacts disability sport, which is unable to fund the support staff to aid para-athletes. This limits the potential for aspiring national teams to compete successfully on the international stage against better-funded nations. Consequently, the transformative potential of inclusive disability policy is severely hampered by a lack of funding to support para-athletes' care needs in Aotearoa's sporting sector.

Figure 6 illustrates the complexities of resourcing within the system. Blue lines represent financial connections between organisations, with dotted blue lines indicating partial funding relationships. Grey lines pertain to athlete funding, where solid lines denote guaranteed funding streams and dotted lines indicate potential sources of funding for athletes.

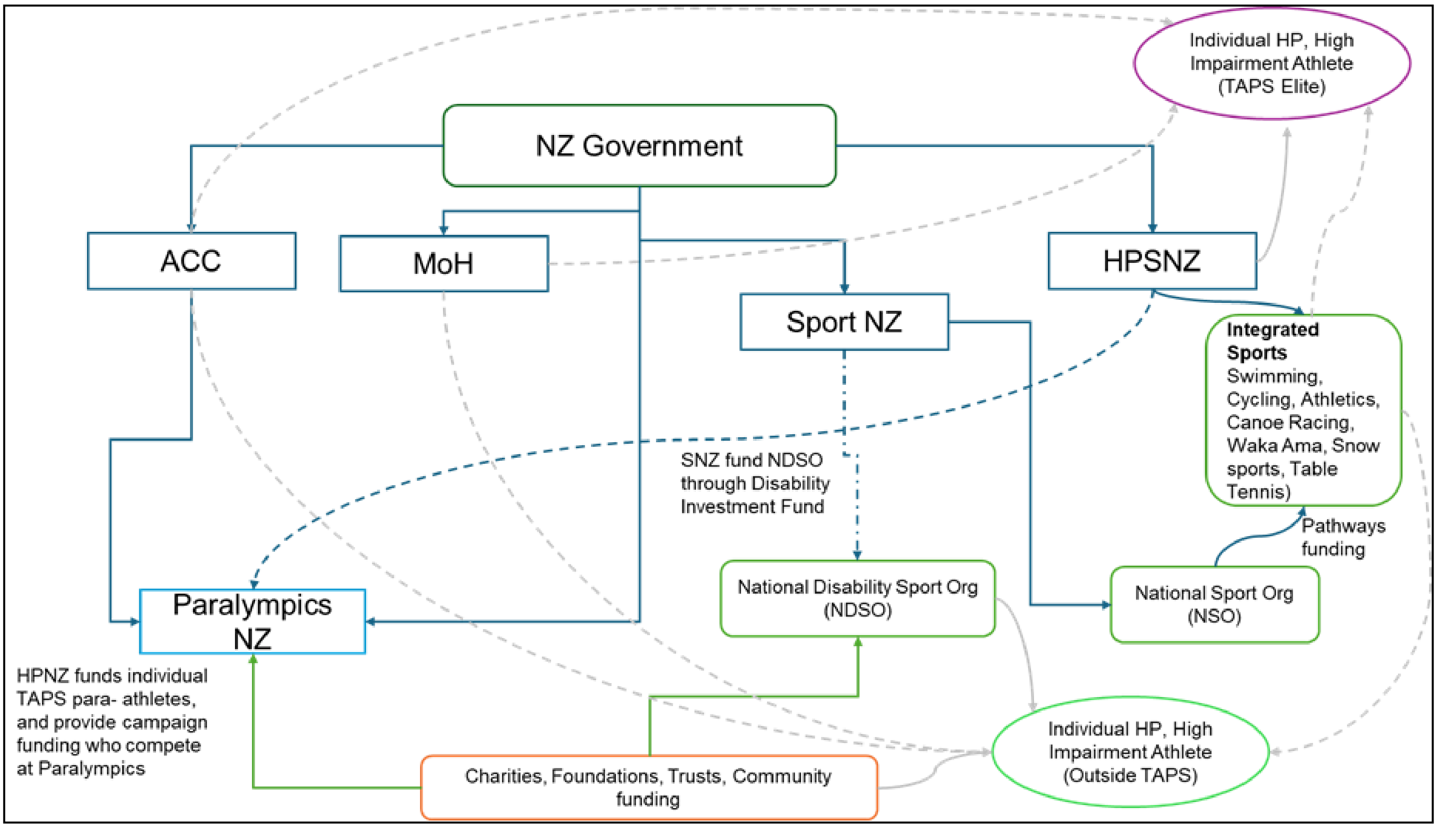

Figure 37 - New Zealand High Performance Sport Funding Landscape

Image created by Kirsten Petrie and Rob Townsend, (2025).

At the strategy level, HPSNZ (2024b) commits to “enhanc[ing] system capability to ensure that wellbeing is everyone’s right and everyone’s responsibility” by “support[ing] our partners to develop sustainable wellbeing best practice in their high performance environments” (p. 9). They state they will “lead wellbeing assessment and accountability in the sector based on the Wellbeing Framework and Guidelines”, through the “effective monitoring and response mechanisms safeguard[ing] the wellbeing of those in the high performance system” (HPSNZ, 2024b, p. 9). Yet, in the Wellbeing Framework Guidelines, HPSNZ’s (2024c) commitment to athlete well-being is articulated in the following: “We are committed to enriching wellbeing in high performance sport environments that empower and support individuals to optimise their potential and enhance their ability to thrive in sporting and non-sporting lives” (p. 2), with no specific details of what a commitment to enriching well-being might entail. Thus, while HPSNZ clearly articulate a commitment to athlete well-being, disability places demands on welfare and care (thus well-being) that is often not accounted for in strategies.

In 2021, high performance cyclist Olivia Podmore died by suspected suicide, having shared on Instagram just hours earlier about the intense pressures she faced in elite sport (New Zealand Herald, 09/08/2021). After a scathing in-depth review of Cycling New Zealand Heron (2018) details significant failings in the organisation's culture and practices, particularly regarding athlete welfare, there was a shift in HPSNZ strategy concerning athlete welfare. In 2022 HPSNZ (2022) committed "131 million direct investment into sports over the next three years to support both performance and well-being outcomes". What is clear however, is that higher level organisational commitments to well-being do not drive necessary organisational change, undermining equitable sporting experiences for disabled athletes (Lowry et al., 2022). As Ahmed (2012) notes, "a symbolic commitment does not necessarily represent an institutional commitment" (p. 130). Without a purposeful organisational focus to understand and embed para-athlete care requirements at the heart of high performance practice, athlete welfare is compromised.

When focused on high performance disability sport, PNZ's (2024) inspiring vision and mission statements assert 'through Para sport, lives will be transformed'. Disappointingly, despite this aspirational commitment, their strategic framework lacks any explicit consideration of athlete and employee well-being and welfare, instead deferring to the broader provisions of New Zealand's Health and Safety at Work Act (2015). This absence of a dedicated focus on well-being, welfare, and care is surprising given the increasing scrutiny that sporting organisations have faced regarding athlete care (Cottrell, 2018; Fitzgerald, 2021; Kavanagh et al., 2021; Lang, 2020; McCulloch, 2020). The lack of clear and directive policy and process embedded in elite sport organisations highlights Aotearoa's laissez-faire approach to welfare and care – an approach that has fuelled intensified scrutiny of athlete well-being and high-performance sport over the past decade (see Heron, 2018, for more detail). How these issues play out in para sport are, concerningly, not well understood.

These structural gaps in sport provision mirror deeper fractures in Aotearoa's healthcare system— where how you became disabled, determines the care you receive, and your access to sport.

"I'm Discriminated Against Because I was Born Disabled"

Sport does not operate in a social or institutional vacuum. Disabled people regularly navigate multiple institutions and systems in their daily lives to achieve minimal self-determination.

These systems range from invasive needs support assessments, fund and personal care management, equipment provision, and often ableist healthcare institutions. Stella sums up the complexity for aspiring high performance athletes:

> Because I'm playing sport it makes me look too able – they hang that over my head all the time. They say if you're able to do that then you should be able to feed yourself, shower yourself, hold down a full-time job. But they just don't get it – I can only play sport because I have the support in place.

Consequently, broader structural dynamics create significant barriers that limit highly impaired athletes' ability to train and compete.

> It's a real tricky one cause the funding from high performance sport only kicks in when you've done well at a certain level, but how can you reach that level without enough health system funding? It is like a perpetual cycle of nothingness, because you need the support to *get somewhere*, but you can't have the support until you *are somewhere*. It's a really strange concept. (Stella)

Aotearoa, like many Western liberal democracies, has policies in place to uphold human rights and combat discrimination, including commitments to the UNCRPD (2006)[28] and the New Zealand Disability Strategy (2016-2026.). Reflective of Ahmed's (2012) articulation of nonperformativity, despite these commitments, disabled people often struggle to access the care they need. As Sakellariou and Rotarou (2017) and Wilkinson-Meyers et al. (2014) confirm, disabled people face numerous obstacles and report greater difficulty accessing healthcare services compared to their non-disabled counterparts. Because there is insufficient guidance on the specific resources (equipment, support, services) needed by individuals with varying impairments for participation, some needs remain unmet (Sakellariou & Rotarou, 2017; Wilkinson-Meyers et al., 2014).

Disability health provision in Aotearoa is uneven. The Accident Compensation Corporation (ACC) and the Ministry of Health (MOH) are the two primary state agencies responsible for

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[28] Article 30, section 5, subsection b. "To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources" (UNCRPD, 2006).

disability support in Aotearoa. ACC provides substantial financial and material assistance to individuals with acquired impairments, while MOH offers more limited support to those with congenital or degenerative conditions (Flood & Hardcastle, 2015), the provision of which is based on personal needs assessments. This creates a stark contrast in the support available for individuals based on whether their impairment is congenital/degenerative or acquired. As detailed in the literature review (Chapter Two), access to care and mobility equipment is a key element in enhancing or undermining involvement in disability sport (Asare et al., 2023). Boccia Paralympian, Stella; Paralympic swimmer and wheelchair rugby player, Zac; and Paralympic sailors, Jack and Anne, are all athletes that receive care from the MOH. The other athletes in this research are supported by ACC.

The rise of populism, coupled with the widespread acceptance of neoliberalism, has presented challenges to Aotearoa’s public health system (Moore, 2017). Within this climate, marginalised groups are often portrayed as undeserving if they fail to reflect the interests or lifestyles of the majority (Moore, 2017). Thus, the state, far from being an abstract entity, is complicit in the creation of the ‘Other’ (Mountz, 2010). Consequently, within the current climate of austerity, highly impaired athletes reliant on the MOH face increasing systemic inequity in public funding, significantly impacting their access to essential care and equipment (Goodyear-Smith & Ashton, 2019; MOH, 2020; Reynolds, 2024). A participant with a congenital impairment explains her experience of her personal needs assessment (PNA).

> Care provision is based on your ability, or lack of it, which entitles you to get a certain number of hours per week. Those are required for personal care or home support… But I use them a lot more creatively – originally it was only for showering and dressing, but now it’s a bit more flexible. But is quite a negative way of operating but as [an adult], and having an impairment all my life I’ve learned how to play the game. The worse you sound, the better support you get. I’m not too ashamed to say this… I don’t clean my house before they come, I don’t look very nice when they come. It’s just about painting a pretty grim picture of what your life looks like… The badder you are, the better you can have it. Don’t present yourself and the best light as its always gonna be counter-productive to what you need and that just wrecks your soul. You are always playing yourself as a victim or needy, and that takes a toll. You have to fit into certain boxes to get certain amount of funding, so if you don’t make yourself look a certain

> way you will get less. And I can't operate with less… On the outside you and I are amazing, but we have to make ourselves small to get what we want to live big lives.
>
> (Personal comment anonymised to protect the identity of the participant)

Morrison et al. (2020), like the participant, had to present her own disabled son's life on the "worst day possible" (p. 10) in order to get the support they needed. She discussed how a "needs assessment process is a highly embodied and emotionally charged experience" and required preparation to "reduce your life into measurable moments" (Morrison et al., 2020, p. 8). There is shame attached to this process (Morrison, 2021); when one's body is monitored, pathologised, and measured against unattainable normative standards (Goodley & Runswick-Cole, 2016). Shame is "the body saying that it cannot fit in although it desperately wants to" (Probyn et al., 2004, p. 345).

Inherent in neoliberalism, there is constant pressure to reduce the state's role which, undermines public health provision (Crampton et al., 2020; Sakellariou & Rotarou, 2017), resulting in chronic underfunding of disability support. Budgets consistently fall short of actual needs, not due to excessive spending but because the allocated funds are simply inadequate (Reynolds, 2024). As a result, the provision and funding for disability support in Aotearoa has not kept pace with need (Health, 2020; Wilkinson-Meyers et al., 2014). As Sakellariou and Rotarou (2017) argued, this constitutes "structural violence, disproportionately affecting the most vulnerable parts of the population, curtailing, directly and indirectly, access to basic rights, such as healthcare" (p. 6). For example, Rashmi's describes how care provision contained no flexibility to enable her life choices. Like the first participant, Rashmi struggles for access to care, "you have to fight to get the hours that you need, but you don't always get the hours that you need".

Her carers only wanted to come between 12 and three in the afternoon which clashed with her training and work commitments. While disabled bodies have always been 'taylorised' to access support services (Wolkowitz, 2006), the system is "primarily organised around the scheduling and efficiency needs of providers" (Wilkinson-Meyers et al., 2014, p. 1545). Rashmi's support, like that of the first participant, is structured on clock time, forcing them to organise schedules, manage funds and "strategies to predict, budget and plan ahead", with no ability to compensate for the “unpredictability of everyday life” (Katzman et al., 2020, p. 521), in a highly impaired, often defiant body.

The disparity in support is further amplified by the different approaches taken toward athletes with acquired injuries versus those with degenerative or congenital impairments. Athletes with acquired injuries receive comprehensive, long-term, individualised rehabilitation and financial support for injury-related care. For example, in 2013, following my injury, I received comprehensive support including a substantial lump sum payment, an extensive care package providing 100 hours of support per week, both a power chair and a manual chair, a new modified self-drive vehicle, a disability allowance equivalent to 80% of my income, and a contribution towards building an accessible home, regular mobility equipment reviews, and sports equipment. This level of support is guaranteed for life. Other participants shared similar experiences of ACC’s comprehensive support. Hunter’s family, for instance, received assistance to build a granny flat onto their home.

Healthcare provision is shaped by and responsive to broader political and economic ideologies. In 2024, the ACC’s integrated system was founded on the principle of providing “comprehensive support for highly impaired clients”, with a focus on enabling them to “live fulfilling lives” despite their impairments” (ACC, 2024). A 2025 search of the ACC website reveals no resources or information specifically related to individuals with permanent impairments. Instead, they generically commit to “improve lives every day through a focus on prevention, care, and recovery for all people in Aotearoa New Zealand who are affected by injury” (ACC, 2025). This shift in discourse is significant. While both statements are problematic, the earlier one, despite framing impairment as inherently negative and something to be overcome (with paternalistic overtones in its use of “enabling” and “comprehensive support”), is still ‘person-centred’. This contrasts sharply with the latter statement where the emphasis on ‘prevention’ aligns with neoliberal ideals of individual responsibility and self-reliance (ACC, 2025). Further, the absence of specific mention of long-term impairments, coupled with the focus on ‘recovery’, suggests a desire to ‘fix’ individuals, and restore them to a productive ‘working’ state, a perspective far removed from the social model of disability. As Campbell (2009) powerfully states, “my impairment cannot be separated from who I am. I cannot overcome my own body” (p. 159).

Ben's experience, however, highlights the stark contrast between the MOH and ACC. Because his accident occurred overseas, he initially fell under the MOH's purview, resulting in significantly less support and a more difficult transition.

> For the first 3-years I was on Ministry of Health. I wasn't on ACC because I was over in Australia when I broke my neck. If I'd done that here, I would have come out of the Burwood Spinal Unit with 24/7 care [168 hours], but I came out with 40 hours a week… While it probably helped with some of my independence, I had to move back to my parents. 'Cause fuck I wouldn't have been able to survive. I was really lucky to have that family support.

While MOH articulates a comprehensive disability support service that includes home and community support services, equipment and modifications, and access to therapies and specialist services, its reach is limited by funding constraints (Goodyear-Smith & Ashton, 2019; MOH, 2020). People with congenital or degenerative impairments often experience limited care, income-tested benefits, lengthy wait times for equipment and therapy, and the need to submit separate applications for each service (Stephens, 2004). These limitations are crucial to note, as a fragmented health system amplifies the challenges faced by disabled individuals and their families, diminishing overall quality of life, undermining social and economic participation (Chin et al., 2018; MOH, 2020; Sheridan et al., 2011; Wilkinson-Meyers et al., 2014) including access to sport (Schur et al., 2017).

The ableism embedded within the healthcare system for those with congenital impairments is poignantly illustrated by one participant after a training injury:

> I am discriminated against because I was born disabled. I had an accident and I wasn't treated the same way as a nondisabled person. My head injury was attributed to my disability. When you are disabled with a congenital impairment, you stay on your side of the tracks, you do not come over to ACC. (Stella)

Although Paralympian, Rashmi, receives individualised MOH funding for health and mobility support, she still had to work part-time to fund her shooting career while on the performance pathway, as she had not met the criteria for HPSNZ funding. As a highly impaired athlete requiring daily care, the need for a support person to travel with her during the New Zealand selection process increased both the pressure and the cost:

> I was fully self-funded which was a pain in the arse and that’s why I had to work part time… I wasn’t able to pay mum, so when we went on all these trips to qualify it was out of our own pocket. (Rashmi)

While funding constraints and the challenges of balancing work and training are common issues for both able-bodied and disabled athletes transitioning to high performance sport, (Gomez et al., 2018), Rashmi's situation was compounded by her need for both assistance, and personal care.

Thus, Aotearoa's dual healthcare system creates an uneven playing field in disability sport opportunities. From the outset, those with congenital or degenerative impairment face significant barriers to access quality healthcare to enable participation in sport, relying extensively on family support and private resources to overcome those barriers. Whereas those with acquired injuries benefit from extensive support.

Adaptive Equipment

For those who are highly impaired, enhancing independence and quality of life encompasses more than physical ‘care’. It includes timely access to appropriate adaptive equipment. Two participants supported by the MOH reported that a standard wait time for a new wheelchair is 3-years, due to the fact that wait thresholds based on need are funding-driven (i.e., are centred on the number of patients who can be treated with the available funds) (Flood & Hardcastle, 2015). Consequently, the athletes in this study must actively self-advocate to obtain even basic mobility equipment. As Stella explains: “When you speak to the providers, you have to say you’ve had another fall, and the response that you get is ‘that’s good it’ll make your case look stronger”. She further describes the process as time-consuming and stressful, adding, “I guess what the process is all about is trying to wear you down so that you give up” (Stella). Like Stella, Rashmi details her struggle to get basic mobility equipment from the MOH:

> Able-bodied people don’t understand how important equipment is. They think it’s just easy, like, ‘Oh, you just buy a tyre’ and ‘oh, that’s okay, that’s easy to change’. It’s like, ‘No, it’s not!’ I have to wait for Accessable[29] to come and do it. I have to book in an appointment with Accessable. Accessable will then tell me they’ll come the following

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[29] Accessable are an Aotearoa organisation that support people to manage their disabilities or injuries. They provide the Ministry for Disabled People equipment, housing, and vehicle modifications.

> day. I have to tell them that it's urgent and that I've only got one chair and then they have to try and slot me in somewhere. I waste a whole day just waiting around. I can't actually do anything, because I don't have a spare.

These experiences illustrate how the complexities of everyday life for disabled people are amplified by the constant navigation of ableist physical and social environments (Goodley, 2017; Oliver & Barnes, 2010; Shakespeare, 2014). As Campbell and Brown (2021) note, this constant struggle requires ongoing emotional and physical labour from athletes simply to "participate in the everydayness that nondisabled athletes would give no regard to" (p. 131).

Existing research on disabled athletes acknowledges many challenges, but it often misses a key point. For some highly impaired people, basic mobility equipment is both a necessity for daily life and a crucial component of their athletic pursuits. The MOH Constitution, however, limits its commitment to provide equipment that enables safe movement within the home, "including access to where a vehicle can reasonably be parked" (Wahaikaha, 2014, p. 61); explicitly excluding funding for community access. These limitations severely restrict athletes' ability to access and participate in sport.

> Before my first World Cup, I went to get my axles changed on my wheelchair. Went to Accessable, thought it was a quick easy job, get it done, go to work. Got there, they… found that there had been little cracks in my frame – little stress marks in the frame. They were like, 'Your wheelchair's a write off'. I'm like – 'hang on, what?' They were like... 'You'll have to get another chair'. I was like, 'but I'm leaving the country in 3-weeks for a competition. This chair that I use for competition. What the hell! (Rashmi)

Under Aotearoa's national healthcare system, Rashmi is near powerless. For a highly impaired wheelchair shooter, 'millimetres are miles'. No amount of effort and training can overcome the limitations of a poor seated position.

> And then they wrote [my chair] off and then they gave me one of the used crappy chairs from Accessable, which I had to modify and try and make into a shooting chair myself. I had that crappy chair for a year and a half before I got my own chair… it was horrible, absolutely horrible! (Rashmi)

Organisations often fail to understand the positive sense of self that comes with well-functioning assistive technology (Asare et al., 2023; Watts Belser, 2016), or the physical and psycho-emotional toll of ongoing equipment dysfunction. Stella eloquently captures the profound impact of inadequate mobility equipment: "We are not whole without our chairs – we are not mobile – we are not free – we do not feel safe; we are disabled even further". This experience is particularly acute for wheelchair users who experience a process of re-embodiment, where the wheelchair becomes integrated into their bodily schema (Asare et al., 2023; Papadimitriou, 2008; Watts Belser, 2016). Asare et al. (2023) details how "athletes incorporate their assistive devices into their sense of self and bodily schema, blurring the boundaries between their physical bodies and material technologies" (p. 7). This perspective underscores the critical importance of wheelchairs, not only as tools for mobility or sport but as enablers of choice, vital for independence and freedom.

Athletes may have the talent, commitment, and potential to succeed, but their access to sport-specific adaptive technology is fundamentally constrained by the limits of healthcare provision. When athletes are forced to train and compete without the equipment they need, their physical safety, performance capacity, and sense of self are all compromised—directly undermining athlete welfare. Unless sporting organisations understand how these structural barriers shape participation, they risk reinforcing a system where success depends not on athletic ability, but on one's capacity to navigate under-resourced and inequitable health systems. Unfortunately, these are not the only barriers that athletes must navigate.

Uneven Playing Field

Research widely recognises the impact of limited funding and higher costs on disability sport, affecting both provision and athlete participation (Cardoso et al., 2019; Purdue & Howe, 2012; Rodriguez Macias et al., 2022). In Aotearoa the issue is further complicated by a siloed disability sporting sector (McBean et al., 2022). The integration of para sport into NSOs is widely visible, with programs now under the responsibility of organisations such as such as Athletics NZ, Swimming NZ, Canoe Racing NZ, Table Tennis NZ, Waka Ama NZ and Cycling NZ etc. This integration however, is not applied across all para sport pathways, where some sports, such as Shooting Para Sport are administered by PNZ, whereas National Disability Sport Organisations (NDSO), such as NZWR and Boccia, are responsible for talent identification, development and by inference welfare and care (e.g. Figure 2, p. 11). The implications of this are integrated sports often lack the capacity, or the will, to engage with the embodied experiences of para-athletes, reflecting a deeper structural ableism embedded in high-performance sport. At the same time, without a clear direction from governing organisations with dedicated resources for athlete well-being (HPSNZ) and disability specific expertise (PNZ), organisations responsible for para-athletes are left to navigate their own athlete welfare and care path without guidance.

For example, despite NZWR's (2010) constitutional commitment to provide quality services "based on the needs of Members" (p. 7), Wheelblacks players report limitations on carer support at training camps and competitions:

> I think that's poor on their behalf. Every time we have a camp, we fuckin skimp on people… How is this high performance? How are they going to the best out of us? If they gave us a little bit more support, it would make things better overall. This way we just wear out the same old people, and the team struggle. (Ben)

In order to garner clarification, I spoke with the administrator of NZWR. The administrator Nikki described the challenges faced by this under-resourced NDSO, noting that the governing body consists of a voluntary board and a single administrator: "It's not enough hours to get everything done when it's from grassroots through to high-performance administration. There's no chance". In trying to justify the absence of carers by pointing to resource constraints, her comments inadvertently revealed the disconnect between disability sporting organisations' understanding of highly impaired athletes' needs and the lived realities of care (Lowry et al., 2022):

> When they've said we need more volunteers, I'm like, what do you need them for? We can't just bring volunteers in; we need to have something for them to do. But wouldn't the team speak up if they really did need [support]? If it was ongoing—every camp, every tournament, or every trip overseas—then it would be highlighted. (Nikki)

When I questioned their lack of focus on athlete welfare and care, the NZWR administrator explained that despite the board being proactive, "they're busy like all volunteers on committees… and it's probably hard to prioritise some things, especially when we've got the Paralympics this year. So that's the major focus" (Nikki). These athletes' stories call out the human cost of a 'resource precarious' disability sporting environment in Aotearoa (McBean et al., 2022), where apologetic ableism and neoliberal discourses enable sport managers to retain control over organisational funding and distribution, ultimately marginalising the very athletes they are meant to support (Crossen et al., 2023; Goodley & Lawthom, 2019; Hammond et al., 2022; McBean et al., 2022).

As Hannah suggests, the people who are making resourcing decisions for disability sport have a "lack of awareness, lack of understanding" of what it takes to support highly impaired athletes to compete at the highest level. As a result, "disability sport is looked down on", that is why the "disability team sport really struggles, for funding, support and recognition" (Hannah). Hannah's experience exemplifies how athletes can be included in policy yet remain excluded in practice (Bundon & Hurd Clarke, 2015; Hammond & Jeanes, 2018).

As the primary contact between athletes and the sporting organisation, coaches are the embodiment of an organisation's approaches to, and enactments of, their 'duty of care'. Marama, outlined how her first coach (who was a tetraplegic himself), expected her to 'toughen up' and manage her care on her own. This expectation reflecting the masculine hegemonic attitudes typical in contact sport dominated by men (Culver et al., 2022; Schalk, 2016; Sparkes & Smith, 2016), where vulnerability and the need for care are often stigmatised. While the majority of the team were supportive of Marama, seeing her talent, a Paralympian player often berated Marama in front of the team, targeting her gender and perceived lack of skill. Disappointingly, the coach failed to intervene. For Marama, this gendered dynamic compounded the challenges she faced in accessing necessary personal support. Marama comments that she was surprised because, "Dave was in a chair, you would have thought he would have had that understanding of different levels [of care required by] different people, but he was a hard man". This finding underscores a complex reality; while the lived experience of disability can provide valuable understanding (Bednarska, 2011), it does not guarantee an absence of ableism.

> He wouldn't let, Tish (my carer) help me strap up. He was like, come on – you need to do that yourself, you need to be independent if you want to be a part of this team, and I just took it and went home and cried. I didn't stand up for myself. (Marama)

Marama stressed, "Because he wasn't very supportive… With him as the coach, I was going to leave the team after the first year". Reflective of the ableist supercrip narrative (Howe, 2011;

Schalk, 2016; Sterba et al., 2022), Dave failed to grasp the complex realities of disability, and as a result, Marama's care needs were ignored (Lowry et al., 2022). This failure is troubling on multiple fronts. As a coach and organisational representative, he held a duty of care to the athletes in his charge. Yet instead of supporting Marama's embodied difference and the necessity of interdependence for her care, he demanded conformity to ableist ideals of independence and self-sufficiency. The impact was deeply personal for Marama, impacting on her welfare. Unfortunately, Marama's experience is far from an isolated case; rather, it reflects a broader pattern in wheelchair rugby that serves to alienate female athletes and those with higher levels of impairment from the high-performance pathway. Marama's experience was echoed by Paralympian Stella at her first New Zealand Wheelchair Rugby development camp.

> I went into it with a really open mind – thought that despite my physical limitations that I might be able to learn how to get faster and be better. But because I've got CP, once again I am the poor cousin to the pretty crips – some of them didn't even look at me all weekend – one of the coaches didn't talk to me. There were so many things going against me. If it stopped to think about it I never would have done it. Music blasting saying derogatory things about women and constant bad language that really put me on the back foot. It was really blokey – I felt so alone and vulnerable. I'm not sure if I want to go back.

While there have been positive changes in this organisation recognising the importance of welfare and care for highly impaired athletes, Stella's development camp experience was challenging.

> The camp was the hardest thing I have ever done in my life, I was completely broken at the end of the first day, but no one came to help me, cause somehow, I got left off the group care chat. It was so hard showering and dressing myself, I'd already used half my energy before I even got on the court. But it's probably my fault, because I didn't speak up – I thought they left me off the list on purpose.

Research has shown that some talented highly impaired athletes quit sports to avoid the ongoing psycho-emotional discomfort of discussing their care needs with unsympathetic organisations and coaches (Bredahl, 2010). Coach Zane reiterates this point referring to the Canadian wheelchair rugby team:

> [Athletes] couldn’t make the [National] team unless they were fully independent. Even the .5’s. They had to be able to transfer and shower and toilet themselves. God knows how they did it but they managed – players that can do that are so strong.

Sometimes organisational cultures and subsequent coaching practices can inadvertently undermine highly impaired athletes even when the intention is to empower (Cronin & Armour, 2019). When coaches and organisations reframe players’ identities to adhere to broader sporting values that celebrate the ‘invisibility of disability’ (DePauw, 1997), such moves are frequently framed as empowering and/or displays of disability-specific resistance (Thomas, 1999; Townsend et al., 2018).

While there are no formal duty of care policies embedded in NZWR’s constitution, there is an ongoing commitment by HPSNZ (2024b) in their recent ‘Strategic Plan 2025 – 2028’ to “lead well-being assessment and accountability in the sector” (p. 9). While it is positive that HPSNZ have committed to a focus on greater support for athlete well-being, there is no recognition of what well-being for para-athletes entails, nor is there a dedicated para-athlete representative within HPSNZ. This leaves a critical gap in leadership, advocacy, and informed decision-making. Ignoring the well-being and welfare needs of para-athletes demonstrates the damaging power of ableism, where Paralympic medals [athletes] hold less value than Olympic medals [athletes] (Kell et al., 2008). Research notes that people with disabilities experience a “unique kind of discrimination” that may require “proactive measures to enable them to enjoy their human rights” (Conroy, 2007, p. 2). Yet, as Ahmed (2012) states: “For a commitment to do something, you must do something ‘with it’” (p. 120).

High-Performance Sports Environment

HPSNZ administers the Targeted Athlete Pathway Support (TAPS) programme, which distributes funding and resources to athletes identified within their performance pathways. While TAPS aims to address athlete ‘identified needs’, its allocation is based on HPSNZ’s performance-driven criteria which demonstrates a system insufficiently nuanced to capture the lived reality of high performance para-athletes. This rigid structure struggles to accommodate the diverse needs of athletes with higher level impairments, particularly those that require specialised equipment or everyday personal care. In addition, the emphasis on performance metrics prioritises athletes in established, well-resourced sports, and marginalises those in emerging para sports like wheelchair rugby. As noted earlier, the lack of a disability sport representative in HPSNZ limits the ability to provide bespoke or a needs-based approach to welfare and care to para-athletes with higher support needs.

As a marginal sport in Aotearoa, wheelchair rugby exemplifies the problematic distribution of resources in disability sport, particularly its impact on highly impaired athletes. While HPSNZ provides Aspirational Sport Funding, eligibility hinges on meeting specific performance criteria, such as maintaining a minimum top-four world ranking as outlined in Figure 6.7. Though organisational criteria are necessary, the arbitrary nature of these assessments is problematic, potentially hindering support for athletes and teams.

Table 4 - HPSNZ Team Sport Funding Criterion

Team Sport			
Category	**Sub-Category**	**Descriptor**	**Evidence Required (Seeking some or all of this evidence alongside the investment decision-making considerations)**
Team sport	NSO focused campaigns	Team sport NSO likely to achieve podium success at the pinnacle event in this cycle, and/or across multiple cycles, and/or contribute to HPSNZ's broader investment objectives	**IN PRIORITY ORDER:** • Strong evidence of the senior national team tracking towards a medal at the agreed pinnacle event/s in this cycle (Olympic/Paralympic Games or world championship/world cup) • A Top 4 placing at the pinnacle event in the last cycle (Olympic/Paralympic Games or world championship/world cup) and strong evidence of tracking towards Top 4 placing at the pinnacle event in this cycle • In sports with significant global competition environments, strong evidence of ability to qualify for the pinnacle event in this cycle (Olympic/Paralympic Games and/or world championship/world cup) • A Top 4 placing at the Commonwealth Games in the last cycle and strong evidence of tracking towards a medal at the Commonwealth Games in this cycle • Athlete depth within the pathway is of sufficient quality and quantity to deliver future podium performance

Adapted from HPSNZ (2024a)

With a world ranking of eighth and qualification for the Tokyo Paralympics (criterion point 3), the Wheelblacks would appear to exemplify high performance sport. Yet, their experience exposes a significant gap in HPSNZ's support. Due to not meeting high performance funding criteria, the team receives limited financial assistance and relies heavily on fundraising, community grants, and volunteer hours. This reliance undermines their capacity to support players and engage the specialists needed to optimise performance and welfare/well-being. As a result, the Wheelbacks' are substantially disadvantaged compared to better-funded international teams – a reality that sits uneasily alongside HPSNZ's (2024) well-publicised commitment to aspiring high performance athlete 'well-being and engagement'.

Ben describes the impact limited funding has on team members:

> We need funding. We're playing up against people, where their job is wheelchair rugby – they don't work, they're fully funded. We need something, if we want to be the best! Our whole team pretty much work full time and are trying to train. It's just physically impossible. You can't get to the top doing all that – especially as tetraplegic.

The Wheelblacks' experience exemplifies how high performance disability sport is shaped by broader socio-political, cultural forces, particularly neoliberal rationalities and free-market values (Hammond et al., 2022). These forces prioritise medal potential, directly influencing funding decisions and the selection of athletes and teams (Purdue & Howe, 2012). This prioritisation is echoed by HPSNZ athlete performance life advisor, Anya, who explains the rationale: "They need to be performing at the top all the time. I don't like this – but [high performance sport] is about the medal count, it's all about the performance". Thus, while it is well documented in the disability sporting literature that high performance sport selects athletes that are more likely to win medals (Howe, 2008; Purdue & Howe, 2012), what has not been acknowledged is how this focus undermines the inclusion of athletes with higher support needs. Furthermore, even when highly impaired athletes are selected, the ableist norms embedded within high performance disability sport actively undermine their care needs, fundamentally compromising both their welfare and performance outcomes.

Paralympic sailor, Jack's experience training for the Games illustrates this point:

> Yachting New Zealand gave us zero… I just don't think they understand the extra support we need; and the extra work and money it takes for someone with a disability

> to get to these events. They don’t understand that a Paralympic campaign is much more expensive than an Olympic campaign because we have to hire a van that can take a wheelchair, bring extra support people, and all the extra expense that goes with that.

The devaluation of Paralympic medals, inherent within the ableist Paralympic structure, perpetuates the second-class status of para sport (DePauw & Gavron, 2005; Howe, 2008; Kell et al., 2008). Even as national representatives, training and competing ahead of the Paralympics, athletes receive minimal organisational support to cover the additional costs associated with being highly impaired, high performance athletes. As Anne explains, “the money that we tried to get from Paralympics New Zealand was like getting blood out of a stone… Still to this day [I] don't know where the money came from”.

Further underscoring the precarious nature of sport funding, two Wheelblacks coaches described their organisational approach to making ends meet through unpaid labour, personal favours, and operating without access to specialist support services essential for a high-performance environment. One coach explained that they rely heavily on “goodwill” (Liam), while another characterised the national programme as “real shoestring stuff, nobody gets paid, not even the coaches” (Zane). To function and support their athletes, they frequently have to “call in some wicked favours” (Liam). Despite representing Aotearoa on the world stage, “there has never been a dedicated nutritionist with understanding of tetraplegic physiology and nutritional requirements, and that hasn’t changed since our Paralympic qualification” leaving the team “to operate on guesswork” (Ben). All of these examples bring to light the invisibility and underfunding of high performance disability sport:

> Funding, funding, funding… It’s always about funding. It’s the big ogre that’s going to keep jumping out. Because wheelchair rugby is a team sport it really struggles. Not only is there expensive equipment, but we are a team that requires a lot of support people. We are only sending team of eight players [to Tokyo] – where most wheelchair rugby teams send 12… And [PNZ] are trying to cut back wherever they can. The carers are forgotten. (Hannah)

Although volunteer reliance and self-funding are common across Aotearoa’s sporting landscape, these challenges are exacerbated for athletes with higher levels of impairment.

Able-bodied athletes often have greater opportunities to work or secure sponsorships to offset costs, and they do not face the additional financial burdens associated with intensive care regimes, specialised equipment, accessible travel, and suitable accommodation. These examples reveal the systemic inequities embedded within disability sport, where athletes with higher support needs encounter additional barriers that limit their ability to participate and compete at their full potential.

While HPSNZ strategically espouses commitment to high performance athletes' welfare and well-being, through national sporting overview and guidance and funding, this section reveals a critical gap in the provision of welfare and care services for highly impaired athletes in Aotearoa. Driven by neoliberal values and a focus on medal potential, the system creates significant funding disparities and systemic ableism, resulting in a lack of nuanced, needs-based services. This forces highly impaired athletes and teams to rely on precarious resources, hindering their capacity to succeed at the highest level. Ultimately, this systemic underfunding coupled with a lack of understanding the welfare and care needs of highly impaired athletes perpetuates the second-class status of para-sport and actively undermines high performance potential. Unfortunately, this structural ableism is not confined to high performance sport, it also underpins performance pathways.

The Illusion of Inclusion

In the world of high performance sport, where every millisecond counts and precision is paramount, highly impaired athletes must battle not only the physical and mental and demands of their sport, but inaccessible competition environments, inexperienced coaches, and institutional neglect of care needs. These obstacles further hinder their high performance journey.

When I first joined the Pathway to Podium [P2P] Paralympics Programme, I told the Paralympic Community Development Manager that I thought "*I was too disabled for Paralympics*". He agreed with my observation and discussed how "historically they have been focused on high performance elite athlete, but they were receptive to making the journey more accessible for highly impaired athletes" (Amanda). The Paralympic representative reinforced the assertion that the only legitimate bodies in high performance disability sport are the 'high performance elite athletes' (the most able disabled supercrips) (Howe, 2023; Schalk, 2016). Howe (2015) suggest, "by its very nature, elite sport is selective" (p. 256) and all but the super-able suffer from exclusion or segregation, suggestive of the ableisation of high performance sport (Quinn et al., 2022). The term ableisation, coined by Bednarska (2011), “describe(s) the way in which expectations of ability underlie and influence our perceptions of embodiment” (p. 6). In the case of this research, I use the term ableisation to refer to the process of ableism within sport; specifically, how expectations of athletic ability are shaped by the preference for able-bodiedness, thereby impacting the integration and inclusion of highly impaired athletes in sport (Quinn et al., 2022).

In preparation for my involvement with the high performance swim team at the International Pan Pacific Para Swimming Championships [PANPAC], the PNZ swimming manager and support crew went to the Auckland Spinal Unit for a presentation about the physiology and care requirements of a C6/C7 tetraplegic. While this may be seen as proactive, the irony is telling. PNZ, an organisation dedicated to celebrating high performance para-sport, has limited understanding of ‘*some of the bodies*’ it champions, bringing to light the contradictory nature of ableist oppression (Bednarska, 2011; Carroll et al., 2021). Some impairments are embraced while others are outright rejected. Organisations are not ‘anti-disabled’, they are ‘pro-nondisabled’ (Howe, 2018):

> I just wish that were prepared – that they already had the knowledge and information so they could say ‘hey come, we welcome you’, rather than a situation where – *because you are there, they’ve had to make changes* [emphasis added]. While that’s great [that they actively sought education], it would be better if disability sports were actually aware of *who they could get involved* in the sport and be prepared to understand what goes with having those athletes. (Hannah)

We travelled to Cairns three days before the PANPAC event for my first international competition. The team was accommodated in some beautiful villas close to the pool. There were access issues from the beginning:

> Despite their beauty, these villas are not accessible! I can’t have a shower as the bathroom has a shower with a high tile edge – my commode chair can’t get over. Gemma is doing my cares in the evening, and I shower at the pool at after racing. I am lifted out of the pool onto the edge, then into my wheelchair. I am then lifted again onto the shower chair. Once showered, Gemma dries and dresses my upper body,

> with another lift back into my wheelchair. We head back to the room, we transfer onto the bed, she gets my lower body clean and dry. We transfer back into my day chair again. 18 transfers in one day is too much for both of us. My arms and shoulders are feeling it – my body is shattered, I feel like public property. (Amanda)

Despite evidence from the spinal unit, PNZ's failure to adequately understand and accommodate my accessibility and care needs increased my 'Otherness' (Wendell, 2006). The extent of my disability magnified as my partner and I navigate a world of physical and societal barriers (Reeve, 2020; Shakespeare, 2014; Thomas, 1999).

Despite personal engagement, this experience was repeated three weeks later at my first high-performance development swim camp. The bathrooms were again inaccessible, and my support worker and I had to be housed in another venue, away from the high-performance swim team:

> PNZ staff are paid to develop and support the high performance swim team, they were with me in Cairns – they saw how hard it was for me and Gemma. They can't fucking understand how hard it is to 'never fit' – to have my disability shoved in my face. I cried in the van as my support worker and I were moved to another venue. (Amanda)

For me, the "deprioritisation of accessibility and disability produce[d] a profound sense of unbelonging" (Brilmyer, 2022a, p. 144). While PNZ facilitated a training camp for New Zealand's high-performance para-swimming team, my participation laid bare the ableist assumptions underpinning its design. The institutional framework failed to comprehend, let alone accommodate, my messy, embodied care needs, exposing the ableist logics that privilege independence, autonomy, and functionality over interdependence and care.

> Parts of care can be unpleasant – that is not the right term – but people perceive it as that, because they're not comfortable, and they don't want to discuss. Everything is covered up and protected… saying – 'we can't talk about this' – but we need to be asking why can't we talk about this? When 25% of the population live with disability – something that is seen by the able-bodied population as undesirable. When we are talking about care [disabled people] are dealing with it every day. I think that's why we haven't moved forward organisationally with understanding the importance of care

> and prioritising care, because do those in charge of sport want to be sitting round a board table, discussing poos and wees? ‘Oh no! We can’t possibly do that!’ (Hannah)

Unable to express normativity I was excluded, abject, made to feel inferior. Grosz (1994, 2020) and Douglas (2003) argue that nothing is dirty or impure about the body, it is only that which is out of place disrupts order. This lack of understanding, indicative of a broader lack of general disability awareness within the organisation, intensified the physical and emotional labour required to manage my care for my carer, Gemma, and myself. When we face inaccessibility in every part of life, barriers compound and accumulate, they are “emotionally expensive” (Brilmyer, 2022b, p. 141).

Zac has been involved with PNZ for the past 20 years as a competitor at five Paralympic games. He was with me at both events.

> The frustrating thing was, I was offering help and support to Paralympics and saying, ‘Hey, I’ve travelled with quads so many times with the Wheelblacks, and none of what Amanda is asking or needing is news to me’. I kept offering help and saying, ‘Hey look, if you’re looking for research around the sport science side of things, how about you look at these places, because that’s where they’ve got a strong history of dealing with spinal cord injuries, and quadriplegics in particular’. Not a lot of that offer was taken up. I get frustrated by that. Then at the same time I go – well, it’s their ship. (Zac)

My ongoing issues with access, and Zacs’ advice about how to solve some of those problems, reveal how power relations “mediate who has voice, autonomy and identity, and who does not” (Townsend et al., 2018, p. 346). Extending the critique of high performance sport, HPSNZ athlete life advisor, Anya, went on to describe how there have been issues at training camps around highly impaired athlete inclusion, accommodation, and access. She stated that there needs to be:

> A lot more consideration than there is currently… Because sometimes HPSNZ misses the mark, and misses quite badly and it’s just not good enough. I’m embarrassed by some of the things that athletes tell me, because it shouldn’t be like that. (Anya)

Anya notes that despite all the effort by HPSNZ to support athletes, sometimes HPSNZ is a little out of touch with athlete’s needs. Anya comments: “sometimes I see in high performance sport, that programmes are happening to the athletes. Not with them, it should be alongside them”. She provided an example of working with a group of para-cyclists. When she saw things that were not “enabling an athlete” with higher support needs, she immediately gave feedback to the person who organised the camp. Their disappointing response was that “the camp worked for 99% of the athletes” (Anya), from their perspective it was successful. Anya responded to the camp organiser:

> Just because it worked for everyone else you’ve just isolated this person, who’s had a range of difficult experiences in the past that have isolated him even more so. It’s a training camp … [It’s supposed to be founded on the principles] where you don’t leave anyone behind… It’s not a team, if you’re missing one person. No, you can’t call this a team!

While training and competing toward the Paralympics, sailor Jack’s degenerative condition progressed and he was losing strength and independence. Jack’s co-sailor, Anne, reiterated how difficult it was for the team: “Care wise, it was very difficult for Jack because we knew he needed care but he had to fight for that because they didn’t understand”. Jack increasingly needed help with every day personal care – transferring to his wheelchair, showering, and dressing. Despite an intense training and competition schedule prior to the Paralympic games, Yachting New Zealand failed to acknowledge care as vital to their success. The fact that care could not be discussed in yachting highlights the symbolism between bodies and the body politic (McClintock, 1995). When ‘normality’ and disability collide, differences are magnified and similarities undervalued (Silva & Howe, 2012).

Jack speaks about the difficulty he had accessing care:

> Honestly, it would have been helpful right from the start to have some extra help, but because in the beginning I could do all my own personal cares. I’d say ‘just’ – I could ‘just’ cope. But it did have a negative effect on competition. It’s easy at home but when you’re in a different environment it doesn’t take much to make things a hell of a lot more difficult, and tiring to do.

High performance yachting, an ableist realm dominated by vast financial resources and peak physically conditioned athletes, ‘invisibilised’ (Schalk, 2016) their own highly impaired sailor’s welfare needs. As Darcy et al. (2017) assert, maintaining the level of training required to excel in high performance disability sport, “support needs require unique consideration” (p. 36).

> Eventually, Steve was able to come on-board and help… It was great to have him on-board. We got him in through the back door. Under the title ‘assistant coach’… We weren’t allowed to call him a carer or anything. My physio taught him how to do my stretches… it was the first time I had anyone that was looking out for my needs… When I was putting my sailing gear on, it was just knowing that he was there. So, if I fell – which I did… I had that peace of mind that he was never that far away. But he was not employed as a carer in Yachting New Zealand’s eyes. (Jack)

Reflecting on the event, Anne added, “I still to this day don’t know where the money came from to pay for Steve and I’m not gonna ask, because I dread to think what the answer would be”. The implication of this quote is that Jack was forced to self-fund his care for Paralympic competition because an integrated NSO did not acknowledge care as fundamental to athlete welfare. As Ahmed (2012) asserts, “[w]hen [integration] is taken up as if it describes what already exists, then it is used by organizations to avoid appointing specialists in the area, or indeed to avoid giving diversity and equality the additional support that it needs” (p. 139). To secure Jack’s essential care, the team resorted to labelling it ‘coaching support’, a workaround necessitated by Yachting New Zealand’s ableism.

In both instances, the pursuit of Paralympic success overshadowed the fundamental importance of athlete welfare and care, essential for high performance. The data highlight the disconnect between athlete lived experiences and organisational duty of care, creating a form of institutional hypocrisy. This hypocrisy, where actions on the ground fail to align with governing bodies’ stated missions, highlights Yachting New Zealand’s non-performativity (Ahmed, 2012). By disengaging organisational welfare and care policies and practices from the lived experience of highly impaired athletes, non-performativity perpetuates ‘symbolic violence’, leading to tangible ‘embodied and lived’ consequences. As Paralympic sailor Jack succinctly summarises for highly impaired athletes, “if you can improve on the support that we get, then the end result is going to improve. That’s it in a nutshell pretty much”.

Research exposes how neoliberal ableism shapes and frames the elite sporting environment (Hammond et al., 2019; Pullen et al., 2019), where disabled participants are expected to fit existing nondisabled programming (Peers et al., 2020). Thus, in sporting organisations founded on normative ideologies (Goodley & Runswick-Cole, 2013; Townsend et al., 2018), stereotypes and misconceptions about the abilities of disabled athletes persist, and coaches lack the training and expertise to effectively include these athletes in their programmes. This disconnect between progressive rhetoric and practice is particularly stark in high performance disability sport, where growing awareness of athlete welfare has failed to translate into tangible care provision. While the fragmented structure of the para sport system in Aotearoa contributes to this gap, national organisations such as HPSNZ and PNZ must prioritise care as central to athlete welfare. Without deliberate focus on the messy, embodied realities of highly impaired athletes' needs, their safety is compromised and the integrity of high performance sport is undermined.

The following section explores the experiences of athletes at the Tokyo 2020 Paralympic Games. The timing of the data collection lent itself to unpacking the event organisation of the games. While I recognise this may or may not reflect all events, it provides valuable opportunity examine the impact of organisational decisions that impact on the welfare and care of highly impaired athletes.

Paralympics

Hosting the Tokyo 2020 Paralympic Games during the COVID-19 pandemic posed unprecedented challenges for the IPC as it struggled to balance athlete safety with the logistical complexities of a global event. One of the key difficulties was the reduction in the number of support staff allowed to accompany athletes due to stringent health and safety protocols. Yet, what was not foreseen by the IPC was how a reduction in staff would impact on athletes that required support. To demonstrate this point, acclaimed US Paralympian swimmer Becca Meyers withdrew because the United States Olympic and Paralympic Committees [USOPC] would not allow her to bring her personal care assistant (Meyers, 2021). Such examples are not uncommon, and serve as a reminder of how highly impaired athletes do not reflect the symbolic order of high performance disability sport, occupying spaces on the margins – "the between, the ambiguous, the composite" (Kristeva, 1982, p. 4), their complex care needs, a disruption to the idealised image of the high performance athlete, are 'Othered' (Lowry et al., 2022).

> The US OPC has denied a reasonable and essential accommodation for me, as a deaf – blind athlete, to be able to compete in Tokyo, telling me repeatedly that I do not need a Personal Care Assistant [PCA] "who I trust" because there will be a single PCA on staff that is available to assist me and the 33 other Paralympic swimmers, nine of whom are also visually impaired. The USOPC has approved me having a trusted PCA (my mom) at all international events since 2017, but this time it's different. With COVID, there are new safety measures and limits of non-essential staff in place, rightfully so, but a trusted PCA is essential for me to compete.

While limiting team numbers made sense in a COVID-19 environment, restricted access to essential support workers meant that highly impaired athletes were unable to participate safely, exposing them to physical and psycho-emotional harm. While the IPC (2024) commitment to "athlete safety and health" is enshrined in its constitution, the experiences of highly impaired athletes participating at the Paralympics exposed a gap in this principle and its practical application. Decision-makers must understand that in a high performance sporting space, highly impaired athletes' 'interdependence' is magnified (Lowry et al., 2022). It is a lack of control over the physical help required that diminishes people's independence and undermines inclusion (Lowry et al., 2022; Morris, 2001; Walmsley, 1993). These actions jeopardise the IPC's (2023) commitment to "fundamental [inclusive] ethical principles" (p. 7). As Becca stated:

> So, in 2021, why as a disabled person am I still fighting for my rights? I'm speaking up for future generations of Paralympic athletes and hope that they never have to experience the pain I've been through. Enough is enough. (Meyers, 2021)

At the Tokyo Paralympics, para-athlete care needs were invisible to the governing organisation (Howe, 2015; Lowry et al., 2022; Slocum et al., 2018). Becca's experiences challenging ableist organisational understandings of athletes' lived realities of interdependence, disrupted narratives of what bodies are supposed to be able to do and how they are supposed to behave (Jonsson, 2017; Lowry et al., 2022). Thus, the political imperative of Othering those who do not conform, serves a powerful purpose of maintaining power and control of masculinism and ableism (Douglas, 1966; Grosz, 1994, 2020; Kristeva, 1982; Longhurst, 2001) inherent in high performance disability sport.

Given the uncertain and dangerous nature of the COVID environment, Aotearoa's highly impaired athletes were understandably concerned prior to departure:

> I feel like for this Paralympics there is so, so much unknown. What happens if someone gets COVID and gets stuck in Japan? Someone like me – I'm going to have to have a caregiver with me so we will both be stuck… We're really light on support – we've only got two caregivers at the moment for the team. If we were to ask someone else who the fuck we would ask? (Ben)

While the IPC placed limitations on the number of team support staff allowed at Tokyo 2020, national disability sporting organisations held the power to support and/or challenge the care needs of highly impaired athletes. Despite knowledge of the high level of personal support many highly impaired players require for the management of everyday impairment effects (as detailed in Chapter Five), the organisation failed to implement a backup support system, resulting in significant consequences for the team. When they reached the Paralympics, the teams' worst fears were realised:

> Ben: Layla (support worker) didn't get on the plane. She didn't turn up for the first 5-days because the Paralympic doctor wouldn't let her travel.
>
> Amanda: So, you only had Suz (team support worker) looking after everybody?
>
> Ben: She was exhausted, because of COVID everything needed to be cleaned down daily. All that added extra bullshit on top of the care work for the whole team. She was pretty worn out, there were tears, there were lots of things.

When the team travels, the demand on support workers is intense. Support workers carry out manual transfers for some athletes, move personal luggage as well as sport wheelchairs, wheel bags, and commode chairs. The intensity continues when the competition begins:

> First bowel cares and showers, then supporting the whole team at the court, strapping us up and helping with transfers, getting food and water, emptying catheters, sometimes changing them. When we come back to accommodation, it doesn't stop, there's dinner, then maybe cares, then they've gotta help get some of us into bed… If

> we just had one extra person, we might've been able to give a caregiver a sleep in the morning. (Ben)

The IPC's long-standing 'Athletes with Severe Disability Committee' (see Chapter One) appears to be more symbolic than effective. Two decades since their inception, highly impaired athletes have seen little improvement in their high performance sport opportunities (Slocum et al., 2018), and examples like that above demonstrate why. This systemic neglect demands a radical shift in understanding and practice of what constitutes 'athlete welfare and care'. To drive global change, the IPC must lead by example, committing the necessary time and resources to embed care into organisational practice. By recognising the vital role of care in the participation of highly impaired athletes, the IPC (2024) can foster a sporting culture founded on supporting the needs of *all* athletes – not just *some* athletes, and deliver on its aim "to achieve sporting excellence" (p. 1).

Change, as Hannah argues, is possible through the active involvement of "disabled athletes and allies involved with disability sporting institutions and organisations – presenting, educating and creating awareness". DePauw (2023b) supports Hannah's approach, stressing individuals with disabilities are "wisdom holders" (p. 17), and sport is both a tool and a site for social change (Bundon & Hurd Clarke, 2015). By embracing athlete representation and amplifying the voices of those with lived experience, the ableism and disablism that marginalises some bodies more than others can be challenged, fostering a truly inclusive and equitable disability sports environment for all. The following section introduces athlete advocates who are changing the disability sporting landscape.

Crip Change and Advocacy

The lack of representation and inclusion of disabled athletes in decision-making processes within sports organisations leads to policies and practices that do not meet the needs of highly impaired athletes, undermining athlete welfare and safety. This exclusion, coupled with the lack of understanding and support for highly impaired athlete care, highlights the urgent need for athlete advocates to drive change (Smith & Sparkes, 2020; Tuakli-Wosornu & Kirby, 2022).

A key step towards inclusivity is exemplified by Swimming New Zealand's 2022 integration of para-swimming into its core operations, unifying the management of able-bodied and para high performance swim teams and domestic competitions. Five-time Paralympian, Zac, SNZ's

Disability and Para Swimming Participation Manager, is a powerful example of the positive influence disabled athletes bring to key roles.

> It's not just system change – to policy and the way things are delivered. It's an organisational mind-shift as well. Personally, I think it's really helpful for Swimming New Zealand having someone with my impairment in the building, because they all see disability every day. They might not see all of the challenges I go through, but they see on a regular basis; me bouncing from prosthetics to wheelchair… That's the knock-on effect of having someone with lived experience in an office; is that they actually do start to subconsciously think of these things… I think it will make a difference in the way they interact in the community and understand accessibility needs. (Zac)

While there is considerable research on the benefits of diversity and inclusion in the workplace more broadly, there is limited research focused on the benefits of employing disabled sportspeople within sporting organisations (Hanlon & Taylor, 2022). The intersection of these topics is a valuable area for future study.

Seeing Zac walk into a pool on prosthetics as a representative for SNZ, opens coaches' eyes to the possibilities for disability coaching in their own clubs. As both a high performance athlete and an organisational advocate, Zac understands how elite sporting ideologies influence coaches in implicit and explicit ways (Hammond et al., 2022), using them proactively to bring change. Coaches' worldviews are often entwined with ableist high performance logics and imperatives (DePauw, 1997; Townsend & Cushion, 2020), explaining their reluctance to proactively include people with disabilities into their regular programmes (Hammond et al., 2022).

> I want to make a difference to clubs and to coaches who have para swimmers. I want that para swimmer to come in, have a positive experience and enjoy themselves. Whether they want to go onto be high performance or not, I want them to have found a sport that works for them and that they enjoy, and that there's a pathway there. If all organisations at that grass roots level are doing it better, then there's going to be way more athletes on that pathway to high performance sport. If you can support them better down low, then it's going to be a better journey for them to actually make it. (Zac)

Zac’s lived experience as an athlete and an advocate for inclusion is invaluable. My own participation in the primarily able-bodied 2020 New Zealand National Opens swimming event offered a glimpse into an ‘inclusive sporting crip future’. Unlike organisations that actively resist broadening participation (Phoenix & Smith, 2011), SNZ, thanks to Zac's influence, adjusted event timing to accommodate my needs as a highly impaired competitor.

> They changed the race protocol for my events as they’d seen me race 4-months earlier, and they knew that it took me time to get in the water and be ready. They put me in a lane near the edge. Before starting the race, waited for my body to calm down before they called the other swimmers up to the blocks. (Amanda)

My experience demonstrates ‘alternative imaginings’ of social inclusion (Hall, 2004), with recognition and response to the actual social, material, and affective conditions that further highly impaired athletes’ participation in high performance sport (Lowry et al., 2022).

Zac’s employment and commitment to inclusion is driving a cultural change of swimming in Aotearoa, opening up pathways for more highly impaired athletes.

> You’re not the only wheelchair athlete, and you will not be the only wheelchair athlete in years to come. But now the work [about how to make swimming in New Zealand more accessible] is done. Organisations just need to even know it exists. They need to know where to find it and implement it… But there are different organisational mindsets. The one size fits all approach doesn’t work… I think that’s why it’s been really good for me to be involved with Swimming New Zealand… I’m someone who is going to take a more constructive approach about accessibility and actually have conversations about it. (Zac)

While integration is important (Quinn et al., 2022), true inclusion, is “an attitude and a process” (DePauw, 2023b, p. 16), requiring a “literal intermixing” (Howe & Silva, 2018, p. 129) where both disabled and non-disabled athletes adapt to a new, shared sporting culture. This necessitates targeted investment in accessible infrastructure, coach education, awareness raising, and outreach programmes. SNZ is actively pursuing these avenues, including para and wheelchair requirements in their bidding process, forcing venues to consider accessibility (Zac). Zac leverages his platform to challenge ableist structures and advocate for nationwide change (Powis, 2018; Smith et al., 2016).

Unlike Swimming, Shooting Para Sport is overseen by PNZ. Five-time Paralympian shooter, Hunter, has witnessed some positive shifts but remains critical of PNZ's understanding and support of highly impaired athletes. "Apart from them not understanding anything [about the care needs of highly impaired athletes], you can kind of understand where [Paralympics] come from. Their business model is medals" (Hunter). He recalls:

> It probably wasn't until after I'd won a Paralympic gold and another gold at the World Champs. They were like, 'Oh yeah, he's got potential, we'll fund him'. [Winning medals] gives you leverage. So, I was able to get an accessible room. I was getting better in myself, in my disability. I was getting better equipment to use and my shooting results were able to get me more [support]… But in the [beginning] it was bad. (Hunter)

Hunter's experiences, detailed in Chapter Five, highlight the discriminatory practices he faced, connected to unchanging ableist hierarchies and the devaluation of impaired bodies (Bundon & Hurd Clarke, 2015; DePauw, 1997; Lowry et al., 2022; Peers, 2012). These experiences have shaped his coaching approach, prioritising athlete welfare (Bundon & Hurd Clarke, 2015; DePauw, 1997; Lowry et al., 2022; Peers, 2012).

> I wouldn't want anyone to have to go through what I experienced… So that was cool focussing on those [new athletes] and making sure they had everything sorted. Cause you've got the disability, you've already got that background, you have empathy, you understand what they might need. (Hunter)

Advocacy in Coaching

Rashmi, one of Hunter's students, articulates the value of having a coach with lived experience:

> I love that Hunter has similar experiences to me and his ability as well because there's so many factors you can try and talk to an able bod about, but they won't get it, because they haven't experienced it… The health stuff always trips me up. And when I try and explain it to somebody [without impairment], they might think [about] me 'She's just being making up an excuse or whatever'. It's like, 'No, this is part of my disability. It's [your denial of my experience that's] making it worse than it should be.'

Rashmi and Hunter’s crip kinship highlights how knowledge of disability is forged not only through the experience of one’s own impairment, but through being with and alongside disability — thinking with disabled bodies, sensations and struggles that shape disabled lives (Johnson & McRuer, 2014). This understanding enables organisations to train coaches to create inclusive disability spaces that promote a sense of belonging for athletes (Morrison et al., 2020). Under Hunter's guidance, Rashmi competed alongside him at the 2024 Paris Paralympics.

Similarly, highly impaired coach, Zane, led the Wheelblacks to Paralympic qualification. The ‘ethics of care’ coaching approach employed by Zane, similar to that of Hunter, illustrates how the prioritisation of athlete welfare and care can be a significant factor in achieving sporting success (Meziani et al., 2017).

> The biggest thing you can do for your athletes [is to] care for them and make sure they know, you care. So, I took that on, [saying to the athletes] ‘I care about you, I care about your family… I care about all of these things, because my role as a coach is to get the best you.… Whatever that is’. (Zane)

A coach’s lived experience of disability, particularly the degree of impairment, shapes their coaching philosophy. Unlike Marama’s higher-functioning coach, Dave, Zane prioritised care, recognising its importance in athlete welfare and achieving high performance outcomes. As both coaches demonstrate, it is possible to cultivate a truly inclusive and empowering environment for athletes with disabilities, offering a powerful counter-narrative to the prevailing ableist culture. The crux of this approach in coaching is founded on the idea of ‘doing’ care which puts “people first and not things first” (Fisher et al., 2018, p. 482). The dominant model is reversed, where the person with the disability has the power to determine the breadth and depth of care that they require for independence (Kittay, 2011; Meziani et al., 2017; Watson et al., 2004). As both Quinn et al. (2022) and Lowry et al. (2022) suggest, ‘cripping’ parasport and celebrating bodily difference, offers powerful strategy to challenge ableism and drive systemic change.

Recognising the gap between the athletes’ embodied experiences and high performance sport provision, Hunter advocated to embed athlete voices within the New Zealand Paralympic Constitution. He worked with other athletes to establish the PNZ Athletes’ Council in 2021, designed “to act as the athlete’s voice within PNZ” (PNZ, 2021b). This aligns with both HPSNZ and PNZ strategies recognising the importance of advocacy for equity, accessibility and inclusion (HPSNZ, 2024b; PNZ, 2021a), ‘cripping’, and subverting taken for granted organisational able-bodied norms (Kafer, 2013; McRuer, 2006; Quinn et al., 2022).

> The Commission’s mission is to represent New Zealand Paralympians and para-athletes and support them to succeed in their sporting and non-sporting careers with empowering participation and voice. (Hunter)

Inclusive policies and legislation alone are insufficient to create real change if decisions about programmes, facilities, and support services continue to be made without the input of those most affected (Howe & Silva, 2015). This exclusion perpetuates a disconnect between athletes and the institutions meant to support them. Meaningful change in high performance sport management and delivery can only occur when the embodied experiences of these ‘insiders’ are prioritised (Howe, 2008; Quinn et al., 2022).

DePauw (2023b) emphasised that individuals with disabilities are “wisdom holders” (p. 17), and sport is both a tool for and a site of social change (Bundon & Hurd Clarke, 2015). Given these challenges, the exclusionary ideologies that persist within sport systems are increasingly being confronted by ‘wisdom holders’ taking more central roles – ensuring that the voices of those with lived experience drive change. They defined inclusion as “active, intentional, and ongoing engagement with disability. It is about changing the culture so that individuals could be and are included. It is about choices and having choices” (DePauw, 2023b, p. 16).

Summary

Drawing on Ahmed’s (2012) concept of non-performativity, this chapter examined the macro spatial scale of high performance disability sport organisations in Aotearoa. Recognising that disabled athletes’ sporting experiences are inextricably linked to healthcare provision, it critically analysed how healthcare provision either undermines or enables highly impaired athletes’ sporting experiences. This chapter exposed the cost of dangerous ableist and gendered ideologies on highly impaired athlete experiences of welfare and care, bringing to light the underfunding of disability sport organisations, the lack of tailored para-athlete support systems, and the failure to acknowledge the vital role of carers in enabling athletes to compete at the highest level. Its focus exposed how sporting organisational declarations of commitment (e.g., to athlete inclusion or welfare/well-being) work as a substitute for real action. As Ahmed (2012) asserts, “[a] symbolic commitment does not necessarily represent an institutional commitment” or enact change, rather becomes part self-serving, ableist organisational affirmations that mask existing ableist inequalities and prevent change (p. 130).

Highlighting a significant gap in disability sport research, this chapter detailed the critical role of healthcare provision in shaping sporting opportunities for highly impaired athletes. It revealed the burden that highly impaired high performance athletes carry as they juggle intensive personal care regimes, work, and high performance training and competition. This finding is particularly poignant for athletes with congenital or acquired impairment who receive limited healthcare support. While this specific issue falls outside the current research, it underscores the urgent need for further studies on the relationship between healthcare provision and disability sporting opportunity. Addressing this gap is essential for creating equitable high performance pathways for these para-athletes.

Yet, amidst these challenges, a powerful narrative of resilience and resistance emerged. The voices of highly impaired athletes, coaches, and allies, amplified through advocacy and athlete-led initiatives, are driving change from within. As Ahmed (2012) argues, “if organisations are saying what they are doing, *then you can show that they are not doing what they are saying*” (p. 121). Because “diversity and equality tend to fall off the agenda unless someone forces them onto the agenda” (Ahmed, 2012, p. 139); thus, “committed individuals remain key to making things happen” (Ahmed, 2012, p. 135). Individuals like Zac, Hunter, and Zane exemplify the transformative potential of lived experience in sport. They challenge ableist assumptions within disability sport delivery and practice, driving organisations towards greater inclusivity and equity. These advocates become the organisational “hearts and minds… “feeling and thinking for the [organisation]… transform[ing] what the [organisation] is for” (Ahmed, 2012, p. 140). This approach is evidenced by the ongoing transformation of SNZ and the establishment of the PNZ Athletes’ Council, where athlete voices and lived experience directly shape the sporting systems that impact their own and other para-athletes’ lives.

This chapter serves as a potent call to action, urging high performance disability sport organisations in Aotearoa to move beyond performative pronouncements and enact concrete change to support athlete welfare and care. True inclusion demands a fundamental shift in organisational cultures, one that prioritises the voices and experiences of highly impaired athletes and operationalises welfare and care in meaningful ways. To forge a truly inclusive and equitable high performance sport system, requires a commitment to providing equitable access to funding, resources, and support systems that genuinely meet the needs of all athletes, regardless of impairment. Only then can a high performance disability sport system that truly lives up to its promise of inclusion and enables all athletes to thrive be created.

Chapter Seven: Conclusion

As athlete welfare and care becomes a global priority for sport organisations, the lived experience of highly impaired athletes who need and receive care remains absent from dominant disability sport narratives. This thesis responds to that exclusion, not by speaking for, but *from* the body. Drawing on a range of critical theories, captured under the theoretical umbrella of critical disability studies, the thesis brings to light the lived and embodied experiences of highly impaired, high performance disabled athletes.

I critically examined the lived and embodied experiences of highly impaired athletes within high performance sport, and the systems that govern their care and participation. Specifically, it:

1. offered an intimate and self-reflexive autoethnography to illustrate my embodied and everyday lived experiences of care needed when training as an elite, highly impaired athlete;
2. amplified the lived and embodied experiences of highly impaired, high performance disabled athletes as they prepare for, train, and compete in sport, and those who support them;
3. analysed how sporting institutions and regulations (within the broader context of government funding and national health care provision) influence welfare and care practices for high performance disabled athletes.

In examining athletes' experiences, I necessarily situated them within a historical and dynamic organisational landscape in which changing responsibilities and priorities work to shape the care practices available for highly-impaired athletes. Responding to DePauw's (1997) challenge to increase the visibility of disability in sport by bringing the body and impairment back into disability discourse, this study highlights the squeamishness that repels higher level engagement with the gritty, fleshy, messy lived realities of highly impaired high performance athletes. In doing so, this thesis has cripped disability sport by unsettling its normative foundations and exposing the ableist assumptions that structure its practices, research, and policies. It does so in the hope that in exposing the embodied care experiences of the most marginal athletes in high performance disability sport can challenge and transform normative understandings of disability, and disability sport provision, research, and practice.

This concluding chapter is organised into seven sections. It begins with Politics of Knowledge and Absence, which summarises key contributions to the literature. The second section, Methodological Interventions, outlines the unique approaches and interventions this research brings to the field. The third section, Cripping Care, revisits my autoethnography and visual ethnography to foreground the intimate, embodied dimensions of care. Section four, The Embodied Experiences of Highly Impaired Athletes, explores the management of impairment effects within high-performance sport, tracing the complexities, daily challenges, and sometimes life-and-death realities these athletes face. This section includes a subsection, Crip Time and Care Time, which brings to light the invisible experiences of support workers. Section five, Athlete Care and the Uneven Playing Field, details how athletes navigate multiple systems — from health care to impairment classification — to access and sustain participation in sport. Section six offers a Call to Action, and the chapter closes with my Final Thoughts.

Politics of Knowledge and Absence

The journey began with a critical examination of disability sport literature, noting that while the body has garnered increasing attention, there has been a reluctance to engage with disability and the complexities of impairment. This inattention, I argued, is symptomatic of an ableist politics of knowledge that implicitly privileges normative able-disabled bodies and supercrip athletic achievements, rendering the experiences and achievements of highly impaired athletes invisible. Contemporary disability sporting discourse theorises *about* the body rather than *from* it, resulting in sanitised, ableist disability sport research, in which only *some* disabled bodies are considered acceptable and *some* disabling experiences worth sociocultural analysis. Thus, highly impaired athletes are included publicly but the structures and institutions that underpin their involvement do not support their 'private' embodied experiences.

This thesis contends that such erasure is far from accidental or benign. It is embedded within a wider politics that sustains the illusion of inclusion, while systematically marginalising those bodies that disrupt the normative, high functioning, autonomous high-performance para athlete ideal. These omissions carry significant costs, perpetuating sustain the 'lived and felt' dimensions of psycho-emotional disablism for highly impaired athletes (Reeve, 2004; Thomas, 2004), that exacerbate both the risk of bodily harm, and the erosion of athlete welfare.

The literature review highlighted the troubling disconnect between the widespread, generalised acceptance of organisational duty of care and its inconsistent practical application; a chasm widened by the underdevelopment of care as a coaching concept, particularly at its intersection with impairment. While impairment effects are often referenced in the literature, the overarching focus remains on structure and agency (Thomas, 1999), neglecting the ‘messy, gritty’ embodied experiences, ‘crip time’, and interdependence that profoundly shape the lives of highly impaired athletes and their carers. Thus, what is overlooked in the literature is echoed in organisational practice. Care remains undervalued, under resourced, and poorly understood, with significant consequences for athlete welfare.

By foregrounding the experiences of highly impaired athletes, this thesis seeks to unsettle these knowledge hierarchies and challenge the structures that render care and interdependence invisible. It calls on researchers, practitioners, and organisations to reflect on how their work may sustain these exclusions, and to take responsibility for driving deeper structural change. From a research perspective, shifting this politics of knowledge demands more than simply expanding datasets or including additional perspectives, it requires a fundamental rethinking of what we value as knowledge, whose bodies we centre, and how we imagine the future of disability sport.

Methodological Interventions

To undertake this critical examination, I engaged crip methodology informed by crip theory and cripistemology. This choice was a deliberate political act, seeking to challenge traditional ableist knowledge production embedded in traditional disability sport research. As Oliver (1992) stated, changing the power relations in disability research requires a paradigm shift from research done *on* disabled people toward research carried out *with* or *by* disabled people. Thus, this research was centred on crip subjectivities, exploring what it is to be disabled in the first place (Hickman & Serlin, 2019; Kafer, 2013; McRuer, 2006; Schalk, 2013) in order to radically disrupt the “socio-political ideologies that assign more value to some bodies… than others” (Minich, 2016, p.7).

This thesis expands cripistemology’s fluid and flexible methodological approach to explore the disabled sporting body, drawing on a combination of autoethnography, visual ethnography, Indigenous methodology pūrākau, and semi-structured interviews. The process laid bare the intimate aspects of daily bodily care. Our bodies and our lived experiences were never offered up for spectacle, they were shared to unsettle, provoke, and challenge normative understandings of what it means to be a para-athlete. This approach - like Kafer's (2013) feminist, queer, crip activism - invites not only academic reflection but collective responsibility. How we research disabled lives shapes the possibilities for disabled futures. Thus, it was a purposeful act, carried out in the hope that our words would contribute to the de-composition of narratives that disable (Peers, 2012a).

In the evolving methodological landscape of cripistemology, the Indigenous methodology pūrākau offers a unique contribution centred on embodied knowing and social justice in research (Lee-Morgan, 2019). Breaking away from the reductive medical lens (Peers, 2012b), pūrākau honours the complexity of the embodied experiences of marginalisation and of Othering. In foregrounding highly impaired athletes' words, pūrākau contributes to the broader struggle for self-determination, fuelling the recovery of ourselves (Lee-Morgan, 2019; Tuhiwai Smith, 2021). In this context, this powerful methodological approach is a form of activism: a means of unsettling the taken-for-granted assumptions that disable, and of contributing to the reimagining of sport systems that might one day do better.

Cripping care

Responding to my first two research objectives the autoethnographic chapter set the scene of the thesis, illuminating my lived realities of impairment and care. The chapter highlighted the intersections between impairment effects of the 'bodies that need bodies', disability' and high performance sport, cripping the conventions and assumptions of care. In detailing my daily embodied experience, the chapter introduced the undocumented material, physical, emotional, moral, and economic components of care required by highly impaired athletes. The narratives revealed the multiple touch points, and how those touch points are magnified and intensified with participation in sport. By focusing on the intersections of impairment, disability, and high performance sport, the research *crips* understandings and assumptions of care. The visual ethnography exposed my daily vulnerability in a raw depiction of care as it unfolds, largely behind closed doors. These images were not curated for comfort. They were designed to confront, evoke, and connect, to pull the reader into the deeply intimate, often invisible labour of bodily care that defines the everyday for highly impaired athletes. Beyond bathrooms and bedrooms, the photographs expose 'cares' as not only physical, but emotional, and moral, work for both parties (irrespective of carers being paid or whānau members). Cares emerges here as an undocumented impairment effect: an area marked by systemic squeamishness and absent from disability sport literature. The study exposes how the fleshy, messy, and often abject realities of impairment — involving fluids, waste, and profound vulnerability - can have direct and unavoidable impact on care provision and coaching within high performance sport. Yet despite being essential, these embodied experiences remain invisible in sporting literature, exposing a broader failure to engage with the complex realities that shape the inclusion of highly impaired athletes. Here, my analysis illustrates how understanding the physiological impacts, time demands, and logistical intricacies of cares is not peripheral, but vital for performance success and the welfare of highly impaired athletes.

Embodied Experiences of Highly Impaired Athletes

Highly impaired athletes' experiences of welfare and care are the empirical heart of this thesis. Responding to my second research objective, through crip theory, abjection, and critical disability research, this thesis extends existing understandings by introducing bio-social dimensions of care and 'dirty work' into the analysis of impairment effects. The athlete's experiences of managing these effects expose the extent to which sporting systems are unprepared for, or unwilling to accommodate, the embodied realities of highly impaired athletes. The chapter demonstrated how impairment effects underpin structural and psycho-emotional barriers that restrict disabled people's lives, and intensify within elite sport. The empirical evidence illustrates how support workers and athletes construct fragile ecosystems of belonging and resistance, providing care and connection absent from institutional structures. Thus, the embodied care experiences of highly impaired athletes and their carers becomes both a critical intervention in disability sporting literature and a necessary provocation for organisational reform.

Potentially prompting readers to sit with the discomfort, Chapter Five brought to light abject impairment effects, detailing how highly impaired athletes and support workers manage assisted 'shitting' and 'urinating' in often inaccessible high performance sporting spaces. While support workers and athletes expressed resistance and pride in their innovative management of 'dirty work' (Rakovski & Price-Glynn, 2010; Wolkowitz, 2006), their stories brought to light the entrenched structural and psycho-emotional barriers that must be overcome to simply participate. Messy bodies do not fit clean high performance sport, nor does the notion of highly impaired athletes' need for support. Interdependence is intimate, and constant, and a defining feature of highly impaired athletes' lives.

This thesis reveals that care is not peripheral to high performance disability sport, it is central to it. The embodied choreography between athletes and support workers forms a powerful ecosystem of belonging and resistance. In the face of institutional neglect, these relationships generate alternative ways of knowing, moving, and being; both on and off the court or field, for both athletes and support workers. This thesis reframes impairment not as something one *has*, but as something one *is*; care not as a deficit, but as radical, relational, and generative.

Crip Time and Care Time

This thesis extends embodied understandings in disability sport by introducing crip time and care time; critical temporal frameworks. Crip time – nonlinear, unpredictable, and often inconvenient - is central to the lived experience of highly impaired athletes (Kafer, 2013; Katzman et al., 2020). Crip time challenges the very foundation of high performance sport; a system built on linear progress toward timed outputs and performance outcomes. Highly impaired athletes' bodies do not bend to the stopwatch, and support workers are often forced to deliver 'care on time' in a system that affords no time for care.

To truly grasp care in in the high performance sporting context, care time must also be recognised. The temporal dissonance support workers navigate as they move between the fluid rhythms of 'crip time' and the rigid structures of 'abled time' (Samuels, 2017), especially within the high-pressure regimes of elite sport. Locating care in a sporting context deepens existing understandings of relational (Kelly, 2016) and emotional (Hochschild, 1983, 2012) labour embedded in care work, exposing the constant code switching, bodily attunement, personal sacrifice and self-erasure required by support workers to keep athletes training, competing, and surviving (Lowry et al., 2022). Care time, is more than an individual juggling act, it brings to light the tension between the needs of bodies and the demands of sport. It reveals how the logistics of highly impaired bodily maintenance such as cares, transfers, dressing, and strapping are incompatible with performance-at-all-costs cultures. These moments of tension are not marginal, nor infrequent, they are central to the experience of highly impaired athletes and their teams.

Despite their critical role, support workers remain invisible in systems built on able-bodied assumptions. This thesis argues that until their labour is recognised, resourced, and valued in high performance sport, meaningful inclusion will not occur.

Athlete Care: An Uneven Playing Field

In response to my third research objective, Chapter Six examined the broader institutional and organisational structures within which athletes are located. A key contribution of this chapter is the finding that national healthcare provision is vital – not a background variable – and a foundational determinant of participation and progression in disability sport. This is particularly poignant in Aotearoa, as the division of healthcare provision on the basis of acquired and congenital or degenerative impairment maps onto the hierarchies of bodies that are well articulated in disability sport literature. This thesis highlighted how athletes with congenital or degenerative impairment face compounding structural and institutional barriers that undermine their access to sport. While beyond the scope of this research, analysis into the impact of healthcare provision on sport development would be an interesting addition to disability sport sociology.

Globally, disability sport provision is founded on aspirational principles that promote a flagship for inclusion. Yet, many national and international disability sporting practices are mired with ableist institutional and structural barriers that disproportionately affect para-athletes. This research exposes the persistent underfunding of disability sports organisations and para-athletes, a neglect that fails to account for the additional costs and complexities associated with impairment effects. The welfare of high-performance para-athletes is left to the goodwill of volunteers, whanāu, and under-resourced staff. This situation would be unthinkable in other domains of high-performance sport. This reality forces highly impaired athletes and their supporters into precarious and emotionally costly arrangements, where inclusion is conditional and fragile. While it recognises that many sports face funding constraints, what is absent from the literature is a recognition of the unique and compounding financial, temporal, and emotional demands placed on highly impaired athletes. For these athletes, juggling time intensive care regimes, paid work, and training, is not merely difficult, it is often unsustainable. It does not make for a level playing field, between athletes and between countries.

Under the intense global scrutiny around athlete welfare and care, high performance sporting organisations have made public commitments to supporting athlete well-being and welfare. Yet these programmes are anchored to a narrow archetype of athlete (Howe, 2015); one that erases impairment, interdependence, and care (Lowry et al., 2022). Data reveal a fundamental disconnect between athletes' lived realities and organisational interpretations of duty of care. Coaches, as organisational representatives charged with operationalising duty of care commitments, often lack both the knowledge and the institutional backing to provide meaningful support to athletes with higher support needs (Hammond et al., 2019). Further, some coaches consciously or not, reinforce the (in)visibility of disability (DePauw, 1997), pushing for autonomy and independence in ways that mirror normative high performance values, further erasing the presence of care from para-athlete sporting lives. This thesis took the analysis further, exposing how organisational commitments to inclusion and welfare frequently function as performative gestures, masking embedded ableist inequalities and impeding structural change (Ahmed, 2012). As Ahmed (2012) powerfully asserts, "For a commitment [to inclusion] to do something, you must do something 'with it'" (p. 120).

This research makes clear that disabled coaches and advocates are not just important voices, but the very agents of change whose embodied expertise is crucial for dismantling ableist norms and cultivating sporting environments that genuinely reflect and support the complex realities of para-athletes. Interdependence is not an exception to be managed, rather, it is raw, intimate, and a constant feature of highly impaired athletes' lives that must be actively built into the fabric of sporting systems, not erased by them. Without this structural transformation, inclusion will remain an empty promise, and high-performance sport will continue to reproduce the exclusions it claims to challenge.

Future Research

While this thesis offers valuable insights, it is important to acknowledge its contextual and temporal boundaries. The primary focus of the empirical research was on experiences within the Aotearoa context. While the theoretical framework and many of the core findings may have broader resonance, the specific nuances of Aotearoa's healthcare system, cultural norms, and disability sport structures may limit transferability to other national contexts.

Future research in diverse geographic and political settings would provide a more comprehensive understanding of the global landscape of welfare and care for highly impaired athletes. Furthermore, I acknowledge that some of the empirical research is dated, and may not reflect the most recent developments in the sporting or healthcare sectors. However, research is always situated in time, and this work provides an important historical and socio-political snapshot amidst a changing and dynamic sector. Its relevance lies not in its currency alone, but in its ability to contextualise ongoing systemic issues, and identify opportunities for change.

This thesis opens up multiple avenues for future research.

1. To embed care meaningfully into sport systems and scholarship, there is a need to investigate the unique welfare and care needs of athletes across a wider spectrum of impairment types and levels.
2. Further examination of the invisible labour force that supports high performance sport; the carers, support workers and whānau. This research is essential to make visible the work that makes participation possible.
3. More targeted research is required to explore the relationship between healthcare provision and access to sport across different national settings, particularly for athletes with congenital or degenerative impairments. These athletes face significant barriers, and there is a critical need to interrogate how structural inequalities actively shape and restrict, their sporting pathways and opportunities.
4. Finally, while the intersection of gender and impairment was acknowledged in this study, a deeper, intersectional analysis attending to race, class, gender identity, and sexuality would provide rich insight into how layered inequalities shape care, access, and exclusion in high performance disability sport. These axes of identity do not operate in isolation but intersect with impairment to produce distinct experiences of marginalisation and resistance. Future research could explore how structural, such as colonial legacies, heteronormativity, and economic precarity, interact with ableist sporting frameworks to constrain (or enable) participation. Attending to these intersections is essential for building a more just and inclusive sporting future, one that accounts not only for impairment, but for the complexity of crip

embodiment. The task for future research is to support the transformation of sport into a space where care, interdependence, and disability justice are embedded at its core.

Call to Action

This thesis does not merely contribute to academic discourse; it issues a challenge. Across its chapters, the research has shown that disability sport research, methodology, and organisational practice can either sustain structural ableism or help dismantle it. The choice is stark. Meaningful change demands more than policy change or inclusion rhetoric, it requires a fundamental shift in how welfare and care are understood and enacted in high performance disability sport. This thesis, tantamount to a flag in the sand, calls for a reorientation of disability sport research: research not done *on* or *for* para-athletes, but from them. Research that is grounded in their lived experience, knowledge, and expertise. Research centred on embodied knowledge, relational care, and the voices of those who have long been marginalised in the sporting domain. To realise this shift, global and national disability sporting organisations, alongside researchers, must engage in critical dialogue. Moreover, disabled athletes, carers, coaches, and advocates should be central to the design and delivery of these transformations. This is not just a matter of representation; it is a matter of justice. Illuminating the embodied realities of impairment effects is not simply a tool to raise awareness, it is a lever for systemic transformation. Without such transformation, inclusion remains an aim, and welfare an empty concept. From this standpoint, global high performance disability sporting organisations, like the IPC, are uniquely positioned to lead meaningful institutional and structural reform. By embedding the embodied experiences of highly impaired athletes into their organisational frameworks, they have the potential to bring the (as yet undefined) ‘duty of care’ to life in tangible and transformative ways. Only through the intentional recognition of the most marginalised and silenced athletes can these organisations begin to realise their vision of “an inclusive world through Para sport” (IPC Committee, 2023), and move toward a genuinely equitable sporting future.

Final Thoughts

This thesis serves as a marker of intent, exposing the gap between the aspirational rhetoric of inclusion and the embodied realities of those of us who live in, and with, messy, interdependent, highly impaired bodies. It renders visible the bodies, the carers, the interdependence, and the labour that underpin participation in high performance sport for highly impaired athletes.

It is not enough to say welfare matters. It is not enough to gesture vaguely toward inclusion. Inclusion without care is lip service. Care without recognition is exploitation. If high performance sport is serious about inclusion and sporting equity, it must stop sanitising disability. It must embed the realities of impairment effects and care work into the foundations of disability sport provision; a step that would impact on policy, funding, coaching and research. This thesis offers more than a contribution to academic discourse, it provides the ground work for change. It issues a challenge and a call to action and a refusal to be left out of the story.

References

Accident Claims Corporation. (2024). *Āwhina tūroa lifelong support*. https://www.acc.co.nz/support

Adams, T. E., & Herrmann, A. F. (2020). Expanding our autoethnographic future. *Journal of Autoethnography*, *1*(1), 1-8. http://dx.doi.org/10.1525/joae.2020.1.1.1

Agnew, D., & Drummond, M. J. (2018). Accepting pain and injury as a career "norm" within the context of a masculinised Australian football subculture. In C. Fogel (Ed.), *Critical perspectives on gender and sport* (pp. 195-211). Common Ground Rearch Networks.

Ahmed, S. (2000). *Strange encounters: Embodied others in post-coloniality*. Routledge.

Ahmed, S. (2012a). Commitment as a non-performative. In *On Being Included: RAism and diversity in institutional life* (pp. 113-140). Duke University Press. https://doi.org/10.2307/j.ctv1131d2g.8

Ahmed, S. (2012b). *On being included: Racism and diversity in institutional life*. Duke University Press.

Ahmed, S. (2013). *Cultural politics of emotion*. Taylor & Francis Group.

Ahmed, S. (2016). An affinity of hammers. *Transgender Studies Quarterly*, *3*(1-2), 22-34. https://doi.org/10.1215/23289252-3334151

Ahmed, S. (2017). *Living a feminist life*. Duke University Press. https://doi.org/10.1515/9780822373377

Allan, V., Blair Evans, M., Latimer-Cheung, A. E., & Côté, J. (2019). From the athletes' perspective: A social-relational understanding of how coaches shape the disability sport experience. *Journal of Applied Sport Psychology*, *32*(6), 1-19. https://doi.org/10.1080/10413200.2019.1587551

Altheide, D., & Johnson, J. (1998). Criteria for assessing interpretive validity in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (Vol. 2, pp. 283-312). SAGE.

Angner, E. (2010). Subjective well-being. *Journal of Socio-Economics*, *39*(3), 361-368. https://doi.org/10.1016/j.socec.2009.12.001

Apelmo, E. (2012). Crip heroes and social change. *Lambda Nordica, 17*(1-2), 27.

Apelmo, E. (2017a). Sporting bodies and gender. In *Sport and the female disabled body* (pp. 115-142). Routledge. https://doi.org/10.4324/9781315610412-12

Apelmo, E. (2017b). Technology, gender and the body. In *Sport and the female disabled body* (pp. 104-114). Routledge. https://doi.org/10.4324/9781315610412

Asare, F., Townsend, R. C., & Burrows, L. (2023). Disentangling assistive technology: Exploring the experiences of athletes with physical impairments in disability sport. *Qualitative Research in Sport, Exercise and Health*, *15*(6), 729-741. https://doi.org/10.1080/2159676X.2023.2197458

Aviram, R., Khvorostianov, N., Harries, N., & Bar-Haim, S. (2022). Perceived barriers and facilitators for increasing the physical activity of adolescents and young adults with cerebral palsy: A focus group study. *Disability and Rehabilitation*, *44*(22), 6649-6659. https://doi.org/10.1080/09638288.2021.1970252

Avner, Z., Bridel, W., Eales, L., Glenn, N., Walker, R. L., & Peers, D. (2014). Moved to messiness: Physical activity, feelings, and transdisciplinarity. *Emotion, Space and Society*, *12*(1), 55-62. https://doi.org/10.1016/j.emospa.2013.11.002

Bailey, M. (2021). The ethics of pace. *South Atlantic Quarterly*, *120*(2), 285-299. https://doi.org/10.1215/00382876-8916032

Barbour, K. (2002). *Embodied ways of knowing: Women's solo contemporary dance in Aotearoa, New Zealand* [Unpublished Doctoral thesis, The University of Waikato]. Waikato. https://hdl.handle.net/10289/13998

Baril, A. (2016). “Doctor, am I an anglophone trapped in a francophone body?”: An intersectional analysis of “trans-crip-t time” in ableist, cisnormative, anglonormative societies. *Journal of Literary & Cultural Disability Studies*, *10*(2), 155-172. https://doi.org/10.3828/jlcds.2016.14

Bednarska, D. (2011). *Ability underneath: Bodies in the literary imagination* [Unpublished Docoral thesis, University of California, Berkeley]. California. https://escholarship.org/uc/item/8793j2j5

Berger, R. J. (2008). Disability and the dedicated wheelchair athlete: Beyond the “supercrip” critique. *Journal of Contemporary Ethnography*, *37*(6), 647-678. https://doi.org/10.1177/0891241607309892

Berger, R. J. (2009). *Hoop dreams on wheels: Disability and the competitive wheelchair athlete*. Routledge. https://doi.org/10.1525/ctx.2009.8.3.40

Betcher, S. V. (2010). Becoming flesh of my flesh: Feminist and disability theologies on the edge of posthumanist discourse. *Journal of Feminist Studies in Religion*, *26*(2), 107-118. https://doi.org/10.2979/FSR.2010.26.2.107

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219-234. https://doi.org/10.1177/1468794112468475

Bochner, A. P. (2000). Criteria against ourselves. *Qualitative Inquiry*, *6*(2), 266-272. https://doi.org/10.1177/107780040000600209

Bochner, A. P., & Ellis, C. (2016). *Evocative autoethnography: Writing lives and telling stories*. Routledge.

Boddy, J., Cameron, C., & Moss, P. (2006). *Care work: Present and future*. Routledge.

Bondi, L. (2008). On the relational dynamics of caring: A psychotherapeutic approach to emotional and power dimensions of women's care work. *Gender, Place and Culture*, *15*(3), 249-265.

Bourke, J. A., Hay-Smith, E. J. C., Snell, D. L., & DeJong, G. (2015). Attending to biographical disruption: The experience of rehabilitation following tetraplegia due to spinal cord injury. *Disability and Rehabilitation*, *37*(4), 296-303. https://doi.org/10.3109/09638288.2014.918188

Bowlby, S. (2012). Recognising the time—space dimensions of care: Caringscapes and carescapes. *Environment and Planning*, *44*(9), 2101-2118. https://doi.org/10.1068/a44492

Braaf, S., Lennox, A., Nunn, A., & Gabbe, B. (2017). Social activity and relationship changes experienced by people with bowel and bladder dysfunction following spinal cord injury. *Spinal Cord*, *55*(7), 679-686. https://doi.org/10.1038/sc.2017.19

Bratton, B. (2022). *The revenge of the real: Politics for a post-pandemic world*. Verso Books.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Bredahl, A. M. (2010). Coaching ethics and paralympic sports. In A. R. Hardman & Carwyn Jones (Eds.), *The ethics of sports coaching* (pp. 134-146). Taylor & Francis. https://doi.org/10.4324/9780203868447

Brighton, J., Townsend, R. C., Campbell, N., & Williams, T. L. (2021). Moving beyond models: Theorizing physical disability in the sociology of sport. *Sociology of Sport Journal*, *38*(4), 386-398. https://doi.org/10.1123/ssj.2020-0012

Brilmyer, G. (2022a). "I'm also prepared to not find me. It's great when I do, but it doesn't hurt if I don't": Crip time and anticipatory erasure for disabled archival users. *Archival Science*, *22*(2), 167-188. https://doi.org/10.1007/s10502-021-09372-1

Brilmyer, G. (2022b). "They weren't necessarily designed with lived experiences of disability in mind": The affect of archival in/accessibility and "emotionally expensive" spatial un/belonging. *Archivaria: The Journal of the Association of Canadian Archivists, 94*(December), 120-153.

Brittain, I., & Beacom, A. (2018). *The Palgrave handbook of Paralympic studies*. Palgrave Macmillan. https://doi.org/10.1057/978-1-137-47901-3

Brown, C., & Pappous, A. (2021). Are mega-events a solution to address physical inactivity? Interrogating the London 2012 Paralympic sport participation legacies among people with disabilities. *European Journal for Sport and Society*, *18*(1), 18-43. https://doi.org/10.1080/16138171.2020.1792112

Budgeon, S. (2003). Identity as an embodied event. *Body & Society*, *9*(1), 35-55. https://doi.org/10.1177/1357034X030091003

Buffart, L. M., Westendorp, T., Van Den Berg-Emons, R. J., Stam, H., & Roebroeck, M. E. (2009). Perceived barriers to and facilitators of physical activity in young adults with childhood-onset physical disabilities. *Journal of Rehabilitation Medicine*, *41*(11), 881-885. https://doi.org/10.2340/16501977-0420

Bundon, A., Ashfield, A., Smith, B., & Goosey-Tolfrey, V. L. (2018). Struggling to stay and struggling to leave: The experiences of elite para-athletes at the end of their sport careers. *Psychology of Sport and Exercise*, *37*, 296-305. https://doi.org/10.1016/j.psychsport.2018.04.007

Bundon, A., & Hurd Clarke, L. (2015). Honey or vinegar? Athletes with disabilities discuss strategies for advocacy within the Paralympic movement. *Journal of Sport and Social Issues*, *39*(5), 351-370. https://doi.org/10.1177/0193723514557823

Burns, A. S., St-Germain, D., Connolly, M., Delparte, J. J., Guindon, A., Hitzig, S. L., & Craven, B. C. (2015). Phenomenological study of neurogenic bowel from the perspective of individuals living with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, *96*(1), 49-55. https://doi.org/10.1016/j.apmr.2014.07.417

Butler, J. (2006). *Gender trouble: Feminism and the subversion of identity*. Routledge. https://doi.org/10.4324/9780203824979

Campbell, F. (2009). *Contours of ableism the production of disability and abledness* (1st ed.). Palgrave Macmillan. https://doi.org/10.1057/9780230245181

Campbell, N. (2021). The intellectual ableism of leisure research: Original considerations towards understanding well-being with and for people with intellectual disabilities. *Journal of Intellectual Disabilities*, *25*(1), 82-97. https://doi.org/10.1177/1744629519863990

Campbell, N., & Brown, D. (2021). The ableism of athlete wellbeing support: Additional needs of the paralympic athlete. In N. Campbell, A. Brady, & A. Tincknell-Smith (Eds.), *Developing and supporting athlete wellbeing: Person first, athlete second* (pp. 122-136). Taylor and Francis. https://doi.org/10.4324/9780429287923

Cardoso, V. D., Haiachi, M. d. C., & Gaya, A. C. A. (2019). Financial support for paralympic athletes in Brazil. *Journal of Physical Education*, *29*, e2963. https://doi.org/10.4025/jphyseduc.v29i1.2963

Carrington, S., Allen, K., & Osmolowski, D. (2007). Visual narrative: A technique to enhance secondary students' contribution to the development of inclusive, socially just school environments - lessons from a box of crayons. *Journal of Research in Special Educational Needs*, *7*(1), 8-15. https://doi.org/10.1111/j.1471-3802.2007.00076.x

Carroll, P., Witten, K., & Duff, C. (2021). "How can we make it work for you?" Enabling sporting assemblages for disabled young people. *Social Science & Medicine, 288*, 113213. https://doi.org/10.1016/j.socscimed.2020.113213

Cavino, H. M. (2019). "He would not listen to a woman": Decolonising gender through the power of pūrākau. In J. A. A. Q. Q. Xiiem, J. B. J. Lee-Morgan, & J. De Santolo (Eds.), *Decolonising research: Indigenous storywork as methodology* (pp. 95-106). Zed Books.

Charlesworth, H., & Young, K. (2006). Injured female athletes: Experiential accounts from England and Canada. In *Pain and injury in sport* (pp. 89-105). Routledge. https://doi.org/10.4324/9780203002995

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press. https://doi.org/10.1525/9780520925441

Chin, M. H., King, P. T., Jones, R. G., Jones, B., Ameratunga, S. N., Muramatsu, N., & Derrett, S. (2018). Lessons for achieving health equity comparing Aotearoa/New Zealand and the United States. *Health Policy*, *122*(8), 837-853. https://doi.org/10.1016/j.healthpol.2018.05.001

Clarke, V., & Braun, V. (2016). Thematic analysis. *Journal of Positive Psychology*, *12*(3), 297-298. https://doi.org/10.1080/17439760.2016.1262613

Clarke, V., & Braun, V. (2021). *Thematic analysis*. SAGE.

Cluley, V. (2020). Becoming-care: Reframing care work as flesh work not body work. *Culture and Organization*, *26*(4), 284-297. https://doi.org/10.1080/14759551.2019.1601724

Collier, J., & Collier, M. (1986). *Visual anthropology: Photography as a research method* (Rev. & Exp. ed.). University of New Mexico Press.

Conroy, E. C. (2007). Aiming for inclusive sport: The legal and practical implications of United Nation's Disability Convention for sport, recreation and leisure for people with disabilities. *Entertainment and Sports Law Journal, 5*(1), 4. https://doi.org/10.16997/eslj.75

Conti, A., Clari, M., Kangasniemi, M., Martin, B., Borraccino, A., & Campagna, S. (2022). What self-care behaviours are essential for people with spinal cord injury? A systematic review and meta-synthesis. *Disability and Rehabilitation*, *44*(7), 991-1006. https://doi.org/10.1080/09638288.2020.1783703

Cottrell, S. (2018). Elite athletes' rights and welfare. *Sport New Zealand*.

Couser, G. T., & Mairs, N. (1997). Recovering bodies: Illness, disability, and life writing. University of Wisconsin Press.

Cousin, G. (2006). An introduction to threshold concepts. *Planet, 17*(1), 4-5. https://doi.org/10.11120/plan.2006.00170004

Crampton, P., Matheson, D., & Cotter, M. (2020). Assessing the design and capability of our public health system in a Covid and post-Covid New Zealand. *Policy Quarterly*, *16*(3). https://doi.org/10.26686/pq.v16i3.6552

Cregan, K., Bloom, G. A., & Reid, G. (2007). Career evolution and knowledge of elite coaches of swimmers with a physical disability. *Research Quarterly for Exercise and Sport*, *78*(4), 339-350. https://doi.org/10.1080/02701367.2007.10599431

Cronin, C. (2023). Care in sport coaching: Different perspectives and alternative voices. *Sports Coaching Review*, *12*(1), 1-5. https://doi.org/10.1080/21640629.2022.2164836

Cronin, C., & Armour, K., M. (2018). *Care in sport coaching: Pedagogical cases* (1st ed.). Taylor and Francis. https://doi.org/10.4324/9781351109314

Cronin, C., & Armour, K., M. (2019a). *Care in sport coaching: Pedagogical cases*. Routledge.

Cronin, C., & Armour, K., M. (2019b). *Introduction to care in coaching*. Routledge. https://doi.org/10.4324/9781351109314-1

Cronin, C., Ryrie, A., Huntley, T., & Hayton, J. (2018). 'Sinking and swimming in disability coaching': An autoethnographic account of coaching in a new context. *Qualitative Research in Sport, Exercise and Health*, *10*(3), 362-377. https://doi.org/10.1080/2159676X.2017.1368695

Cronin, C., Whitehead, A. E., Webster, S., & Huntley, T. (2019). Transforming, storing and consuming athletic experiences: A coach's narrative of using a video application. *Sport, Education and Society*, *24*(3), 311-323. https://doi.org/10.1080/13573322.2017.1355784

Crossen, W., Wadsworth, N., Ronkainen, N., Haslett, D., & Tod, D. (2023). Identity in elite level disability sport: A systematic review and meta-study of qualitative research. *International Review of Sport and Exercise Psychology*, 1-27. https://doi.org/10.1080/1750984X.2023.2214993

Culver, D. M., Shaikh, M., Alexander, D., & Fournier, K. (2022). Gender equity in disability sport: A rapid scoping review. *Journal of clinical sport psychology*, 1-23. https://doi.org/10.1123/jcsp.2021-0074

Culver, D. M., & Werthner, P. (2017). Voices: Para-athletes speak. *Qualitative Research in Sport, Exercise and Health*, *10*(2), 167-175. https://doi.org/10.1080/2159676x.2017.1393004

Cushion, C., Huntley, T., & Townsend, R. (2021). Disability sport coaching: You just coach the athlete not the disability. In J. Wallis & J. Lambert (Eds.), *Sport coaching with diverse populations: Theory and practice* (Vol. 1, pp. 131-141). Routledge. https://doi.org/10.4324/9780367854799-10

Darcy, S., Lock, D., & Taylor, T. (2017). Enabling inclusive sport participation: Effects of disability and support needs on constraints to sport participation. *Leisure Sciences*, *39*(1), 20-41. https://doi.org/10.1080/01490400.2016.1151842

de Villiers, C., Muhammad Bilal, F., & Molinari, M. (2022). Qualitative research interviews using online video technology – challenges and opportunities. *Meditari Accountancy Research*, *30*(6), 1764-1782. https://doi.org/10.1108/MEDAR-03-2021-1252

Dehghansai, N., Lemez, S., Wattie, N., & Baker, J. (2017). A systematic review of influences on development of athletes with disabilities. *Adapted Physical Activity Quarterly*, *34*(1), 72-90. https://doi.org/10.1123/APAQ.2016-0030

Dehghansai, N., Lemez, S., Wattie, N., Pinder, R. A., & Baker, J. (2020). Understanding the development of elite parasport athletes using a constraint-led approach: Considerations for coaches and practitioners. *Frontiers in Psychology*, *11*, 502981. https://doi.org/10.3389/fpsyg.2020.502981

Denzin, N. K. (1997). *Interpretive ethnography: Ethnographic practices for the 21st century*. SAGE.

Denzin, N. K. (2003). Performing [auto] ethnography politically. *Review of Education/Pedagogy/Cultural Studies*, *25*(3), 257-278. https://doi.org/10.1080/10714410390225894

Denzin, N. K. (2006). Analytic autoethnography, or déjà vu all over again. *Journal of Contemporary Ethnography*, *35*(4), 419-428. https://doi.org/10.1177/0891241606286985

Denzin, N. K. (2017). Critical qualitative inquiry. *Qualitative Inquiry*, *23*(1), 8-16. https://doi.org/10.1177/1077800416681864

Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research* (2nd ed.). SAGE.

Denzin, N. K., & Lincoln, Y. S. (2003). *Collecting and interpreting qualitative materials* (2nd ed.). SAGE.

DePauw, K. P. (1997). The (in)visibility of disability: Cultural contexts and “sporting bodies”. *Quest*, *49*(4), 416-430. https://doi.org/10.1080/00336297.1997.10484258

DePauw, K. P. (2000). Social-cultural context of disability: Implications for scientific inquiry and professional preparation. *Quest*, *52*(4), 358-368. https://doi.org/10.1080/00336297.2000.10491723

DePauw, K. P. (2008). Disability sport: Historical context. In H. Fitzgerald & R. Bailey (Eds.), *Disability and youth sport* (pp. 11-23). Routledge. https://doi.org/10.4324/9780203889732

DePauw, K. P. (2022). Disrupting ableism in adaptive physical activity through anti-ableist research and practice. In D. Goodwin & M. Connolly (Eds.), *Reflexivity and change in adaptive physical activity* (pp. 11-20). Routledge. https://doi.org/10.4324/9781003196747-3

DePauw, K. P. (2023). Disabled female sporting bodies: Reflections on (In)visibility of disAbility in sport. In B. Powis, J. Beighton, & P. D. Howe (Eds.), *Disability sport and physical activity cultures. Researching disability sport: Theory, method, practice* (1st ed., pp. 85-99). Routledge. https://doi.org/10.4324/9781003153696

DePauw, K. P., & Gavron, S. J. (2005). *Disability sport* (2nd ed.). Human Kinetics.

Donaldson, E. J., & Prendergast, C. (2011). Introduction: Disability and emotion: ‘There’s no crying in disability studies!’. *Journal of Literary & Cultural Disability Studies*, *5*(2), 129-135. https://doi.org/10.3828/jlcds.2011.11

Douglas, M. (1966). *Purity and danger: An analysis of concepts of pollution and taboo*. Routledge. https://doi.org/10.4324/9781315015811

Downs, P. (2015). Do coaches need knowledge of impairment to coach athletes with disabilities? *Palaestra*, *29*(2), 42.

Drake, P. (2010). Grasping at methodological understanding: A cautionary tale from insider research. *International Journal of Research & Method in Education*, *33*(1), 85-99. https://doi.org/10.1080/17437271003597592

Duarte, T., & Culver, D. M. (2014). Becoming a coach in developmental adaptive sailing: A lifelong learning perspective. *Journal ofAapplied Sport Psychology*, *26*(4), 441-456. https://doi.org/10.1080/10413200.2014.920935

Duffy, M., Albelda, R., & Hammonds, C. (2013). Counting care work. The empirical and policy applications of care theory. *Social Problems*, *60*(2), 145-167. https://doi.org/10.1525/sp.2013.60.2.145

Dutia, I., & Tweedy, S. (2021). *The Paralympics strive for inclusion. But some rules unfairly exclude athletes with severe disabilities*. https://theconversation.com/the-paralympics-strive-for-inclusion-but-some-rules-unfairly-exclude-athletes-with-severe-disabilities-166347

Edwards, J. (2020). Disability politics and care: The challenge of direct funding: by Christine Kelly. *Disability & Society*, *35*(6), 1024-1026. https://doi.org/10.1080/09687599.2019.1639595

Ellingson, L. L. (1998). "Then you know how I feel": Empathy, identification, and reflexivity in fieldwork. *Qualitative Inquiry*, *4*(4), 492-514. https://doi.org/10.1177/107780049800400405

Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. AltaMira Press.

Ellis, C., & Bochner, A. (2003). Auto-ethnography, personal narrative, reflexivity: Researcher as subject. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (2nd ed., Vol. 2, pp. 773-768). SAGE.

Ellis, C. S., & Bochner, A. P. (2006). Analyzing analytic autoethnography: An autopsy. *Journal of Contemporary Ethnography*, *35*(4), 429-449. https://doi.org/10.1177/0891241606286979

Ellis, K., Garland-Thomson, R., & Kent, M. (2019). *Manifestos for the future of critical disability studies. Volume 1*. Routledge.

England, P. (2005). Emerging theories of care work. *Annual Review of Sociology*, *31*(1), 381-399. https://doi.org/10.1146/annurev.soc.31.041304.122317

England, K., & Dyck, I. (2011). Managing the body work of home care. *Sociology of Health & Illness*, *33*(2), 206-219. https://doi.org/10.1111/j.1467-9566.2010.01331.x

Fairhurst, K. E., Bloom, G. A., & Harvey, W. J. (2017). The learning and mentoring experiences of paralympic coaches. *Disability and Health Journal*, *10*(2), 240-246. https://doi.org/10.1016/j.dhjo.2016.10.007

Falcous, M., & Scott, G. (2023). New Zealand's princess of the pool: Post-ableism and the media narrativisation of Sophie Pascoe. *International Review for the Sociology of Sport*, *58*(5), 889-907. https://doi.org/10.1177/10126902221135031

Fineman, M. (2004). *The autonomy myth: A theory of dependency*. New Press.

Fisher, L. A., Larsen, L. K., Bejar, M. P., & Shigeno, T. C. (2019). A heuristic for the relationship between caring coaching and elite athlete performance. *International Journal of Sports Science & Coaching*, *14*(2), 126-137. https://doi.org/10.1177/1747954119827192

Fisher, L. A., Shigeno, T. C., Bejar, M. P., Larsen, L. K., & Gearity, B. (2018). Caring practices among U.S. National Collegiate Athletic Association Division I female and male assistant coaches. *International Journal of Sports Science & Coaching*, *13*(4), 471-484. https://doi.org/10.1177/1747954117743114

Fitzgerald, H. (2009). *Disability and youth sport*. Routledge.

Fitzgerald, H. (2021). The welfare of disabled people in sport. In M. Lang (Ed.), *Routledge handbook of athlete welfare* (pp. 183-195). Routledge. https://doi.org/10.4324/9780429201745

Fitzgerald, H., & Joblin, A. (2009). Future directions in disability and youth sport: Development, aspirations and research. In H. Fitzgerald & R. Bailey (Eds.), *Future directions in disability and youth sport: Development, aspirations and research* (pp. 160-170). Routledge. https://doi.org/10.4324/9780203889732-22

Flood, C. M., & Hardcastle, L. (2015). A two-tier health care system: The New Zealand story. *Ottawa Faculty of Law Working Paper No. 2015-30*. https://dx.doi.org/10.2139/ssrn.2627709

Frank, A. W. (2011). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (Eds.), *Varieties of narrative analysis* (p. 22). SAGE. https://doi.org/10.4135/9781506335117.n3

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). The University of Chicago Press.

Fraser, N. (1995). From redistribution to recognition? Dilemmas of justice in a 'Post-Socialist' age. *New Left Review*, *212*(212), 68-93.

Fraser, N. (2007). Feminist politics in the age of recognition: A two-dimensional approach to gender justice. *Studies in Social Justice*, *1*(1), 23-35. https://doi.org/10.26522/ssj.v1i1.979

Fraser, N., Dahl, H. M., Stoltz, P., & Willig, R. (2004). Recognition, redistribution and representation in capitalist global society: An interview with Nancy Fraser. *Acta Sociologica*, *47*(4), 374-382.

French, L., Le Clair, J. M., Beacom, A., & Brittain, I. (2018). Game changer? Social media, representations of disability and the Paralympic Games. In I Brittain & A Beacom (Eds.), *The Palgrave handbook of Paralymic studies* (pp. 99-121). Palgrave Macmillan. https://doi.org/10.1057/978-1-137-47901-3_6

Gannon, S. (2013). Sketching subjectivities. In T. E. Adams, S. Holman Jones, & C. Ellis (Eds.), *Handbook of autoethnography* (pp. 228-244). Routledge. https://doi.org/10.4324/9781315427812

Garland-Thomson, R. (1996). *Freakery: Cultural spectacles of the extraordinary body*. New York University Press.

Garland Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. Columbia University Press.

Gomez, J., Bradley, J., & Conway, P. (2018). The challenges of a high-performance student athlete. *Irish Educational Studies*, *37*(3), 329-349. https://doi.org/10.1080/03323315.2018.1484299

Goodley, D. (2014). *Dis/ability studies: Theorising disablism and ableism* (1st ed.). Routledge.

Goodley, D. (2017). *Disability studies: An interdisciplinary introduction* (2nd ed.). SAGE.

Goodley, D., & Lawthom, R. (2019). Critical disability studies, Brexit and Trump: A time of neoliberal–ableism. *Rethinking History*, *23*(2), 233-251. https://doi.org/10.1080/13642529.2019.1607476

Goodley, D., & Runswick-Cole, K. (2011). The violence of disablism. *Sociology of Health & Illness*, *33*(4), 602-617. https://doi.org/10.1111/j.1467-9566.2010.01302.x

Goodley, D., & Runswick-Cole, K. (2013). The body as disability and possability: Theorizing the 'leaking, lacking and excessive'bodies of disabled children. *Scandinavian Journal of Disability Research*, *15*(1), 1-19. https://doi.org/10.1080/15017419.2011.640410

Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: Thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, *37*(1), 1-15. https://doi.org/10.1080/01596306.2014.930021

Goodwin, D., Johnston, K., Gustafson, P., Elliott, M., Thurmeier, R., & Kuttai, H. (2009). It's okay to be a quad: Wheelchair rugby players sense of community. *Adapt Physical Activity Quarterly*, *26*(2), 102-117. https://doi.org/10.1123/apaq.26.2.102

Goodwin, D., & Peers, D. (2013). Disability, sport and inclusion. In S. Dagkas & K. Armour (Eds.), *Inclusion and exclusion through youth sport* (1st ed., pp. 186-202). Routledge. https://doi.org/10.4324/9780203852392

Goodyear-Smith, F., & Ashton, T. (2019). New Zealand health system: Universalism struggles with persisting inequities. *The Lancet*, *394*(10196), 432-442. https://doi.org/10.1016/s0140-6736(19)31238-3

Grey-Thompson, T. (2017). *Duty of care in sport: Independent report to government*. Department for Culture, Media & Sport.

Grosz, E. (1989). *Sexual subversions: Three french feminists*. Allen & Unwin.

Grosz, E. (1994, 2020). *Volatile bodies: Toward a corporeal feminism*. Routledge.

Grue, J. (2016). The problem with inspiration porn: A tentative definition and a provisional critique. *Disability & Society*, *31*(6), 838-849. https://doi.org/10.1080/09687599.2016.1205473

Hall, E. (2004). Social geographies of learning disability: Narratives of exclusion and inclusion. *Area*, *36*(3), 298-306. https://doi.org/10.1111/j.0004-0894.2004.00227.x

Hammond, A., & Jeanes, R. (2018). Federal Government involvement in Australian disability sport, 1981-2015. *International Journal of the History of Sport*, *35*(5), 431-447. https://doi.org/10.1080/09523367.2017.1337000

Hammond, A., Jeanes, R., Penney, D., & Leahy, D. (2019). "I feel we are inclusive enough": Examining swimming coaches' understandings of inclusion and disability. *Sociology of Sport Journal*, *36*(4), 311-321. https://doi.org/10.1123/ssj.2018-0164

Hammond, A. M., Bundon, A., Pentifallo Gadd, C., & Konoval, T. (2022). Enactments of integrated, disability-inclusive sport policy by sporting organizations. *Sociology of Sport Journal*, *39*(1), 35-46. https://doi.org/10.1123/ssj.2020-0151

Hanlon, C., & Taylor, T. (2022). Workplace experiences of women with disability in sport organizations. *Frontiers in Sports and Active Living*, *4*, 792703. https://doi.org/10.3389/fspor.2022.792703

Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, *14*(3), 575-599. https://doi.org/10.2307/3178066

Hardin, M. (2007). "I consider myself an empowered woman": The interaction of sport, gender and disability in the lives of wheelchair basketball players. *Women in Sport & Physical Activity Journal*, *16*(1), 39-52. https://doi.org/10.1123/wspaj.16.1.39

Hardin, M., & Hardin, B. (2004). The 'supercrip' in sport media: Wheelchair athletes discuss hegemony's disabled hero. *Sociology of Sport Online*, *7*(1).

Hargreaves, J. (2000). *Heroines of sport the politics of difference and identity*. Routledge.

Harper, D. (1998). An argument for visual sociology. In J. Prosser (Ed.), *Image-based research* (pp. 24-41). Falmer Press.

Hebson, G., Rubery, J., & Grimshaw, D. (2015). Rethinking job satisfaction in care work: Looking beyond the care debates. *Work, Employment & Society*, *29*(2), 314-330. https://doi.org/10.1177/0950017014556412

Heron, M. (2018). *Independent review of cycling New Zealand High Performance Programme*. High-performance Sport New Zealand. https://hpsnz.org.nz/wp-content/uploads/2018/10/CNZ-Review-Final.pdf

Hertz, R. (Ed.). (1997). Introduction: Reflexivity and voice. In *Reflexivity and voice* (pp. xxii-xviii). SAGE.

Hickman, L., & Serlin, D. (2019). Towards a crip methodology for critical disability studies. In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (Eds.), *Interdisciplinary approaches to disability. Looking towards the future* (pp. 131-141). Routledge.

High Performance Sport Zealand. (2022). *Well-being a key priority in HPSNZ 2022–2024 investments*. High Performance Sport Zealand. https://hpsnz.org.nz/journal-entries/wellbeing-a-key-priority-in-hpsnz-2022-2024-investments/#:~:text=%E2%80%9CWe%20already%20provide%20holistic%20support,and%20conditioning%2C%20nutrition%2C%20medical%2C

High Performance Sport Zealand. (2024a). *High performance investment programme 2025-2028*. High Performance Sport Zealand. https://hpsnz.org.nz/about-us/news-media/high-performance-athletes-set-to-receive-significant-funding-increase/

High Performance Sport Zealand. (2024b). *High Performance Sport New Zealand's strategic plan 2025–2028*. High Performance Sport Zealand. https://cdn.hpsnz.org.nz/content/uploads/2024/10/11114502/HPSNZ-2025-2028-Strategic-Plan.pdf

High Performance Sport Zealand. (2024c). *HPSNZ well-being framework and guidelines*. High Performance Sport Zealand. https://hpsnz.org.nz/wp-content/uploads/2024/04/HPSNZ-Wellbeing-Framework-and-Guidelines.pdf

High Performance Sport Zealand. (2024d). *Pathway to sustainable success*. High Performance Sport Zealand. https://hpsnz.org.nz/athletes/athlete-pathways/

Himmelweit, S. (1999). Caring labor. *Annals of the American Academy of Political and Social Science*, *561*(1), 27-38. https://doi.org/10.1177/0002716299561001002

Hochschild, A. R. (1983, 2012). *The managed heart: Commercialization of human feeling*. University of California Press. (Original work published 1983). https://doi.org/10.1525/j.ctt1pn9bk

Holman Jones, S. (2011). Lost and found. *Text and Performance Quarterly*, *31*(4), 322-341. https://doi.org/10.1080/10462937.2011.602709

Holman Jones, S. (2016). Living bodies of thought: The "critical" in critical autoethnography. *Qualitative Inquiry*, *22*(4), 228-237. https://doi.org/10.1177/1077800415622509

Holman Jones, S. L., Adams, T. E., & Ellis, C. (2013). *Handbook of autoethnography*. Left Coast Press.

Holman Jones, S. L., & Harris, A. M. (2019). *Queering autoethnography*. Routledge.

Howe, P. D. (2007). Integration of Paralympic athletes into athletics Canada. *International Journal of Canadian Studies, 35*, 133-150. https://doi.org/10.7202/040767ar

Howe, P. D. (2008). The tail is wagging the dog: Body culture, classification and the Paralympic movement. *Ethnography*, *9*(4), 499-517. https://doi.org/10.1177/1466138108096989

Howe, P. D. (2008). *The cultural politics of the paralympic movement: Through an anthropological lens* (1st ed.). Routledge. https://doi.org/10.4324/9780203506097

Howe, P. D. (2009). Reflexive ethnography, impairment and the pub. *Leisure Studies*, *28*(4), 489-496. https://doi.org/10.1080/02614360903071746

Howe, P. D. (2011). Cyborg and supercrip: The paralympics technology and the (dis)empowerment of disabled athletes. *Sociology*, *45*(5), 868-882. https://doi.org/10.1177/0038038511413421

Howe, P. D. (2015). Disability and sport: The case of the paralympic games. In R. Giulianotti (Ed.), *Routledge handbook of the sociology of sport* (pp. 251-261). Taylor & Francis. https://doi.org/10.4324/9780203404066

Howe, P. D. (2018). Athlete, anthropologist and advocate: Moving towards a lifeworld where difference is celebrated. *Sport in Society*, *21*(4), 678-688. https://doi.org/10.1080/17430437.2016.1273628

Howe, P. D. (2023). Cultural politics, disability sport and physical activity research. In B. Powis, J. Beighton, & P. D. Howe (Eds.), *Disability sport and physical activity cultures. Researching disability sport: Theory, method, practice* (1st ed., pp. 41-54). Routledge. https://doi.org/10.4324/9781003153696

Howe, P. D., & Jones, C. (2006). Classification of disabled athletes: (Dis)empowering the paralympic practice community. *Sociology of Sport Journal, 23*(1), 29-46. https://doi.org/10.1123/ssj.23.1.29

Howe, P. D., & Silva, C. F. (2015). The Paralympic Games and the agenda of empowerment. In D. Jackson, C. E. M. Hodges, M. Molesworth, & R. Scullion (Eds.), *Reframing diability: Media, (dis)empowerment and voice in the 2012 Paralymics* (pp. 202-217). Routledge. https://doi.org/10.4324/9781315757285-17

Howe, P. D., & Silva, C. F. (2018). The fiddle of using the Paralympic Games as a vehicle for expanding [dis]ability sport participation. *Sport in Society*, *21*(1), 125-136. https://doi.org/10.1080/17430437.2016.1225885

Huang, C. J., & Brittain, I. (2006). Negotiating identities through disability sport. *Sociology of Sport Journal*, *23*(4), 352-375. https://doi.org/10.1123/ssj.23.4.352

Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability and Society*, *12*(3), 325-340. https://doi.org/10.1080/09687599727209

Hutchinson, S. L., & Kleiber, D. A. (2000). Heroic masculinity following spinal cord injury: Implications for therapeutic recreation practice and research. *Therapeutic Recreation Journal*, *34*(1), 42-54.

Introna, A. (2023). Pandemic lived experience, crip utopias, and dismodernist revolutions: For a more-than-social model of disability. *Social Inclusion*, *11*(1), 82-91. https://doi.org/10.17645/si.v11i1.5754

Institutional Review Board. (2010). *Avoid 'deductive' disclosures by revamping informed consent*. Institutional Review Board Advisor.

International Paralympic Committee. (2023). *Strategic Plan 2023 – 2026*. https://www.paralympic.org/sites/default/files/2023-03/2023_01%20Strategic%20Plan_ACC.pdf

International Paralympic Committee. (2024). *Constitution*. https://www.paralympic.org/sites/default/files/2024-04/FINAL_IPC%20Constitution%20%28ENGLISH%20VERSION%29_16.11.22_Apr24.pdf

Jaarsma, E. A., Geertzen, J. H., de Jong, R., Dijkstra, P. U., & Dekker, R. (2014). Barriers and facilitators of sports in Dutch Paralympic athletes: An explorative study. *Scandinavian Journal of Medicine & Science in Sports*, *24*(5), 830-836. https://doi.org/10.1111/sms.12071

Jefferies, P., Gallagher, P., & Dunne, S. (2012). The Paralympic athlete: A systematic review of the psychosocial literature. *Prosthetics and Orthotics International*, *36*(3), 278-289. https://doi.org/10.1177/0309364612450184

Johnson, M., & McRuer, R. (2014). Cripistemologies: Introduction. *Journal of Literary & Cultural Disability Studies*, *8*(2), 127-147. https://doi.org/10.3828/jlcds.2014.12

Jones, R. L. (2009). Coaching as caring (the smiling gallery): Accessing hidden knowledge. *Physical Education and Sport Pedagogy*, *14*(4), 377-390. https://doi.org/10.1080/17408980801976551

Jonsson, K. (2017). Paralympics and the fabrication of 'freak shows': On aesthetics and abjection in sport. *Sport, Ethics and Philosophy*, *11*(2), 224-237. https://doi.org/10.1080/17511321.2017.1286375

Kacen, L., & Chaitin, J. (2006). The times are a changing: Understanding qualitative research in ambiguous, conflictual and changing contexts. *Qualitative Report*, *11*, 209-228. https://doi.org/10.46743/2160-3715/2006.1671

Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.

Kafer, A. (2021). After crip, crip afters. *South Atlantic Quarterly*, *120*(2), 415-434. https://doi.org/10.1215/00382876-8916158

Karlsson, M., Rydström, M., & Rydström, J. (2023). Crip theory: A useful tool for social analysis. *NORA-Nordic Journal of Feminist and Gender Research*, *31*(4), 395-410. https://doi.org/10.1080/08038740.2023.2179108

Katzman, E. R., Kinsella, E. A., & Polzer, J. (2020). 'Everything is down to the minute': Clock time, crip time and the relational work of self-managing attendant services. *Disability & Society*, *35*(4), 517-541. https://doi.org/10.1080/09687599.2019.1649126

Kavanagh, E., Rhind, D., & Gordon-Thomson, G. (2021). Duties of care and welfare practices. In R. Arnold & D. Fletcher (Eds.), *Stress, well-being, and performance in sport* (pp. 313-331). Routledge.

Kell, P., Kell, M., & Price, N. (2008). Two games and one movement? The Paralympics and the Olympic movement. University of Wollongong. https://ro.uow.edu.au/articles/chapter/Two_games_and_one_movement_The_Paralympics_and_the_Olympic_movement/27691107/1/files/50428632.pdf

Kelly, C. (2013). Building bridges with accessible care: Disability studies, feminist care scholarship, and beyond. *Hypatia*, *28*(4), 784. https://doi.org/10.1111/j.1527-2001.2012.01310.x

Kelly, C. (2016). *Disability politics and care: The challenge of direct funding*. UBC Press.

Kerschbaum, S. L., & Price, M. (2017). Centering disability in qualitative interviewing. *Research in the Teaching of English*, *52*(1), 98-107. https://doi.org/10.58680/rte201729202

Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, *24*(1), 49-58. https://doi.org/10.1111/j.1467-9337.2010.00473.x

Kobayashi, Y., Kordecki, M., Bettner, J., & Makowski, A. (2016, October). Cervical radiculopathy. *Emergency Physicians Monthly*. https://epmonthly.com/article/cervical-radiculopathy/

Kohe, G. Z., & Peters, D. M. (2017). *High performance disability sport coaching*. Routledge.

Kohe, G. Z., Purdy, L. G., Litou, A., Brady, A., Campbell, N., Tincknell-Smith, A., Campbell, N., Tincknell-Smith, A., & Brady, A. (2022). Athlete welfare, stakeholder responsibility, and ethics of care in elite sport: An examination of para-sport organisation approaches in France. In N. Campbell, A. Brady & A. Tincknell-Smith (Eds.), *Developing and supporting athlete well-being* (pp. 211-224). Routledge. https://doi.org/10.4324/9780429287923-15

Kristeva, J. (1982). *The power of horror: An essay on abjection*. Columbia University Press.

Krouwel, M., Jolly, K., & Greenfield, S. (2019). Comparing Skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome-an exploratory comparative analysis. *BMC Medical Research Methodology*, *19*(1), 219. https://doi.org/10.1186/s12874-019-0867-9

Kuntz, A. M. (2015). *The responsible methodologist: Inquiry, truth-telling, and social justice*. Taylor & Francis.

Kvale, S. (2007). *Doing interviews*. SAGE.

Lang, M. (Ed.). (2020). Developments in international policy on athlete welfare. In *Routledge handbook of athlete welfare* (pp. 15-23). Taylor and Francis. https://doi.org/10.4324/9780429201745

Langmann, S., & Pick, D. (2018). *Photography as a social research method*. Springer Singapore. https://doi.org/10.1007/978-981-10-7279-6

Lawson, J. A., Williams, T., & Latimer-Cheung, A. E. (2023). Exploring athletes' and classifiers' experiences with and understanding of classification in Para sport. *Qualitative Research in Sport Exercise and Health*, *15*(4), 516-531. https://doi.org/10.1080/2159676X.2022.2152084

Lawson, V. (2007). Geographies of care and responsibility. *Annals of the Association of American Geographers*, *97*(1), 1-11. https://doi.org/10.1111/j.1467-8306.2007.00520.x

Le Clair, J. M. (2009). Sport and health: Global challenges to biomedical definitions of disability. *vis-à-vis: Explorations in Anthropology*, *9*(2), 203-219. https://vav.library.utoronto.ca/index.php/vav/article/view/3404/3501

Lee, J. (2008). *Ako: Pūrākau of Māori teachers' work in secondary schools* [Unpublished Doctoral thesis, University of Auckland]. Auckland.

Legg, D., Orr, K., Patatas, J. M., Pankowiak, A., Wong, J., Higgs, C., & Hamamoto, G. (2022). Paralympic pathways. In N. Dehghansai, R. A. Pinder, & J. Baker (Eds.), *Talent development in paralympic sport* (pp. 7-23). Routledge.

Lietz, C. A., Langer, C. L., & Furman, R. (2006). Establishing trustworthiness in qualitative research in social work: Implications from a study regarding spirituality. *Qualitative Social Work: Research and Practice*, *5*(4), 441-458. https://doi.org/10.1177/1473325006070288

Lindemann, K. (2010). Cleaning up my (father's) mess: Narrative containments of "leaky" masculinities. *Qualitative Inquiry*, *16*(1), 29-38. https://doi.org/10.1177/1077800409350060

Lindemann, K., & Cherney, J. L. (2008). Communicating in and through "murderball": Masculinity and disability in wheelchair rugby. *Western Journal of Communication*, *72*(2), 107-125. https://doi.org/10.1080/10570310802038382

Lindlof, T. R., & Taylor, B. C. (2019). *Qualitative communication research methods* (4th ed.). SAGE.

Linton, S. (1998). *Claiming disability knowledge and identity*. New York University Press.

Linton, S. (2006). *My body politic: A memoir*. University of Michigan Press.

Liston, K., McDowell, M., Malcolm, D., Scott-Bell, A., & Waddington, I. (2018). On being 'head strong': The pain zone and concussion in non-elite rugby union. *International Review for the Sociology of Sport*, *53*(6), 668-684. https://doi.org/10.1177/1012690216679966

Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2012). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, *28*(2), 190-203. https://doi.org/10.1080/09687599.2012.705057

Longhurst, R. (2001). *Bodies: Exploring fluid boundaries*. Routledge. https://doi.org/10.4324/9780203193600

Lowry, A., Townsend, R. C., Petrie, K., & Johnston, L. (2022). 'Cripping' care in disability sport: An autoethnographic study of a highly impaired high-performance athlete. *Qualitative Research in Sport, Exercise and Health*, *14*(6), 956-968. https://doi.org/10.1080/2159676X.2022.2037695

Lumsdaine, G., & Lord, R. (2021). (Re)creating a healthy self in and through disability sport: Autoethnographic chaos and quest stories from a sportswoman with cerebral palsy. *Disability & Society*, *38*(7), 1231-1250. https://doi.org/10.1080/09687599.2021.1983415

Lyons, L. (2013). Transformed understanding or enlightened ableism? The gap between policy and practice for children with disabilities in Aotearoa New Zealand. *International Journal of Early Childhood*, *45*(2), 237-249. https://doi.org/10.1007/s13158-013-0086-1

Maher, A. J., McVeigh, J., Thomson, A., & Knight, J. (2022). Exclusion, inclusion and belonging in mainstream and disability sport: Jack's story. *Qualitative Research in Sport, Exercise and Health*, *15*(1), 123-138. https://doi.org/10.1080/2159676X.2022.2111457

Manderson, L., & Peake, S. (2005). Men in motion: Disability & the performance of masculinity. In C. Sandahl & P. Auslander (Eds.), *Bodies in commotion: Disability and performance* (pp. 230-242). University of Michigan Press.

Marcellini, A. (2018). The extraordinary development of sport for people with dis/abilities. What does it all mean? *Alter*, *12*(2), 94-104. https://doi.org/10.1016/j.alter.2018.04.005

Martin, J. J. (2013). Benefits and barriers to physical activity for individuals with disabilities: A social-relational model of disability perspective. *Disability and Rehabilitation*, *35*(24), 2030-2037. https://doi.org/10.3109/09638288.2013.802377

Mason, B. S., Van der Woude, L. H. V., & Goosey-Tolfrey, V. L. (2013). The ergonomics of wheelchair configuration for optimal performance in the wheelchair court sports. *Sports Medicine*, *43*(1), 23-38. https://doi.org/10.1007/s40279-012-0005-x

Mauerberg-deCastro, E., Campbell, D. F., & Tavares, C. P. (2016). The global reality of the Paralympic movement: Challenges and opportunities in disability sports. *Motriz: Revista de Educação Física*, *22*(3), 111-123. https://doi.org/10.1590/S1980-6574201600030001

McBean, C., Townsend, R. C., & Petrie, K. (2022). An historical analysis of disability sport policy in Aotearoa New Zealand. *International Journal of Sport Policy and Politics*, *14*(3), 419-434. https://doi.org/10.1080/19406940.2022.2052147

McClintock, A. (1995). *Imperial leather: Race, gender, and sexuality in the colonial contest*. Routledge. https://doi.org/10.4324/9780203699546

McCulloch, E. (2020). *The experience of care in sport: An institutional ethnography of youth competitive volleyball* [Unpublished Doctoral thesis, York University]. Toronto. https://yorkspace.library.yorku.ca/server/api/core/bitstreams/bbf14720-3142-4d68-a979-63da184b5a1e/content

McKay, C. (2022). Embodiment, identity and disability sport: An ethnography of elite visually impaired athletes. *Sport, Education and Society*, *27*(2), 224-227. https://doi.org/10.1080/13573322.2021.2010851

McKenzie, G., Willis, C., & Shields, N. (2021). Barriers and facilitators of physical activity participation for young people and adults with childhood-onset physical disability: A mixed methods systematic review. *Developmental Medicine & Child Neurology*, *63*(8), 914-924. https://doi.org/10.1111/dmcn.14830

McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York University Press.

Meyers, B. [@becca_myers]. (2021, June 20). X.

Meziani, M., Valet, A., & Kiuppis, F. (2017). Disability and care in the context of physical excellence - Revisiting the ecology of sport. *Loisir et société*, *40*(1), 7-24. https://doi.org/10.1080/07053436.2017.1282038

Miller, B., Barker, J. B., Hunton, E., Plateau, C. R., & Beauchamp, M. R. (2024). Understanding experiences of and influences on well-being in elite para-sport: A qualitative exploration of U.K. para-athletes. *Sport, Exercise, and Performance Psychology*, *13*(2), 126-143. https://doi.org/10.1037/spy0000342

Miller, T. (2019). Re-thinking care: Disability and narratives of care in Dinah Mulock Craik's, A noble life (1866). In R. Garland-Thomson, K. Ellis, M. Kent, & R. Robertson (Eds.), *Interdisciplinary approaches to disability* (1st ed., Vol. 2, pp. 91-98). Routledge. https://doi.org/10.4324/9781351053228-9

Milligan, C., & Wiles, J. (2010). Landscapes of care. *Progress in Human Geography*, *34*(6), 736-754. https://doi.org/10.1177/0309132510364556

Minich, J. A. (2016). Enabling whom? Critical disability studies now. *Lateral: Journal of the Cultural Studies Association,* (5.1). https://doi.org/doi.org/10.25158/L5.1.9

Ministry of Health. (2020). *Health and disability system review–final report–Pūrongo Whakamutunga*. https://www.health.govt.nz/system/files/2022-09/health-disability-system-review-final-report.pdf

Mira, T., Monteiro, D., Costa, A., Morouço, P., Matos, R., & Antunes, R. (2022). Tokyo 2020: A sociodemographic and psychosocial characterization of the portuguese paralympic team. *Healthcare 2022, 10*(7), 1185. https://doi.org/10.3390/healthcare10071185

Mitchell, D. T., & Snyder, S. L. (2000). *Narrative prosthesis: Disability and the dependencies of discourse*. University of Michigan Press.

Mitchell, D. T., & Snyder, S. L. (2001). *Corporealities: Discourses of disability: Narrative prosthesis: Disability and the dependencies of discourse*. University of Michigan Press.

Moola, F. J., & Norman, M. E. (2012). Transcending 'hoop dreams': Toward a consideration of corporeality, crossroads and intersections, and discursive possibilities in disability and theory. *Qualitative Research in Sport, Exercise and Health*, *4*(2), 284-295. https://doi.org/10.1080/2159676X.2012.685103

Moore, A. (2017). *Critical elitism: Deliberation, democracy, and the problem of expertise*. Cambridge University Press.

Morris, J. (1995). Creating a space for absent voices: Disabled women's experience of receiving assistance with daily living activities. *Feminist Review*, *51*(1), 68-93. https://doi.org/10.1057/fr.1995.34

Morris, J. (1997). Care or empowerment? A disability rights perspective. *Social Policy and Administration*, *31*(1), 54-60. https://doi.org/10.1111/1467-9515.00037

Morris, J. (2001). Impairment and disability: Constructing an ethics of care that promotes human rights. *Hypatia*, *16*(4), 1-16. https://doi.org/10.1111/j.1527-2001.2001.tb00750.x

Morrison, C. A. (2021). A personal geography of care and disability. *Social & Cultural Geography*, *23,* 1041-1056. https://doi.org/10.1080/14649365.2021.1884741

Morrison, C. A., Woodbury, E., Johnston, L., & Longhurst, R. (2020). Disabled people's embodied and emotional geographies of (not)belonging in Aotearoa New Zealand. *Health & Place*, *62*, 102283-102289. https://doi.org/10.1016/j.healthplace.2020.102283

Mountjoy, M., Brackenridge, C., Arrington, M., Blauwet, C., Carska-Sheppard, A., Fasting, K., Kirby, S., Leahy, T., Marks, S., & Martin, K. (2016). International Olympic Committee consensus statement: Harassment and abuse (non-accidental violence) in sport. *British Journal of Sports Medicine*, *50*(17), 1019-1029. https://doi.org/10.1136/bjsports-2016-096121

Mountz, A. (2010). *Seeking asylum: Human smuggling and bureaucracy at the border* (NED - New ed.). University of Minnesota Press. https://doi.org/10.5749/j.ctttv40b

Naci, H., & Ioannidis, J. P. A. (2015). Evaluation of wellness determinants and interventions by citizen scientists. *JAMA*, *314*(2), 121-122. https://doi.org/10.1001/jama.2015.6160

Nevedal, A., Kratz, A. L., & Tate, D. G. (2016). Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: Life controlled by bladder and bowel. *Disability and Rehabilitation*, *38*(6), 573-581. https://doi.org/10.3109/09638288.2015.1049378

New Zealand Herald. (2021, August). New Zealand Olympic cyclist Olivia Podmore dies aged 24. *Author*. https://www.nzherald.co.nz/sport/new-zealand-olympic-cyclist-olivia-podmore-dies-aged-24/YQSZCDQYGMPAB7BXWDMMFUBXYU/

New Zealand Wheelchair Rugby. (2010). *Association incorporated rules*. https://www.wheelblacks.com/asset/downloadasset?id=10b16bc9-6fc5-4fa6-88e8-fd36f25f272c

Noddings, N. (1988). An ethic of caring and its implications for instructional arrangements. *American Journal of Education*, *96*(2), 215-230. https://doi.org/10.1086/443894

Noddings, N. (2010). Moral education in an age of globalization. *Educational Philosophy and Theory*, *42*(4), 390-396. https://doi.org/10.1111/j.1469-5812.2008.00487.x

Noddings, N. (2016). *Philosophy of education* (4th ed.). Westview Press.

Nussbaum, M. (1988). Nature, function, and capability: Aristotle on political distribution. *Oxford Studies in Ancient Philosophy*, 145-184. https://www.wider.unu.edu/sites/default/files/WP31.pdf

Oliver, M. (1996). *Understanding disability: From theory to practice*. Macmillan.

Oliver, M., & Barnes, C. (2010). Disability studies, disabled people and the struggle for inclusion. *British Journal of Sociology of Education*, *31*(5), 547-560. https://doi.org/10.1080/01425692.2010.500088

Orr, K., Tamminen, K. A., Sweet, S. N., Tomasone, J. R., & Arbour-Nicitopoulos, K. P. (2018). "I've had bad experiences with team sport": Sport participation, peer need-thwarting, and need-supporting behaviors among youth identifying with physical disability. *Adapted Physical Activity Quarterly*, *35*(1), 36-56. https://doi.org/10.1123/apaq.2017-0028

Padgett, D. K. (2008). *Qualitative and mixed methods in social work research*. SAGE. https://doi.org/10.1093/sw/54.2.101

Papadimitriou, C. (2008). Becoming en-wheeled: The situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury. *Disability & Society*, *23*(7), 691-704. https://doi.org/10.1080/09687590802469420

Paralympics New Zealand. (2020). *New Zealand para-athletes classification code and standards.* Paralympics New Zealand. https://paralympics.org.nz/wp-content/uploads/2023/12/2020-NZ-Para-athlete-Classification-Code-and-Standards-Final-Dec-2020.pdf

Paralympics New Zealand. (2021a). *Paralympics New Zealand strategic plan 2021–2032*. Paralympics New Zealand. https://paralympics.org.nz/wp-content/uploads/2023/12/PNZ_Strategic-Plan_Web.pdf

Paralympics New Zealand. (2021b). *PNZ athletes' council*. Paralympics New Zealand. https://paralympics.org.nz/about/our-people/pnz-athlete-council/

Paralympics New Zealand.(2024c). *What are the Paralympic Games?* Paralympics New Zealand. https://paralympics.org.nz/news/what-are-the-paralympic-games/

Patatas, J. M., De Rycke, J., De Bosscher, V., & Kons, R. L. (2021). It's a long way to the top: Determinants of developmental pathways in Paralympic sport. *Adapted Physical Activity Quarterly*, *38*(4), 605-625. https://doi.org/10.1123/apaq.2020-0147

Peers, D. (2009). (Dis)empowering Paralympic histories: Absent athletes and disabling discourses. *Disability & Society*, *24*(5), 653-665. https://doi.org/10.1080/09687590903011113

Peers, D. (2012a). Interrogating disability: The (de)composition of a recovering Paralympian. *Qualitative Research in Sport, Exercise and Health*, *4*(2), 175-188. https://doi.org/10.1080/2159676X.2012.685101

Peers, D. (2012b). Patients, athletes, freaks: Paralympism and the reproduction of disability. *Journal of Sport & Social Issues*, *36*(3), 295-316. https://doi.org/10.1177/0193723512442201

Peers, D. (2015). *From eugenics to Paralympics: Inspirational disability, physical fitness, and the white Canadian nation* [Unpublished Doctoral thesis, University of Alberta]. https://doi.org/10.7939/R3377623P

Peers, D., & Eales, L. (2017). Moving materiality: People, tools, and this thing called disability. *Art/Research International: A Transdisciplinary Journal*, *2*(2), 101-125. https://doi.org/10.18432/R2JS8W

Peers, D., Konoval, T., & Naturkach, R. M. (2020). (Un)imaginable (Para-)athletes: A discourse analysis of athletics websites in Canada. *Adapted Physical Activity Quarterly*, *37*(1), 112-128. https://doi.org/10.1123/apaq.2019-0062

Phoenix, C., & Smith, B. (2011). Telling a (good?) counterstory of aging: Natural bodybuilding meets the narrative of decline. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *66*(5), 628-639. https://doi.org/10.1093/geronb/gbr077

Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education*, *16*(2), 175-196. https://doi.org/10.1080/0951839032000060635

Pink, S. (2011). Multimodality, multisensoriality and ethnographic knowing: Social semiotics and the phenomenology of perception. *Qualitative Research*, *11*(3), 261-276. https://doi.org/10.1177/1468794111399835

Pink, S. (2013). *Doing visual ethnography* (3rd ed.). SAGE.

Pink, S. (2015). *Doing sensory ethnography* (2nd ed.). SAGE.

Powis, B. (2018). Transformation, advocacy and voice in disability sport research. In T. F. Carter, D. Burdsey, & M. Doidge (Eds.), *Transforming sport: Knowledges, practices, structures* (pp. 248-259). Routledge. https://doi.org/10.4324/9781315167909

Powis, B. (2020). *Embodiment, identity and disability sport: An ethnography of elite visually impaired athletes*. Taylor and Francis. https://doi.org/10.4324/9780429317675

Powis, B., Brighton, J., & Howe, P. D. (2023). *Researching disability sport: Theory, method, practice*. Routledge. https://doi.org/10.4324/9781003153696

Probyn, E. (2004). Everyday shame. *Cultural Studies, 18*(2), pp. 328-349. Routledge. https://doi.org/10.4324/9781003209331-11

Prosser, J. (1998). *Image-based research a sourcebook for qualitative researchers*. Falmer Press.

Prosser, J., & Schwartz, D. (1998). Photographs within the sociological research process. In J. Prosser (Ed.), *Image-based research a sourcebook for qualitative researchers* (pp. 115-130). Falmer Press.

Pryor, J., Haylen, D., & Fisher, M. J. (2021). The usual bowel care regimes of people living in the community with spinal cord injury and factors important for integrating bowel care into everyday life. *Disability and Rehabilitation*, *44*(21), 6401-6407. https://doi.org/10.1080/09638288.2021.1966678

Puce, L., Okwen, P. M., Yuh, M. N., Akah Ndum Okwen, G., Pambe Miong, R. H., Kong, J. D., & Bragazzi, N. L. (2023). Well-being and quality of life in people with disabilities practicing sports, athletes with disabilities, and para-athletes: Insights from a critical review of the literature. *Frontiers in Psychology*, *14*, 1071656. https://doi.org/10.3389/fpsyg.2023.1071656

Pullen, E., Jackson, D., & Silk, M. (2019). (Re-)presenting the paralympics: Affective nationalism and the “able-disabled”. *Communication and Sport*, *8*(6), 715-737. https://doi.org/10.1177/2167479519837549

Purdue, D. E. J., & Howe, P. D. (2012). See the sport, not the disability: Exploring the Paralympic paradox. *Qualitative Research in Sport, Exercise and Health*, *4*(2), 189-205. https://doi.org/10.1080/2159676X.2012.685102

Purdue, D. E. J., & Howe, D. P. (2013). Who’s in and who is out? Legitimate bodies within the Paralympic Games. *Sociology of Sport Journal*, *30*(1), 24-40. https://doi.org/10.1123/ssj.30.1.24

Quinn, N., & Misener, L. (2023). It's classified: Classification, disability rights and Commonwealth Games. *Frontiers in Sports and Active Living*, *5*, 1130703. https://doi.org/10.3389/fspor.2023.1130703

Quinn, N., Misener, L., & Howe, P. D. (2022). All for one and one for all? Integration in high-performance sport. *Managing Sport and Leisure*, *27*(6), 558-576. https://doi.org/10.1080/23750472.2020.1829989

Rakovski, C. C., & Price-Glynn, K. (2010). Caring labour, intersectionality and worker satisfaction: An analysis of the national nursing assistant study. *Sociology of Health & Illness*, *32*(3), 400-414. https://doi.org/10.1111/j.1467-9566.2009.01204.x

Reeve, D. (2002). Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. *Disability & Society*, *17*(5), 493-508. https://doi.org/10.1080/09687590220148487

Reeve, D. (2004). Psycho-emotional dimensions of disability and the social model. In C. Barnes & G. Mercer (Eds.), *Implementing the social model of disability: Theory and* *research* (pp. 83-100). The Disability Press. https://donnareeve.co.uk/wp-content/uploads/2014/03/ReeveChapter2004b.pdf

Reeve, D. (2006). Towards a psychology of disability: The emotional effects of living in a disabling society. In D. Goodley & R. Lawthorn (Eds.), *Disability and psychology: Critical introductions and reflections* (pp. 94-107). Palgrave Macmillan.

Reeve, D. (2020). Psycho-emotional disablism: The missing link? In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (2nd ed., pp. 102-116). Routledge. https://doi.org/10.4324/9780429430817-8

Reynolds, P. (2024). *Whaikaha – Changes to Disability Support Services – EMS and flexible funding*. New Zealand Disability Support Network. https://nzdsn.org.nz/whaikaha-changes-to-disability-support-services-ems-and-flexible-funding/

Rhind, D., McDermott, J., Lambert, E., & Koleva, I. (2015). A review of safeguarding cases in sport. *Child Abuse Review*, *24*(6), 418-426. https://doi.org/10.1002/car.2306

Richard, R., Joncheray, H., & Duquesne, V. (2023). Cripping sport and physical activity: An intersectional approach to gender and disability. *Sport, Ethics and Philosophy*, *17*(3), 327-341. https://doi.org/10.1080/17511321.2022.2161611

Rivas, L. M. (2011). Invisible care and the illusion of independence. In A. I. Carey & K. V. Hansen (Eds.), *At the heart of work and family: Engaging the ideas of Arlie Hochschild* (pp. 180-190). Rutgers University Press.

Rodriguez Macias, M., Gimenez Fuentes-Guerra, F. J., & Abad Robles, M. T. (2022). The sport training process of para-athletes: A systematic review. *International Journal of Environmental Research and Public Health*, *19*(12), 7242. https://doi.org/10.3390/ijerph19127242

Rohrer, J. (2005). Toward a full-inclusion feminism: A feminist deployment of disability analysis. *Feminist Studies*, *31*(1), 34-63. https://doi.org/10.2307/20459006

Ross, M. (2020). The throat of Parata. In A. Hodge (Ed.), *Imagining decolonisation* (pp. 21-39). Bridget Williams Books. https://doi.org/10.7810/9781988545783

Rubin, H. J., & Rubin, I. (2012). *Qualitative interviewing: The art of hearing data* (3rd ed.). SAGE.

Sage, D. J. (2012). Building contacts: The trials, tribulations and translations of an ethnographic researcher in construction. In S. Pink, D. Tutt, & A. Dainty (Eds.), *Ethnographic research in the construction industry* (pp. 91-107). Routledge. https://doi.org/10.4324/9780203834671

Sakellariou, D., & Rotarou, E. S. (2017). The effects of neoliberal policies on access to healthcare for people with disabilities. *International Journal for Equity in Health*, *16*, Art. No. 199. https://doi.org/10.1186/s12939-017-0699-3

Sales, D. J. (2022). *Understanding para-athlete development: An examination of para swimming* [Unpublished Doctoral thesis, University of Western Ontario]. Canada. https://ir.lib.uwo.ca/etd/8688

Samuels, E. (2017). Six ways of looking at crip time. *Disability Studies Quarterly*, *37*(3). https://doi.org/10.18061/dsq.v37i3.5824

Scarpa, S., & Palumbo, C. (2017). Physical self-concept in athletes with congenital versus acquired disabilities. *Saggi di Pedagogia Dello Sport*, *2*(2), 1-15.

Schalk, S. (2013). Coming to claim crip: Disidentification with/in disability studies. *Disability Studies Quarterly*, *33*(2). https://doi.org/10.18061/dsq.v33i2.3705

Schalk, S. (2016). Reevaluating the supercrip. *Journal of Literary & Cultural Disability Studies*, *10*(1), 71-86,128. https://doi.org/10.3828/jlcds.2016.5

Schur, L., Han, K., Kim, A., Ameri, M., Blanck, P., & Kruse, D. (2017). Disability at work: A look back and forward. *Journal of Occupational Rehabilitation*, *27*(4), 482-497. https://doi.org/10.1007/s10926-017-9739-5

Sen, A. K. (1999). *Development as freedom*. Knopf.

Shakespeare, T. (2014). *Disability rights and wrongs revisited* (2nd ed.). Routledge. https://doi.org/10.4324/9781315887456

Sheridan, N. F., Kenealy, T. W., Connolly, M. J., Mahony, F., Barber, P. A., Boyd, M. A., Carswell, P., Clinton, J., Devlin, G., & Doughty, R. (2011). Health equity in the New Zealand health care system: A national survey. *International Journal for Equity in Health*, *10*, 1-14. https://doi.org/10.1186/1475-9276-10-45

Sherrill, C. (1999). Disability sport and classification theory: A new era. *Adapted Physical Activity Quarterly*, *16*(3), 206-215. https://doi.org/10.1123/apaq.16.3.206

Sherry, M. (2016). A sociology of impairment. *Disability & Society*, *31*(6), 729-744. https://doi.org/10.1080/09687599.2016.1203290

Shildrick, M., & Price, J. (2002). Bodies together: Touch, ethics and disability. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 63--75). Bloomsbury Publishing.

Shilling, C. P. (2003). *The body and social theory* (2nd ed.). SAGE.

Sienko, S. (2019). Understanding the factors that impact the participation in physical activity and recreation in young adults with cerebral palsy (CP). *Disability and Health Journal*, *12*(3), 467-472. https://doi.org/10.1016/j.dhjo.2019.02.008

Silva, C. F. (2023). Confronting ableism from within: Reflections on anti-ableism research in disability sport. In B. Powis, J. Brighton, & D. P. Howe (Eds.), *Researching disability sport* (Vol. 1, pp. 157-170). Routledge. https://doi.org/10.4324/9781003153696-14

Silva, C. F., & Howe, P. D. (2012a). Difference, adapted physical activity and human development: Potential contribution of capabilities approach. *Adapted Physical Activity Quarterly*, *29*(1), 25. https://doi.org/10.1123/apaq.29.1.25

Silva, C. F., & Howe, P. D. (2012b). The (in)validity of supercrip representation of paralympian athletes. *Journal of Sport and Social Issues*, *36*(2), 174-194. https://doi.org/10.1177/0193723511433865

Slasberg, C., & Beresford, P. (2017). The need to bring an end to the era of eligibility policies for a person-centred, financially sustainable future. *Disability & Society*, *32*(8), 1263-1268. https://doi.org/10.1080/09687599.2017.1332560

Slocum, C., Blauwet, C. A., & Anne Allen, J. B. (2015). Sports medicine considerations for the paralympic athlete. *Current Physical Medicine and Rehabilitation Reports*, *3*(1), 25-35. https://doi.org/10.1007/s40141-014-0074-x

Slocum, C., Kim, S., & Blauwet, C. (2018). Women and athletes with high support needs in paralympic sport: Progress and further opportunities for underrepresented populations. In I. Brittain & A. Beacom (Eds.), *The Palgrave handbook of paralympic studies* (pp. 371-388). Palgrave Macmillan. https://doi.org/10.1057/978-1-137-47901-3

Smith, B. (2013). Disability, sport and men's narratives of health: A qualitative study. *Health Psychology*, *32*(1), 110-119. https://doi.org/10.1037/a0029187

Smith, B., & Bundon, A. (2018). Disability models: Explaining and understanding disability sport in different ways. In I. Brittain & A. Beacom (Eds.), *The Palgrave handbook of paralympic studies* (pp. 15-34). Palgrave Macmillan. https://doi.org/10.1057/978-1-137-47901-3_2

Smith, B., Bundon, A., & Best, M. (2016). Disability sport and activist identities: A qualitative study of narratives of activism among elite athletes' with impairment. *Psychology of Sport & Exercise*, *26*, 139-148. https://doi.org/10.1016/j.psychsport.2016.07.003

Smith, B., & McGannon, K. R. (2018). Developing rigor in qualitative research: Problems and opportunities within sport and exercise psychology. *International Review of Sport and ExercisePpsychology*, *11*(1), 101-121. https://doi.org/10.1080/1750984X.2017.1317357

Smith, B., & Perrier, M. J. (2014). Disability, sport, and impaired bodies A critical approach. In R. J. Schinke & K. R. McGannon (Eds.), *The psychology of sub-culture in sport and physical activity: Critical perspectives* (pp. 95-106). Routledge. https://doi.org/10.4324/9781315778495

Smith, B., & Sparkes, A. C. (2005). Men, sport, spinal cord injury, and narratives of hope. *Social Sciences & Medicine*, *61*(5), 1095-1105. https://doi.org/10.1016/j.socscimed.2005.01.011

Smith, B., & Sparkes, A. C. (2006). Narrative inquiry in psychology: Exploring the tensions within. *Qualitative Research in Psychology*, *3*(3), 169-192. https://doi.org/10.1191/1478088706qrp068oa

Smith, B., & Sparkes, A. C. (2020). Disability, sport and physical activity. In N. Watson & S. Vehmas (Eds.), *Routledge handbook of disability studies* (2nd ed., Vol. 2, pp. 391-403). Routledge. https://doi.org/10.4324/9780429430817-28

Snyder, S. L., & Mitchell, D. T. (2001). Re-engaging the body: Disability studies and the resistance to embodiment. *Public Culture*, *13*(3), 367-389. https://doi.org/10.1215/08992363-13-3-367

Sparkes, A. C. (1996). The fatal flaw: A narrative of the fragile body-self. *Qualitative Inquiry*, *2*(4), 463-494. https://doi.org/10.1177/107780049600200405

Sparkes, A. C. (2004). From performance to impairment: A patchwork of embodied memories. In J. Evans, B. Davies, & J. Wright (Eds.), *Body knowledge and control: Studies in the sociology of physical education and health* (pp. 181-196). Routledge. https://doi.org/10.4324/9780203563861-21

Sparkes, A. C. (2020). Autoethnography: Accept, revise, reject? An evaluative self reflects. *Qualitative Research in Sport, Exercise and Health*, *12*(2), 289-302. https://doi.org/10.1080/2159676X.2020.1732453

Sparkes, A. C., & Brighton, J. (2020). Autonomic dysreflexia and boosting in disability sport: Exploring the subjective meanings, management strategies, moral justifications, and perceptions of risk among male, spinal cord injured, wheelchair athletes. *Qualitative Research in Sport, Exercise and Health*, *12*(3), 414-430. https://doi.org/10.1080/2159676X.2019.1623298

Sparkes, A. C., Brighton, J., & Inckle, K. (2018). 'It's a part of me': An ethnographic exploration of becoming a disabled sporting cyborg following spinal cord injury. *Qualitative Research in Sport, Exercise and Health*, *10*(2), 151-166. https://doi.org/10.1080/2159676X.2017.1389768

Sparkes, A. C., & Smith, B. (2002). Sport, spinal cord injury, embodied masculinities, and the dilemmas of narrative identity. *Men and Masculinities*, *4*(3), 258-285. https://doi.org/10.1177/1097184X02004003003

Sparkes, A. C., & Smith, B. (2008). Men, spinal cord injury, memories and the narrative performance of pain. *Disability & Society, 23*(7), 679-690. https://doi.org/10.1080/09687590802469172

Sparkes, A. C., & Smith, B. (2014). *Qualitative research methods in sport, exercise and health: From process to product*. Routledge. https://doi.org/10.4324/9780203852187

Sparkes, A. C., & Smith, B. (2016). Sport, spinal cord injury, embodied masculinities, and the dilemmas of narrative identity. *Men and Masculinities*, *4*(3), 258-285. https://doi.org/10.1177/1097184x02004003003

Sport and Recreation New Zealand Act. (2002). *Sport and Recreation New Zealand Act 2002*. Parliamentary Counsel Office. https://www.legislation.govt.nz/act/public/2002/0038/latest/whole.html

Sport New Zealand. (2019). *Sport New Zealand outcomes framework*. New Zealand Government. https://sportnz.org.nz/media/1144/sport-nz-outcomes-framework2.pdf

Sport New Zealand. (2020). *Everybody active*. New Zealand Government. https://www.sportsthinktank.com/uploads/sport-nz-strategy-doc-201219.pdf

Stacey, C. L. (2005). Finding dignity in dirty work: The constraints and rewards of low-wage home care labour. *Sociology of Health & Illness*, *27*(6), 831-854. https://doi.org/10.1111/j.1467-9566.2005.00476.x

Stacey, C. L., Armenia, A., & Duffy, M. (2015). *Caring on the clock the complexities and contradictions of paid care work*. Rutgers University Press.

Stacey, C. L., & Ayers, L. L. (2019). Caught between love and money the experiences of paid family caregivers. In M. Duffy, A. Armenia, & C. L. Stacey (Eds.), *Caring on the clock: The complexities and contradictions of paid care work* (pp. 201-212). Rutgers University Press. https://doi.org/10.36019/9780813563138-021

Stephens, R. (2004). Horizontal equity for disabled people: Incapacity from accident or illness. *Victoria University of Wellington Law Review*, *35*(4), 783-800. https://doi.org/10.26686/vuwlr.v35i4.5720

Stephens, T. (2021). Embrace the taniwha. *E-Tangata*. https://e-tangata.co.nz/reo/embrace-the-taniwha/

Sterba, D., Stapleton, J. N., & Kennedy, W. (2022). The supercrip athlete in media: Model of inspiration or able-bodied hegemony? *International Journal of Sport Communication*, *15*(3),185-189. https://doi.org/10.1123/ijsc.2022-0062

Stevens, S., E (2018). Care time. *Disability Studies Quarterly*, *38*(4). https://doi.org/10.18061/dsq.v38i4.6090

Storli, L., Aune, M. A., & Lorås, H. (2022). Aspects of developmental pathways toward world-class parasport. *Sports*, *10*(8), 123. https://doi.org/10.3390/sports10080123

Syed, M., & Nelson, S. C. (2015). Guidelines for establishing reliability when coding narrative data. *Emerging Adulthood*, *3*(6), 375-387. https://doi.org/10.1177/2167696815587648

Tawse, H., Bloom, G. A., Sabiston, C. M., & Reid, G. (2012). The role of coaches of wheelchair rugby in the development of athletes with a spinal cord injury. *Qualitative Research in Sport, Exercise and Health*, *4*(2), 206-225. https://doi.org/10.1080/2159676x.2012.685104

Taylor, S. J., Bogdan, R., & Devault, M. (2015). *Introduction to qualitative research methods: A guidebook and resource* (4th ed.). John Wiley & Sons.

Te Whatu Ora Health New Zealand. (2023). *Needs assessment*. https://www.abuseincare.org.nz/assets/Evidence-library/Part-7/Te-Whatu-Ora-Health-New-Zealand-website-Needs-Assessment-2023.pdf

Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Open University Press.

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, *19*(6), 569-583. https://doi.org/10.1080/0968759042000252506

Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. Bloomsbury Publishing.

Thomas, C. (2010). Medical sociology and disability theory. In G. Scambler & S. Scambler (Eds.), *New directions in the sociology of chronic and disabling conditions: Assaults on the lifeworld* (pp. 37-56). Springer.

Thomas, C. (2016). De-constructing concepts of care. *Sociology*, *27*(4), 649-669. https://doi.org/10.1177/0038038593027004006

Thomas, N., & Guett, M. (2014). Fragmented, complex and cumbersome: A study of disability sport policy and provision in Europe. *International Journal of Sport Policy and Politics*, *6*(3), 389-406. https://doi.org/10.1080/19406940.2013.832698

Townsend, R., & Cushion, C. (2018). Athlete-centred coaching in disability sport: A critical perspective. In S. Pill (Ed.), *Perspectives on athelete-centred coaching* (pp. 47-56). Routledge. https://doi.org/10.4324/9781315102450-5

Townsend, R. C., & Cushion, C. J. (2020). 'Put that in your fucking research': Reflexivity, ethnography and disability sport coaching. *Qualitative Research*, 146879412093134. https://doi.org/10.1177/1468794120931349

Townsend, R. C., Cushion, C. J., & Smith, B. (2018). A social relational analysis of an impairment-specific mode of disability coach education. *Qualitative Research in Sport, Exercise and Health*, *10*(3), 346-361. https://doi.org/10.1080/2159676X.2017.1407355

Townsend, R. C., Huntley, T. C., Christopher, J., & Fitzgerald, H. (2018). 'It's not about disability, I want to win as many medals as possible': The social construction of disability in high-performance coaching. *International Review for the Sociology of Sport*, *55*(3), 344-360. https://doi.org/10.1177/1012690218797526

Townsend, R. C., Huntley, T. D., Cushion, C. J., & Culver, D. (2022). Infusing disability into coach education and development: A critical review and agenda for change. *Physical Education and Sport Pedagogy*, *27*(3), 247-260. https://doi.org/10.1080/17408989.2021.1873932

Townsend, R. C., Smith, B., & Cushion, C. J. (2015). Disability sports coaching: Towards a critical understanding. *Sports Coaching Review*, *4*(2), 80-98. https://doi.org/10.1080/21640629.2016.1157324

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837-851. https://doi.org/10.1177/1077800410383121

Trainor, L. R., Bennett, E. V., Bundon, A. M., Tremblay, M., Mannella, S., & Crocker, P. R. (2023). Inescapable tensions: Performance and/or psychological well-being in Olympic and Paralympic athletes during sport disruption. *Qualitative Research in Sport, Exercise and Health*, *15*(5), 601-618. https://doi.org/10.1080/2159676X.2023.2175899

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. Routledge.

Tuakli-Wosornu, Y. A., & Kirby, S. L. (2022). Safeguarding reimagined: Centering athletes' rights and repositioning para sport to chart a new path. *Frontiers in Psychology*, *13*, 815038. https://doi.org/10.3389/fpsyg.2022.815038

Tuhiwai Smith, L. (2021). *Decolonizing methodologies: Research and indigenous peoples*. Bloomsbury Academic & Professional.

Twigg, J. (2000). *Bathing: The body and community care*. Routledge. https://doi.org/10.4324/9780203190876

Tyler, I. (2021). *Revolting subjects: Social abjection and resistance in neoliberal Britain*. Zed Books. https://doi.org/10.5040/9781350222359

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

Van Dongen, E., & Elema, R. (2001). The art of touching: The culture of 'body work' in nursing. *Anthropology & Medicine*, *8*(2-3), 149-162. https://doi.org/10.1080/13648470120101345

Van Dornick, K., & Spencer, N. L. I. (2020). What's in a sport class? The classification experiences of paraswimmers. *Adapted Physical Activity Quarterly*, *37*(1), 1-19. https://doi.org/10.1123/apaq.2019-0007

Van Lindert, C., Scheerder, J., & Brittain, I. (Eds.). (2023). *Understanding disability, disability sport and inclusion*. Springer.

Wagner, J. (2020). Visual studies and empirical social enquiry. In L. Pauwels & D. Mannay (Eds.), *The SAGE handbook of visual research methods* (2nd ed., pp. 57-75). SAGE.

Walmsley, J. (1993). Contradictions in caring: Reciprocity and interdependence. *Disability, Handicap & Society*, *8*(2), 129-141. https://doi.org/10.1080/02674649366780111

Wareham, Y., Burkett, B., Innes, P., & Lovell, G. (2017). Coaching athletes with disability: Preconceptions and reality. *Sport in Society*, *20*(9), 1185-1202. https://doi.org/10.1080/17430437.2016.1269084

Watermeyer, B., & Swartz, L. (2008). Conceptualising the psycho-emotional aspects of disability and impairment: The distortion of personal and psychic boundaries. *Disability & Society*, *23*(6), 599-610. https://doi.org/10.1080/09687590802328477

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)Dependence, needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology (Oxford)*, *38*(2), 331-350. https://doi.org/10.1177/0038038504040867

Watts Belser, J. (2016). Vital wheels: Disability, relationality, and the queer animacy of vibrant things. *Hypatia*, *31*(1), 5-21. https://doi.org/10.1111/hypa.12217

Wedgwood, N. (2014). Hahn versus Guttmann: Revisiting 'sports and the political movement of disabled persons'. *Disability & Society*, *29*(1), 129-142. https://doi.org/10.1080/09687599.2013.776488

Wendell, S. (2006). Toward a feminist theory of disability. In J. Davis Leonard (Ed.), *The disability studies reader* (2nd ed., pp. 243-256). Routledge.

Whaikaha. (2014). *Equipment and modification services*. New Zealand Government. https://www.whaikaha.govt.nz/for-service-providers/equipment-and-modification-services/manuals-and-practice-guidelines#scroll-to-3

Whaikaha Ministry of Disabled People. (2025). *New Zealand Disability Strategy*. (2016-2026). New Zealand Government. https://www.whaikaha.govt.nz/about-us/programmes-strategies-and-studies/programmes-and-strategies/new-zealand-disability-strategy

Wheeler, S., & Peers, D. (2023). Playing, passing, and pageantry: A collaborative autoethnography on sport, disability, sexuality, and belonging. In B. Powis, J.

Brighton & P. D. Howe (Eds.), *Research disabiilty sport* (Vol. 1, pp. 100-113). Routledge. https://doi.org/10.4324/9781003153696-9

Wilkinson-Meyers, L., Brown, P., Reeve, J., McNeill, R., Patston, P., Dylan, S., Baker, R., Ryan, B., & McEldowney, J. (2014). Reducing disablement with adequate and appropriate resources: A New Zealand perspective. *Disability & Society*, *29*(10), 1540-1553. https://doi.org/10.1080/09687599.2014.966803

Wolbring, G. (2012). Expanding ableism: Taking down the ghettoization of impact of disability studies scholars. *Societies (Basel, Switzerland)*, *2*(3), 75-83. https://doi.org/10.3390/soc2030075

Wolkowitz, C. (2006). Bodywork as a social relationship and as labour. In *Bodies at work*. SAGE.

World Wheelchair Rugby. (2022). *World Wheelchair Rugby classification rules*. Author. https://worldwheelchair.rugby/wp-content/uploads/2021/12/WWR-Classification-Rules-2022.pdf

Wu, S. K., & Williams, T. (1999). Paralympic swimming performance, impairment, and the functional classification system. *Adapted Physical Activity Quarterly*, *16*(3), 251-270. https://doi.org/10.1123/apaq.16.3.251

Young, S. (2014). *I'm not your inspiration, thank you very much.* https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much

Appendices

Appendix A: Participant Information Sheet

INFORMATION SHEET ATHLETES

The embodied and lived experiences
of welfare and care
for highly impaired, high performance para-sport athletes.

Amanda Lowry

I would like to invite you to take part in this research.

Background

I am a PhD student at the University of Waikato. The findings from this research will be presented to organisations that govern high performance disability sport and published in academic journals.

I am conducting the research in order to understand the lived experiences of care and welfare in high performance disability sport. At present ideas and theories about care are appearing sport coaching literature but these theories of care do not account for para-athletes. The research will investigate welfare and care from four different perspectives. The first perspective is from the individual athlete, the second is from the athletes' carers/support workers, family and friends, and the third from representatives of the organisations that govern disability sport.

The research has three tiers. The first tier is centred on the individual athlete experiences of welfare and care; examining everyday realities and in the high performance competitive context. Second tier explores the experiences of coaches, carers/support workers (employed and/or family and friends) working with and caring for high performance para-athletes in both their daily lives and in the competition environment. The third tier examines the understandings of welfare and care embedded in the organisations that govern high performance para-sport.

Aim

The aim of this research is to understand what care actually means and its use in high performance disability sport. The results may inform coaches and organisations that govern disability sport.

Methods

You have been approached because you are a high performance para-athlete. If you agree to be a participant, over a two-month period, you will take part in two interviews, and complete one timeline. The first interview is a semi-structured interview aimed at understanding your experiences of welfare and care. The second interview will just expand on elements of your story both. Both interviews will be relatively informal and can take place at a time and location chosen by you. If we cannot meet in person interviews can be via Skype or Zoom. The interviews have no set time limit but I envisage they will take no longer than an hour and ½. The 'day in the life' timeline is a record of your moment by moment experiences of care on a day of competition.

Given the small world of high performance disability sport, it is important that you understand that confidentiality cannot be assured, but if requested I will do everything I can to protect your identity. For example, one way to obtain anonymity is to use a pseudonym and/or change your sporting code, age and gender.

However, I support participants' choice to be open, and identities known. Thus, confidentiality in this research will be a negotiated protocol. In my conversation with your sporting organisation, none of the research will pertain to you. This part of the research is to understand the organisational approach to the welfare and care of all highly impaired athletes in your code.

Questions

Participants have the right to ask any questions about the research that occurs to them during the interview process. Participants also have the right to decline to answer any particular question and to withdraw from the project within three weeks of the interview. If you wish to withdraw, the digital audio-file of your contributions will be destroyed.

Anticipated benefits of the research

This research will help inform coaches how to ‘enact care’. It will educate and inform broader organisations about the lived realities of high performance disability sport experienced by para-athletes. It will embed para-athletes’ voices into the literature with the hope of challenging views of athleticism; where individuals with disabilities are seen as athletes regardless of impairment.

Collection and Storage of Research Findings

All Intellectual Property arising from or relating to the research undertaken by me as part of the scholarship (excluding the copyright in my final report/thesis) will be the property of the University. My supervisors and I will have access to the audio-files, transcripts and any informal field notes. In accordance with the University of Waikato Human Research Ethical Guidelines I will retain hard copies until 2026, after which they will be destroyed.

Access to findings/publications

If you would like I can notify you when material is published and provide you with a summary of the main findings.

Thank you for your time reading this sheet and considering this invitation.

CONTACT DETAILS

If you wish to request a publication or follow up with questions or withdraw please contact the researcher or supervisors by phone or email. Our contacts are given below:

Amanda Lowry: Ph 021525824.

Email al51@students@waikato.ac.nz

Dr Robert Townsend: Te Huataki Waiora School of Health. Ph 07 837 9491

Email robert.townsend@waikato.ac.nz

Associate Professor Kirsten Petrie: Te Huataki Waiora School of Health. PH 07 838 4466 ext; 6544

Email kpetrie@waikato.ac.nz

Professor Lynda Johnston: Division of Arts, Law, Psychology, and Social Sciences. Ph 07 262 0568

Email lynda.johnston@waikato.ac.nz

Appendix B: Consent Form

Research project title: The embodied and lived experiences

of welfare and care for highly impaired, high performance para-sport athletes.

Researcher name: Amanda Lowry, University of Waikato, Aotearoa New Zealand

Research participant name: …………………………………………………..

Thank you for your interest in this research!

This interview will take about 60 minutes. This consent form is to make sure that you understand the purpose of your involvement in the interview. After reading the following information, and by signing this form, you will certify that you approve the following:

- This interview will be audio-recorded and transcribed;
- You can request the transcript to be send to you by providing your email address;
- If you wish to remain anonymous, you will be given a pseudonym (a fake name) and your identity and information provided will be treated with confidentiality;
- The researcher Amanda, her supervisors and a professional transcriber are the only ones who will have access to the transcript, other than yourself;
- We will analyse the transcript as part of this research;
- Any content provided might be used in publications (publicly available online), such as articles for academic journals, conference presentations, reports, and media reports.
- The actual audio-recording will be kept for five years and then destroyed.

Your rights as a participant are to:

Their rights - as set out in the information and consent sheets - are that no one is obliged to participate in the research, including the right to:

- decline to participate;
- decline to answer any particular question;
- withdraw from the research up until three weeks following receipt of the interview transcript;
- decline to be audio-recorded;
- ask for the audio recorder to be turned off at any time;
- ask for the erasure of any materials you do not wish to be used in reports of this study; and
- ask any questions about the study at any time during participation.

By signing this form, I agree that:

- I have read and agree with the information stated on this sheet;
- My participation in this project is entirely voluntary;
- Part of the content of this interview may be used for publication;
- I do not expect any financial or material benefit for participating in this research;
- I can always ask questions and decline to answer a question;
- I can stop the interview at any given time.

Participant's signature **Date**

Researcher's signature **Date**

Appendix C: Interview Guide – Athletes

Semi-structured athlete interview questions (guide)

1. Introduction

Introductions

Explain purpose of research

Outline general topics that could be covered in the session

Explain purpose of audio recording

Assure anonymity and confidentiality and have the participant sign the consent form

2. Getting to know you

Tell me about you, your family, whanau.

What is your impairment? If acquired how long have you been impaired?

What are the effects of your impairment? /How does your impairment impact on everyday life?

Are there differences in the understandings of care if you are born with your impairment versus acquired injuries?

- Do you need every day care? No: When do you need care? Who does it?
- If yes: What does that look like… Tell me what your support workers do?
- What does support work look like on a day of competition?
- What does care mean to you? In a personal context… In a sporting context?
- Did your family have an opportunity to access care when you were young?
- Tell me the process of accessing care and resources as an adult.
- Who do you go to?
- Is it/was it challenging?
- Do you think the system could be better?
- Do you get enough support to enable a good life?

3. Understanding your relationship with sport

How long have you been a high performance athlete?

What is your next goal?

How does sport shape your identity? Do you self-define as an athlete?

If we were to be introduced, and I asked did… What would you say?

What level of support do you need to achieve these goals?

4. Your understandings/experiences of care and welfare

How do you take care of yourself?

Physically?

What about your mental health?

Does the sport you do contribute to your sense of well-being? If so how?

If not, how might things change in order to support your personal development and growth?

Does your coach take care of you? In what ways?

Do the relationships that you have in your sport contribute to your sense of well-being?

If so how?

If not, how might things change in order to support your personal development and growth?

What are your coping strategies for difficult situations?

5. Relationship with organisation

Who are your governing body?

Does the organisation contribute to your care?

In your time and sport have you ever encountered a disabled admin or employee?

- If yes how you think their involvement changed the organisation?

If you go away on a tournament or a training camp does what does care look like?

Has access ever been an issue?

Does the organisation do anything to ensure that the competitive space is a positive space for you?

If yes, what do they do?

If not, what could they will do?

Is there an economic component to your relationship?

Does economics impact your relationship with the organisation?

If so how?

How does the organisation treat you? Are you an athlete? Are you disabled? Are you a disabled athlete?

Is your relationship with the organisation reciprocal? How do you value them? Do they value you?

Does the organisation fully understand the requirements of the disabled athletes they support? How do you think this could be improved?

Does the organisation have any disabled employees?

Employees?

6. Classification

Tell me about your experiences of classification?

Does classification change your sense of self?

Does classification change those sporting relationships?

If so how?

7. Final comments

Have you got anything else you would like to add that will add to understandings of care and welfare in high performance disability sport?

Appendix D: Interview Guide – Carers

Semi-structured carer/support worker interview questions (guide)

1. Introduction

Introductions

Explain purpose of research

Outline general topics that could be covered in the session

Explain purpose of audio recording

Assure anonymity and confidentiality and have the participant sign the consent form

2. Getting to know you

Tell me about you, your family, whanau.

How long have you been a support worker?

When did you start support work with the athlete?

3. Understanding the relationship with sport

Were they high performance when you began?

No: Has the support work changed since they became a high performance athlete?

Can you detail the differences/changes?

With these changes been positive for you? For the athlete?

What competitions have you attended with your athlete?

Is the work you do different on the day of competition?

Can you talk me through it…

4. Understanding the relationship with sport

Do you enjoy supporting a high performance athlete?

Does the athlete involvement in high performance sport provide you with opportunity?

Yes: Can you give me some examples?

What are the challenges that you face as a carer for a high performance athlete?

What changes have you seen in your athlete since they began their high performance journey?

5. Your understandings/experiences of care and welfare

Does involvement in high performance sport contribute to your sense of well-being? If so how?

How do you take care of yourself; not just your physical self but your mental and spiritual self while you are caring for the athlete?

Does the athlete take care of you?

Yes: In what way?

Is there recognition for the work that carers do to support high performance athletes?

Yes: Can you please give me some examples?

6. Relationship with organisation

How does the organisation treat you?

Does the organisation recognise your care is a vital ingredient to the high performance athlete's success?

Yes: What do they do to acknowledge your contribution?

No: What could they do?

Do they fund your attendance to high performance events?

Does the organisation do all they can to support your athlete?

Are you recognised as part of the team?

What are your coping strategies for difficult situations?

Do you have power to resolve issues that you may face?

7. Classification

Have you supported your athlete through classification?

Was classification a positive or a negative experience for your athlete?

Can you tell me why?

8. Final comments

Have you got anything else you would like to add that will add to understandings of care and welfare in high performance disability sport?

Appendix E: Interview Guide – Coaches

Semi structured interview questions coach (guide)

1. Introduction

Introductions

Explain purpose of research

Outline general topics that could be covered in the session

Explain purpose of audio recording

Assure anonymity and confidentiality and have the participant sign the consent form

2. Getting to know you

Tell me about you.

Tell me about the athlete that you train.

3. Understanding your relationship with the athlete

How long have you been a high performance coach?

Do you work with able-bodied and disabled athletes?

Given that you work with able-bodied and disabled athletes is there a difference in the way you coach?

Is there a difference in the level of care required between your able-bodied and disabled athlete/s?

If so, what do you do differently?

What does care look like at national and international competitions?

Is the support you provide vital in the athlete achieving their goals?

4. Your understandings/experiences of care and welfare

Do you have an in-depth understanding of the level of care required for your athletes to participate in high performance sport?

Do you know what they have to do every day to show up?

Do you think you have a duty of care to support your athlete?

What does duty of care mean to you?

How do you care for your athlete/s?

Do you think that the athlete/s involvement in high performance sport contributes to their sense of well-being? If so how?

If not, how might things change in order to support their personal development and growth?

Do you recognise and support the idea that training is not just about developing the athlete/s physical self, but their mental and spiritual self?

Do you think the relationship that you have with athlete contributes to their sense of well-being?

If so how?

If not, how might things change in order to support their personal development and growth?

As a coach of a disabled athlete describe some of the difficult situations you have encountered.

What did you have to do to support your athlete?

Did this event impact on them?

5. Relationship with organisation

Does the organisation do anything to ensure that the competitive space is a positive space for your athlete?

If yes, what do they do?

If not, what could they do?

Is there an economic component to your relationship with the overarching organisation?

Does economics impact your relationship with your athlete?

If so how?

Does the organisation support you to negotiate difficult situations that you have encountered with your athlete?

6. Classification

Have you supported an athlete through the classification process?

What are your experiences of classification?

How did the classification process impact on your athlete?

7. Final comments

Have you got anything else you would like to add that will add to understandings of care and welfare in high performance disability sport?

Appendix F: Interview Guide – Organisational Representatives

Semi structured interview questions organisational representative (guide)

1. Introduction

Introductions

Explain purpose of research

Outline general topics that could be covered in the session

Explain purpose of audio recording

Assure anonymity and confidentiality and have the participant sign the consent form

2. Getting to know you

Tell me about you.

Tell me about the organisation you represent.

Are there disabled people working in your organisation?

3. Understanding your relationship with the athletes

Does your organisation work with able-bodied and disabled athletes?

Yes: Given that your organisation works with (able-bodied and) disabled athletes is there a difference in the benefits they receive?

Do you recognise that there is a difference in the level of care required between your able-bodied and disabled athlete/s?

If so, what does the organisation do differently to support your disabled athletes?

Does the level of care provided for your disabled athletes versus your able-bodied athletes differ at national and international competitions?

Do you believe that the support you provide is vital in the athlete achieving their goals?

4. Organisations understandings/experiences of care and welfare

Would you say that your organisation has a duty of care to support your athletes?

If yes, what does that look like?

If no, why?

Do you understand all of the elements of care required to get a highly impaired athletes ready for competition?

Organisationally, what mechanisms are in place to support highly impaired athletes and their carers?

Do you think your organisation does enough?

If no, then what could your organisation do better?

From an organisational perspective do you think that disabled athlete’s involvement in high performance sport contributes to their sense of well-being? If so how?

What does your organisation do to nurture this?

If not, how might things change in order to better support their personal development and growth?

Do you think the organisational relationship with your disabled athletes contributes to their sense of well-being?

If so how?

If not, how might things change in order to support their personal development and growth?

Describe some of the difficult situations you have encountered to facilitate disabled athletes sporting journeys.

What mechanisms are in place to support your disabled athletes?

5. Relationship with athlete

Does the organisation do anything to ensure that the competitive space is a positive space for your athlete?

If yes, what do they do?

If not, what could they do?

Is there an economic component to your relationship with your athletes?

If yes, how does that impact on the relationship with your athletes?

What is the process that your organisation uses to negotiate difficult situations encountered by disabled athletes under your care?

6. Classification

What does classification of disabled athletes mean for your organisation?

What do you do as an organisation to support athletes in this process?

Is there anything you think you could do better?

7. Final comments

Have you got anything else you would like to add that will add to understandings of care and welfare in high performance disability sport?

Appendix G: Ethics Approval

The University of Waikato
Private Bag 3105
Gate 1, Knighton Road
Hamilton, New Zealand

Human Research Ethics Committee
Roger Moltzen
Telephone: +64021658119
Email:humanethics@waikato.ac.nz

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

5 June 2020

Dear Amanda

HREC(Health)2020#32: Who cares? Investigating the lived experience of welfare and care for highly impaired, high performance para-sport athletes.

Thank you for submitting your amended application HREC(Health)2020#32 for ethical approval and for your very clear and coherent responses to the Committee's feedback.

We are now pleased to provide formal approval for your project.

Please contact the committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you well for this interesting and important study.

Regards,

____

Emeritus Professor Roger Moltzen MNZM
Chairperson
University of Waikato Human Research Ethics Committee