From theory to practice example: How programs can more intentionally support living well with spinal cord injury

A thesis submitted to fulfil the requirements of the degree of

Doctor of Philosophy

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Statement of originality

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

Acknowledgements

To my supervisors: Michelle Villeneuve and Shane Clifton: I'm not sure how to begin thanking you for your support, encouragement, wise insights and thoughtful guidance. This made the PhD journey smooth and enjoyable, helped shape a thesis I'm proud to present, and fostered a genuine excitement about my future research career. I know I have a lot more to learn from you both.

Michelle, thank you for deepening my understanding of our shared OT profession, while extending me in new directions; I've loved getting my head around program theory and a range of research methods. Thank you, too, for your mentoring and guidance as you've supported me as a research student and early-career academic; it has shaped my thinking and confidence in ways I'll carry forward.

Shane, I've appreciated your wise insights from your academic and lived expertise. You've prompted and supported me to see things in new ways, in this research and beyond. My writing has also developed immensely under your guidance (though I'll never quite match your turn of phrase).

To the research participants: Thank you for volunteering your time to share your knowledge and experiences. I hope I have done your individual and collective perspectives justice, and that this research contributes in the way you hoped when you scanned or clicked that link to take part.

To my family: Thank you, Dave, for your endless wisdom and patience, especially in these last few months as I disappeared into the thesis one minute, then chewed your ear off about it the next. Bess: I know I've been doing something *so boring* for *nearly your whole life*, but I hope this inspires you to remain curious, think deeply and challenge systems in your own way someday.

On Country: Much of the research and writing took place on Gadigal land. The case study program sits on Gayamaygal country, a beautiful natural setting that supported the well-being experiences at the heart of this thesis and offered a lovely environment for observational data collection. I pay my respects to the Traditional Custodians and Elders, whose knowledge continues across these lands, including wisdom about living well and in connection with Country and with each other.

Authorship attribution statement

Chapter two of this thesis is presented as an Author Accepted Manuscript of a journal article published as Simpson, B., Villeneuve, M., & Clifton, S. (2022). The experience and perspective of people with spinal cord injury about well-being interventions: A systematic review of qualitative studies. *Disability and Rehabilitation*, 44(14), 3349-3363

Chapter three presents an abridged version of the Author Accepted Manuscript of a published scoping review: Simpson, B., Villeneuve, M., & Clifton, S. (2021). *Exploring well-being services from the perspective of people with SCI: A scoping review of qualitative research. International Journal of Qualitative Studies on Health and Well-being*, 16(1), 1986922.

I designed the studies, conducted the literature search and study selection, analysed the data and wrote the drafts of the manuscripts. The co-authors (my PhD supervisors) checked excluded studies, provided a sounding board during the reflexive process, and contributed to reviewing and refining the manuscript drafts.

Candidate	Lead supervisor
Bronwyn Simpson	Prof. Michelle Villeneuve
13 February 2026	14 February 2026

Artificial intelligence

Generative AI helped with refining the writing at times, acting as a ‘interactive thesaurus’ to help with precision or finding a better term.

In terms of **academic integrity**, the content and ideas are all my own. Most of the writing was not supported by AI. When I used AI, I did so only after drafting the text myself, providing a specific sentence and prompt, reviewing suggestions critically, and manually refining any adopted wording.

Data privacy was another consideration, both for research-ethics compliance and for safeguarding IP-protected unpublished data. I only used *Cogniti* or *Microsoft Copilot for Microsoft 365 (Enterprise)*, both of which operate within the University’s secure organisational environment and do not use user content to train AI models. On the rare occasions when participant quotations were supplied to the engine for context, they were fully de-identified and left unedited.

I did **not** use AI for:

- The systematic or scoping reviews
- Analysing or interpreting research data, including coding, theme development, or insight generation.
- Producing substantive academic content, such as large sections of chapters or literature review text.
- Making methodological, analytical, or conceptual decisions.
- Handling or processing participant data, including reading, extracting, summarising, or storing it.

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Notes to readers

A PDF reader with a back button (or equivalent keyboard shortcut) would be helpful in navigating this document, which has the following features to support readability:

- In-text citations are presented in numbered format to avoid disrupting the flow of reading. Hovering over a citation will reveal a short version of the reference, and clicking will take you directly to the reference list. Citations are numbered individually so each one remains accessible on its own.
- Internal links appear in green font. Some are provided for convenient reference to specific information (such as appendices), while others signal conceptual connections to previous ideas. Because many ideas re-emerge throughout the thesis, I have included links only when I felt they would be most helpful: when a section's main purpose is to connect ideas, when an earlier idea may not be easily recalled, or to avoid the appearance of unnecessary repetition.

I have made every effort to avoid repetition; many rounds of revision focused specifically on this. However, given the nature of the research, the themes cannot be neatly isolated into discrete chapters. I recognise that readers may have different preferences for where information appears, but I trust that most points will become clear as the thesis progresses.

The complexity and richness of the case study data also required difficult decisions about scope and emphasis. The data could have taken the analysis and reporting in many directions – some of which I went quite a long way down before turning back. I note some themes that are reserved for separate publications, which I genuinely intend to complete. I hope readers find the chosen scope engaging and worthwhile.

Abstract

Background and aim

Rehabilitation and disability services are increasingly called to focus more explicitly on improving well-being; however, there is limited practical guidance on how to design or deliver programs to achieve this. This thesis investigates how services can be intentionally designed to support well-being outcomes for people with spinal cord injury (SCI), a population for whom achieving a meaningful and satisfying life may require support beyond initial rehabilitation. It explores intentional design for well-being in the existing literature, and examines through an empirical study how such an approach was adopted by a novel program.

Methods

A multi-phase qualitative design was employed. Phase one comprised a systematic review of qualitative studies and a scoping review of well-being-focused programs, examining how well-being is conceptualised, targeted, and experienced in existing research. The review findings were published as peer-reviewed journal articles. They also informed analysis and interpretation in the subsequent research phase.

Phase two involved an in-depth qualitative case study of a community-based program intentionally designed to impact well-being. Data were collected through interviews with multiple participant groups, observations, and document analysis. An inductive analytic approach was combined with a theory of change framework to examine how program design and delivery contributed to outcomes.

Findings

The reviews identified a well-developed understanding of factors influencing well-being, but limited insight into how programs actively address these factors in practice. Findings highlighted the importance of explicitly targeting well-being through intentional program design. The case study demonstrated that a program structured around a clear well-being aim and an integrated model of service delivery can generate outcomes across multiple domains of well-being. Outcomes were achieved through interrelated mechanisms, including accessible and appealing program entry points, integration of supports that facilitate both immediate positive experiences and longer-term capacity building, and embedded opportunities for informal peer interaction and support. Repeat engagement and the

development of a sense of community further amplified these effects. Together, these mechanisms contributed both directly to well-being and to a more positive and expansive outlook on life.

Conclusion

This thesis demonstrates the potential of programs intentionally designed to impact well-being and provides transferable insights into how such outcomes can be achieved in practice. The findings support a shift towards holistic, explicitly articulated well-being aims in rehabilitation and disability services and offer a framework to inform program design, implementation, and evaluation.

CHAPTER ONE:

INTRODUCTION AND OVERVIEW

1.1 Introduction to the thesis context

Rehabilitation and disability services have been challenged to place greater emphasis on promoting well-being. However, this remains largely a theoretical proposition, with limited practical guidance for programs seeking to respond to this call. The thesis addresses that gap by presenting a program of research that explores how services can be more intentionally designed to target explicit well-being outcomes.

In this section I review the relevant literature to establish the academic foundation of the thesis: summarising existing knowledge, conceptualising key ideas, identifying service limitations and challenges, and highlighting unanswered questions that shaped the research focus. I then introduce a complementary lens by outlining the context from my professional perspective. Finally, I outline the proposed way forward – a more deliberate focus on well-being – and how the thesis aims to support the field in pursuing that path.

1.1.1 The impact of SCI on well-being

Well-being is arguably an important aspiration for all people [1, 2], understood in this thesis as living a 'good life' that is meaningful and satisfying. Disability can challenge or disrupt well-being [3], though its impact is often more nuanced and less severe than commonly assumed [4, 5]. Many people with disability report high levels of life satisfaction, even under circumstances that may appear undesirable to others: the "disability paradox" [6].

This paradox may be particularly striking in the context of spinal cord injury (SCI), which is frequently viewed through the ableist lens that life with such a condition is no longer worth living [6, 7, 8, 9, 10]. A 1978 study revealed the surprising finding that lottery winners reported similar levels of happiness as people with paralysis [11]. This somewhat influential

study [12, 13] challenged – and probably also reinforced – stereotypes of this condition as representing a 'worst-case scenario'. The subsequent literature from the disability and rehabilitation fields, explored in the upcoming chapter, presents a more detailed and nuanced picture. Many people with SCI report living fulfilling lives [6, 14, 15], even those with the highest level of disability [16]. Some identify growth or positive changes that follow, or arise from, their injury [17, 18, 19, 20, 21, 22]. On the other hand, others experience consistently low well-being and emotional distress [14, 16, 17, 18, 23, 24]. Since a good life post-SCI is possible but sometimes challenging, promoting well-being should be a focus for SCI services.

1.1.2 The potential of rehabilitation services to enhance well-being

Various kinds of services may seek or claim to support well-being of people with SCI. For example, care providers may influence well-being by meeting daily needs in ways that are responsive, appropriate, and meaningful. However, I am most interested in services that support people to *build* a good life. In the absence of a better term – a challenge I return to in the discussion chapter – the field most closely aligned with this aim is rehabilitation

Since the thesis is primarily interested in rehabilitation services, it is important to define this term. The thesis draws on two definitions of rehabilitation that highlight its important, ongoing role in helping people rebuild and shape their lives after injury. First, the broad understanding proposed by the World Health Organization (WHO), which defines rehabilitation as a set of interventions aimed at improving function, offered across the lifespan (not just in the immediate aftermath of an injury) and with well-being as an ultimate purpose or benefit [25, 26]. Second, Hammel's definition of rehabilitation as "a process of enhancing well-being and of attaining – or regaining – a meaningful life in the context of disease, illness, or impairment" [3] p76, which offers a helpful understanding of its purposes for people with long-term, life-altering conditions like SCI. According to these definitions, rehabilitation services should play a significant and intentional role in addressing factors that enhance well-being.

Other scholars have recognised or argued for similar purposes [27, 28, 29, 30], and Gibson observes that improving quality of life is "a pervasively stated goal of rehabilitation programs the world over" [31] p51. Gibson's hyperbolic tone seems to imply this well-being focus has become somewhat 'trendy' – and it certainly does appear to reflect broader trends.

One such trend has been a recognition that people can live fulfilling lives even with untreatable conditions, shaped by a deeper understanding of the multifaceted nature and causes of disability [32]. This understanding has enabled rehabilitation to shift away from a narrow focus on pathology [9] and embrace a broader and more life-enhancing role. Parallel to these shifts has been growing societal interest in well-being in popular and policy discourse [2, 33, 34, 35].

The idea that rehabilitation should promote a good life appears uncontested and is perhaps taken for granted as a core principle that requires little justification or debate. Certainly no one seems to argue against it, and to do so would probably seem churlish. The debates in the literature are not about whether rehabilitation services *should* aim to enhance well-being, but rather the extent to which they do so in reality.

1.1.3 Limitations and challenges to enhancing well-being

Hammel's definition of rehabilitation above is aspirational: it presents a vision of what it could and should be. This offers both an opportunity and challenge to the field, which Hammel and other scholars have long critiqued for its shortcomings in realising this mandate. In this section, I outline limitations and challenges that restrict rehabilitation's ability to align practice with its stated ideals, then discuss the explicit focus on well-being that has been proposed as a way forward.

Well-being is not a clear priority or focus

Despite it being a stated purpose, promoting well-being is not a clear driving focus that shapes rehabilitation design, delivery, evaluation or research. Well-being aims and impacts often appear to be assumed or overlooked rather than made explicit [9, 36, 37, 38, 39].

For example, the WHO demonstrates its broad commitment to well-being as a central goal through various initiatives and statements [1, 2, 40], including in its broad definition of health [41]. Yet the role of rehabilitation in promoting this aspiration is not always clearly articulated. Well-being was explicitly identified as a key purpose of rehabilitation in 2019 documents [25]. Yet it appears less prominently in more recent documents [26, 42], where it is mentioned in the text as an assumed aim used to justify the importance of rehabilitation, rather than being clearly integrated into the definition. Similarly the WHO's *International Classification of Functioning, Disability and Health* (ICF) [43] does not explicitly mention

well-being [30, 34]. While well-being may not fit within the framework's intended scope, the omission is a missed opportunity to connect the ICF more directly to the WHO's overarching aims.

My own field of occupational therapy has similarly overlooked the opportunity to explicitly link its stated aims of promoting well-being [35, 36] to its guiding frameworks. Well-being is mostly absent, poorly defined, or underexplored in occupational therapy frameworks, which is unfortunate given the well-established links between occupations and well-being [44, 45, 46, 47, 48, 49]. While some newer frameworks are more explicit about the link between occupations and well-being [50, 51, 52, 53, 54], their influence so far been limited.

Without these theoretical foundations, rehabilitation services are subject to more powerful historical, political, and economic forces that shape their priorities, and which can detract from their ostensible purpose [55]. For example, the drive to demonstrate efficiency and reduce costs is a powerful influence shaping and restricting what services can provide [3, 56]. These are particularly pressing in inpatient rehabilitation, where discharge planning is a dominant priority and may be hastened by cost drivers. There are different opportunities and challenges for fostering well-being later in the journey, yet the potential of community-based services to impact well-being appears under-appreciated and underresourced [57, 58]. The lack of theoretical clarity also weakens advocacy for more enabling policies and practices – in a context where the needs of systems rather than people often direct the focus [59, 60, 61].

Critics also point out the ableist, neoliberal and individualist values that underpin these drivers and shape rehabilitation priorities. They argue these values play out in an emphasis on doing things without help, privileging 'essential' or 'productive' activities, and centring the individual while neglecting systemic barriers [4, 59, 62, 63, 64, 65, 66, 67, 68, 69]. These priorities are evident in the rehabilitation outcome indicators used in New South Wales (NSW), Australia: the immediate context of the thesis. These indicators capture only burden of care in basic daily activities, length of stay, and discharge destination [70], and offer little insight into participation or well-being – the areas rehabilitation claims to promote. A brief quality-of-life scale is listed among the recommended patient-reported outcome measures [71], but it is optional, and its activity-based indicator similarly centres on independence and basic daily tasks [72].

An undeveloped understanding of what influences well-being

Even if well-being was a clearer focus, rehabilitation services also need to understand how to promote it. Rehabilitation has been critiqued for its overall lack of theoretical foundations [55, 73]; this is particularly evident in regard to its role for people with disability [31], including how to understand and promote a good life with disability [55, 69].

Ideas about what constitutes a good life may instead be shaped by broader societal values, including those discussed above. Within this dominant cultural frame, some rehabiltiation scholars critique the assumption that a good life is associated with 'normal' body functions and independence in the activities valued by society [10, 59, 64, 65, 66, 67, 68, 69, 74]. Critics argue that relying on these assumptions perpetuates – or at least fails to offer an alternative to – a narrow, misguided conception that becomes problematic in the face of significant and lifelong disability. It also overlooks the needs and potential contributions of groups who hold different values or imagine a good life in other ways [64, 75, 76, 77].

These societal assumptions may also be held by those undergoing rehabilitation [10, 21, 78, 79], especially people with newly acquired disability who have not yet had the opportunity to reimagine life and identity [80]. For example, it may at first be difficult to concieve of a good life without the ability to walk [21]. Yet uncritically prioritising this understandable goal may delay or hinder adjustment to a new reality [10], and limit engagement with other opportunities that enhance well-being, like learning to navigate the community in a wheelchair [81]. On the other hand, hope is important for adjusting to disability [22, 31, 82, 83, 84], and the potential for some recovery is still possible but uncertain in the early rehabilitation phase. People undergoing rehabilitation are also at varying stages in journey of rebuilding life with SCI [85, 86, 87, 88, 89], and this journey is not always linear [80, 90].

Clinicians and clients alike face a complex challenge as they navigate rebuilding a good life in this early, uncertain context [83, 91, 92]. A clearer understanding of what enables people to thrive after SCI could provide crucial guidance.

A growing body of health and rehabilitation literature explores the perspectives of people with SCI about what influences their well-being, which I discuss in the next chapter. Literature from disability theorists offers an important complement, bringing a more nuanced and critical perspective. For example, disability scholars argue against a simplistic adoption of the social model of disability, arguing that well-being is also embodied [74, 93, 94, 95].

They offer alternative framings to the dominant ideal of 'independence', such as interdependence and autonomy [65, 96]. They also point to the possibility of embracing an 'abnormal' body [97], and remind us not to overlook intersectional identities [98] in shaping how a good life is understood and experienced.

There is also a growing recognition of broader and ancient conceptions of well-being from fields such as philosophy and psychology [32, 62, 99]. For example the Aristotelian ideal of *eudaimonia* – a flourishing life defined by virtue, practical wisdom, and self-realisation – has been revisited in positive psychology [100, 101, 102, 103] and, to some extent, disability theory [5, 47, 99, 104].

This diverse body of literature identifies well-being factors that rehabilitation could target, but it has yet to permeate the field [68, 79, 105]. A further barrier is that much of this work remains theoretical while rehabilitation practice requires more concrete guidance. To be useful for practice, they need to be translated into frameworks and tools that enable practitioners to define and measure well-being [32] and – of greater relevance to this thesis – support it.

Terminology and measurement challenges

When well-being is discussed in rehabilitation literature, this is often dominated by the challenge of how to define and measure it. Striking a balance between the need to be succinct, precise and objective, but also capture the broad, multifaceted, and individualised nature of well-being, is an inherently complex task [39, 49, 52]. I discuss terminology and measurement challenges in the next chapter and focus here on two issues particularly relevant to the thesis context.

First, the task of describing a good life remains complex and unresolved. There has been a historical shift from narrower, health-related terms [9] to more encompassing terms like 'well-being' and 'quality of life', which are used widely – and often interchangeably – in disability and rehabilitation research [39, 106]. Yet there is no consensus on what these terms mean, and their usage frequently assumes a shared understanding that is unwarranted [31]. Gibson critiques the "catch-all, unreflective" use of such terms, arguing that this "incredibly powerful" concept has often been rendered "almost meaningless" [31] p. 69. Rather than fruitlessly pursuing a universal definition, Gibson [31] and others [39, 52] call for a more reflective and explicit articulation of whichever term is chosen.

This argument has implications for services seeking to focus more explicitly on well-being, as they will need to thoughtfully define and communicate what they understand the concept to mean within their context.

The argument also underscores the importance of clarity and transparency in this thesis, which requires a clear conceptualisation of well-being. Influenced by Post's arguments, I have chosen to primarily use the term 'well-being', which emphasises a more subjective perspective, as opposed to 'quality of life', which may imply a more objective, external evaluation [39]. 'Well-being' may also align better with the inclusive, lay terminology some have advocated for [38, 107], as opposed to the medicalised and 'official' connotations of "Quality of Life", which the cited author deliberately signals using title case [107]. I review the suitability of the term in the discussion chapter. The thesis adopts a broad understanding of well-being, which incorporates subjective well-being (including positive emotions and life satisfaction) and psychological well-being (including meaning, purpose and character) [101, 108].

Second, while some progress has been made in designing well-being measures that account for its nuanced and complex nature [109], the measures commonly used in rehabilitation research are often designed by researchers without disability, to measure the health of the general population [8, 9, 110, 111, 112, 113]. Such measures have been criticised for emphasising functions like walking, which may be neither possible nor central to well-being for people, and for overlooking other factors that are [106, 114, 115, 116]. As a result, claims about the impact of interventions on well-being may require closer scrutiny [39]. Further, given the variability in definitions and measurement approaches, it may also be possible for almost any program to identify and report a well-being impact if desired.

Additionally, the dominant focus on defining and retrospectively measuring well-being highlights a neglected area of research: how programs can be designed and delivered to proactively target it.

Challenges promoting well-being in practice

These challenges influence rehabilitation service delivery. People with disability describe some services as problem-focused, overly standardised and inflexible, restrictive, driven by service needs rather than the needs of clients, and misaligned with their values, goals, and

real lives [87, 117, 118]. These shortcomings would limit the potential to positively impact well-being, and would instead contribute to negative and demoralising experiences.

Conversely, people with disability appreciate services that are relevant to their real lives, help them integrate their past and future selves, and are tailored to their individual needs and values. Services that instill hope, foster connections with peers, and focus on meaningful goals are particularly valued [3, 82, 87, 117, 118]. People also appreciate services that promote hope, resilience, motivation and a growing acceptance of new abilities; and enable them to re-engage in meaningful activities [117, 119, 120, 121, 122, 123] – which are all known well-being contributors.

The challenges described so far relate to rehabilitation research, theory, and systemic issues rather than to practitioners. But given the influence of clinicians over the experience of service users, and their role in shaping the goals and direction of services [59], it is worth considering their contribution to well-being.

While some have criticised rehabilitation clinicians for uncritically – or even willingly – accepting the status quo [64, 66, 67, 83, 124], the constrained context would be a reasonable defense. In my own (albeit limited) experience, most colleagues would agree with the principles promoted here, but feel poorly equipped or supported to enact them any more than they currently do. Challenging the status quo involves courage, determination and 'going above and beyond' in a context that may not value or reward this [59, 125].

One aspect of service delivery clinicians can control, however, is their interpersonal approach. Service users value practitioners who are positive, empowering, warm, respectful, trustworthy, light-hearted, hopeful and motivating, work in partnership with them, and treat them with dignity and value [3, 59, 74, 115]. Conversely, some staff were described as pessimistic, restrictive, disempowering, disrespectful, superior and disconnected [3, 61, 87, 118].

The studies were unclear about the prevalence of these staff approaches, yet very clear about their important influence on experience and outcomes. This may be an affirmation – or perhaps challenge – to rehabilitation practitioners, and underpins another call from Hammel: "… if financial resources were allocated according to the priorities of rehabilitation clients, these would be targeted not at elegant buildings or cool equipment but at the recruitment and retention of caring, client orientated staff" [3] p. 80.

1.1.4 My perspective on the potential and challenges of rehabilitation

My experience as an occupational therapist also shaped this body of research. As well as influencing data analysis and interpretation (explored in the methods chapter), my professional background provided another lens for understanding the thesis context, and influenced the challenges I sought to explore.

In inpatient rehabilitation, I worked within constraints and a culture that prioritised safety and discharge goals. Yet I suspected these were not always the areas most critical to well-being, which I could see was particularly challenged during this early stage. I also struggled to know how to support people whose lives had changed so significantly they didn't have clear goals or activities to return to. I suspected exploring meaningful occupations should be central to not just goal-setting but to occupational therapy intervention itself, but didn't know how to go about this.

A conversation with a colleague left a lasting impression. A person with SCI had praised her as a "can-do OT", contrasting this with his usual experience of therapists who had low expectations, and acted as gatekeepers rather than enablers. While I hoped I embodied a similar approach, I also reflected on times I might have limited rather than empowered rehabilitation clients. Even with the best intentions, it was too easy to subtly redirect people toward more goals I was more familiar and confident addressing, especially when the setting required choosing between competing priorities. I felt uneasy about the power I held to shape the direction of rehabilitation services.

I was inspired by colleagues who challenged the usual priorities of an acute setting by supporting people with SCI to get out of the hospital and participate in valued activities in the community. In hindsight, they appear to have appreciated the purposes of rehabilitation Hammel proposed – even in the very early stages post-SCI. In a setting with significant constraints, staff designed an expansive program then found creative ways to resource it, rather than their imaginations being limited by these constraints.

Later, in a community-based setting, I observed new opportunities but also noted gaps in service delivery. I welcomed the introduction of the National Disability Insurance Scheme (NDIS) mid-way though my clinical career, appreciating its potential to support longer-term services and broader priorities like social participation. Yet over time I recognised the same limited perspectives and priorities that constrained inpatient rehabilitation.

Moving into occupational therapy education highlighted in a new way the profession's limited focus on well-being. I found myself telling students to "start by listing the occupational performance issues" and struggled to find frameworks that were less deficit-focused and more attuned to identifying what was meaningful.

These experiences shaped my interest in exploring how services can better support people to live meaningful, satisfying lives with disability, both in the early stages and longer term. As an OT, I am especially interested in how to identify and prioritise the occupations that have the most impact on well-being. Having worked in collaborative, multidisciplinary teams, I also appreciate a range of contributions to occupational performance and engagement, and to well-being more broadly.

1.1.5 The proposed way forward: An explicit focus on well-being

Partly in response to these contextual challenges, there have been prominent calls for rehabilitation to focus more explicitly and unambiguously on well-being [27, 28, 29, 30, 37, 45, 48, 50]. Advocates of this approach have argued the field should raise its sights [62], aiming for people not just to survive, but thrive [31]. While this aspiration is inherently vague and difficult to define, it can nonetheless offer a 'guiding' or 'sensitising' concept for program design, delivery and evaluation [31, 107] Amongst many competing priorities, it could guide services to identify and prioritise what matters most [68].

The discussion above has highlighted areas of need if the sector is to adopt this explicit, unambiguous focus. The definition and purpose of rehabilitation need reframing based on a clearer understanding of how disability affects well-being and how rehabilitation can promote it. Hammell's definition (above) would serve this purpose. Understanding acquired disability as a significant life disruption rather than an impaired body could help reorient the purpose of rehabilitation [3, 80, 126]. Ultimately, rehabilitation should help people "(re)establish themselves into a socially meaningful and satisfying life" [127] p. 14, and build a more positive sense of self and capability, even in the presence of significant impairments [3, 10, 80, 85].

Guidance is required on how to address these aims. Since well-being is broad, it would be helpful to understand and target specific influencing factors [31]. To support this, the well-being factors identified by literature in a range of fields need to be transformed into

integrated, actionable frameworks. Programs should also be informed by the perspectives of people with disability about what they need and value from services [3].

The proposed approach may refine existing rehabilitation services. But given the call for a significant reframing of rehabilitation [3, 31, 127], there may also be a need for new, innovative services that are intentionally designed to respond to this call. Program design has been largely neglected in rehabilitation research, and much more needs to be known about how to design services that have well-being as a central focus from the start.

1.2 Broad contribution of the thesis

This thesis seeks to advance rehabilitation along the proposed path by addressing the areas of need outlined above. Its central focus is advancing existing theoretical insights closer to practice – reflected in the thesis title – by exploring how they have been taken up in practice, and by generating insights transferrable to practice. Its principal contribution is to the design and delivery of services. While SCI was the primary focus, the insights may extend to other conditions with comparable impacts or service needs.

The research was conducted in two phases. The first phase involved a review and synthesis of peer-reviewed literature through two studies. The first phase explored practice examples in the existing peer-reviewed literature. The second phase examined a program that exemplified the proposed approach to rehabilitation, as a case study. I now provide an overview of each study, including the aims, research questions, methods and specific contributions.

1.2.1 Phase one: Review and synthesis of the peer-reviewed literature

Purpose

The issues outlined in this chapter shaped the first research phase, which sought to understand what is already known about well-being programs for people with SCI, particularly from their perspective. To achieve this, I reviewed and synthesised qualitative studies about programs that purported to address well-being among people with SCI.

The reviews pursued two overarching aims: (1) to synthesise the perspectives of people with SCI regarding these programs, including their experiences, outcomes, and perceived gaps; and (2) to examine how well-being was conceptualised and addressed in the qualitative literature. The purpose was to inform practice, theory, and the subsequent empirical phase of the thesis.

Addressing these aims ultimately required two distinct studies. I began with a systematic review (study one), the most suitable method for synthesising program outcomes. However, during study selection it became clear that some excluded studies still offered valuable insights, about program activities or participants' perspectives, for example. I also developed a clearer understanding of the field as I read, including how well-being was defined and operationalised across studies. These insights, alongside my evolving knowledge of review methodologies as a novice researcher, highlighted the need for a complementary scoping review (study two).

While both studies drew on the same body of literature their specific aims required different inclusion criteria, data charting, and analytic approaches. The systematic and scoping review methods are presented in more detail in Chapters 2 and 3, respectively.

Contribution of the reviews to the field

Both studies have been published as journal articles in peer-reviewed, high-impact journals across different fields, underscoring their broad reach and relevance to scholars and practitioners in areas such as disability, rehabilitation, qualitative research, and well-being.

The findings and implications of each review are presented within the published manuscripts that form the core of their respective chapters. Following each article, I include a brief concluding section outlining its specific contribution to the overall thesis and how it informed the subsequent studies.

Collectively, the reviews contributed to the limited literature on how people with SCI perceive services [3], identifying valued aspects, limitations, and areas of need. They reinforced the importance of, and added detail about, known well-being determinants for people with SCI, explored how they can be addressed in practice, and examined perceived outcomes.

Importantly, the reviews also shaped and refined the second phase of the research : the case study. While affirming the potential of services to impact well-being, they highlighted an important gap in the literature: detailed information about programs intentionally designed to do so. The case study was designed to address this gap. The reviews also identified key theories, definitions, and methodological considerations that informed the case study questions and design. I now provide an overview of the case study.1.2.2 Phase two: Case study of a program intentionally designed to target well-being aims

Purpose of the case study

This chapter has outlined the need for an explicit, intentional focus on well-being, which is rare and lacking practical and theoretical guidance. Into this context emerged a new – and apparently world-first [128] – program for people with SCI, centred on well-being. Sargood on Collaroy offers short-term accommodation, recreation and clinical services in an accessible, resort-like facility. The program appeared to embody the type of well-being-focused service that had been widely called for, and there were anecdotal reports of significant well-being impacts.

One testimonial particularly captured my attention and propelled me into this study. A social media post featured a photo of program staff supporting someone to surf, and a person with SCI had commented:

> *"The one thing I enjoy most in the world is this. Thanks Sargood on Collaroy for helping me fall back in love with my life."*

I was inspired and intrigued by what this program was doing to create such life-changing outcomes, at least for this person. It seemed a promising practice example that could shed light on the challenges raised by the background literature and the two reviews.

Case study research was therefore a good fit: it can serve both these 'intrinsic' and 'instrumental' purposes [108]. The potential to generate detailed insights about program design and delivery also drew me to this methodology.

Outcome or program evaluation methodologies were also considered, including experimental or quasi-experimental designs, as well as program evaluation. While these approaches can provide valuable evidence on effectiveness and program functioning, they are typically oriented toward assessing performance against predefined criteria or outcomes. In contrast,

this study sought to generate rich, contextualised understanding of how the program operates and produces its reported effects, and to identify practical, transferrable insights for design and delivery. A case study approach was therefore better aligned with the thesis aims. The selection of a case that is not obviously a rehabilitation service may initially appear misaligned with the context discussed in this chapter. The program does not position itself as a rehabilitation service; in fact, it deliberately distinguishes itself from such programs.

I was drawn to the program as a case study because it represents the significant reimagining the rehabilitation sector has been challenged to adopt. It offers insights for rehabilitation because of its distinctiveness, but also because a rehabilitation-like thread has been fundamental to the program since its inception. The program is administered by a rehabilitation organisation, rehabilitation practitioners shaped its design and influence its delivery, and amongst other things it targets capacity, independence and participation. The deliberate shift away from rehabilitation represented not a dismissal of its aims but a new way of addressing them – while simultaneously broadening the offering to target well-being from new angles. While there are lessons for other sectors such as travel and accommodation, the context and issues outlined in this chapter informed the scope and focus of the thesis: offering practical guidance about explicit, intentional design to impact well-being, and understanding the place of rehabilitation, as (re)defined above, within that.

Case study research questions

The research questions for the case study were:

1. **What is the structure, design, and purpose of this novel program?**
    a. What are the key program components (inputs, activities, outputs, and intended impacts)?
    b. Is well-being intentionally embedded in the program's design, and if so, how?
    c. What is the socio-historical, institutional, policy and physical context of the program as a bounded case?
2. **What are the reported outcomes?**
    a. How do these align with the program's intended outcomes?
    b. How do they relate to each other?
    c. How do they impact well-being?
3. **How does the program achieve its well-being outcomes?**

a. What are the key mechanisms that explain how the program's activities lead to well-being outcomes, and what assumptions underlie the design?
b. What operational factors enable or influence the program's ability to achieve its well-being outcomes?
c. What are the program's limitations, and contextual supports and constraints?

The development of the research questions was an iterative process, evolving and refining as the study progressed. I initially began with a longer list of research questions, which I later trimmed to maintain the scope and focus established here.

Case study methodology and methods

The research adopted a qualitative case study methodology, which aligned well with the aims. Case studies examine a 'bounded system' of any kind, including programs, and seek "a holistic understanding of a phenomenon within real-life contexts from the perspective of those involved" [129] p1268. They can serve intrinsic purposes (to satisfy curiosity) and/or instrumental purposes (to inform broader issues) [130, 131, 132], both of which are reflected in the research aims.

Key elements of case study research include a focus on the singularity of a specific case, an intensive and holistic approach to data collection from multiple perspectives, and an exploration of the interaction between the case and its context [129, 131, 132, 133, 134]. A qualitative approach was most suitable for gaining these insights [131, 135], as well as facilitating co-construction of knowledge about a subjective phenomenon: well-being [135].

These elements shaped the design of the study, including the three data collection methods: multiple perspective interviews, observation and document review. These methods are characteristic of case study research [131, 135, 136], and provided qualitative insights from a range of sources and perspectives. Data analysis was organised by research question rather than data source, with all three sources of data contributing in different ways to each research question. Analysis began inductively and holistically, with later stages tailored to the requirements of each question.

Program theory provided a useful analytic framework, because it specialises in describing the structure of complex programs and examining how they achieve their outcomes. Specifically, a *program logic* provided an overview of the case [137] and a *theory of change* framework examined how the outcomes were achieved [138].

A more detailed description of the case study methods is presented in Chapter 4.

Contribution of the case study to the field

The case study methodology was primarily chosen for the transferrable insights it can offer, and the study designed with that purpose in mind. The discussion chapter explores the contribution of the case study to the field, informed by the possibilities, challenges and gaps highlighted by the first phase of the research: *issue questions* that are a key contribution of case study research [131].. The discussion chapter opens by exploring how insights from the theory of change can support adaptation of the case study findings to other contexts. The discussion chapter also considers broader insights about intentionally designing programs to address well-being, including formulating and communicating well-being aims, and how influencing factors from a range of well-being theories may be addressed to impact well-being more holistically. Specific insights for rehabilitation services are also discussed, focusing on how these services can more meaningfully reach and support people in their pursuit of a good life beyond the initial rehabilitation period.

1.3 Overview of the thesis

Chapter Two presents the systematic review, presented as an Author Accepted Manuscript of a published journal article: Simpson, B., Villeneuve, M., & Clifton, S. (2022). The experience and perspective of people with spinal cord injury about well-being interventions: A systematic review of qualitative studies. *Disability and Rehabilitation*, *44*(14), 3349-3363.

Chapter Three presents the scoping review, as a slightly abridged Author Accepted Manuscript of a published journal article: Simpson, B., Villeneuve, M., & Clifton, S. (2021). Exploring well-being services from the perspective of people with SCI: A scoping review of qualitative research. *International Journal of Qualitative Studies on Health and Well-being*, *16*(1), 1986922.

Chapter Four presents the qualitative case study methodology and methods, extending on the overview above. It discusses the stages of study design, limitations of the study, and the theoretical, epistemological and personal standpoints that underpinned the research. Demographics of study participants are also presented.

The case study findings are then presented across four chapters. **Chapter Five** introduces the case by providing descriptive overview of program components and their relationships, addressing the first research question: *What is the structure, design, and purpose of this novel program?* **Chapter Six** explores reported program outcomes, the second research question, predominantly drawing on the perspectives of interviewees with SCI.

Chapters 7-9 then explore how these outcomes were achieved, the third research question, using a *program theory of change*. **Chapter Seven** identifies the *mechanisms* through which the program achieves the outcomes, and the *assumptions* underlying these design decisions. **Chapter Eight** explores underlying *operational factors* that influence the program's ability to achieve its outcomes. **Chapter Nine** turns to the program context, considering the supports and barriers that enable and constrain the program.

Chapter Ten, the discussion chapter, considers insights about intentionally targeting well-being in practice, framed by the issue questions listed earlier.

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CHAPTER TWO:

SYSTEMATIC REVIEW OF QUALITATIVE STUDIES ABOUT WELL-BEING INTERVENTIONS

This chapter is presented as an Author Accepted Manuscript of a journal article published as Simpson, B., Villeneuve, M., & Clifton, S. (2022). The experience and perspective of people with spinal cord injury about well-being interventions: A systematic review of qualitative studies. *Disability and Rehabilitation*, 44(14), 3349-3363.

Minor formatting adjustments have been made to the Author Accepted Manuscript to align with thesis presentation requirements (e.g. adding thesis-style headings and relocating tables supplementary to the thesis to the appendices). Spelling and style reflect the version accepted by the journal, and the scholarly content remains unchanged.

2.1 Introduction

Promoting well-being (or 'a life worth living' [1, 2, 3, 4]) is a key aim of rehabilitation [5, 6, 7, 8]. Spinal cord injury (SCI) causes significant life disruption and has the potential to affect well-being. Of interest to those working in SCI rehabilitation is whether, and how, their interventions can influence well-being.

Research about the impact of SCI on well-being has produced varying findings. Many studies report that well-being is lower on average for people with SCI than the general population [9, 10, 11, 12, 13, 14]. However, mean scores may hide large variations between individuals. Many people with significant disabilities report that they live a satisfying life, despite circumstances that many external observers would describe as undesirable. Albrecht and Devlieger [15] coined the term 'disability paradox' to describe this phenomenon, and found over half of the people with significant and permanent disabilities they interviewed

(including people with SCI) reported their well-being to be good or excellent. Other researchers have found similarly high self-reported well-being amongst people with SCI [16, 17], including people with high-level tetraplegia requiring ventilatory support [18]. Many people with SCI report that their experience has enhanced their well-being in some ways [19, 20, 21, 22, 23]. Not all people with SCI experience good well-being, however. In Albrecht and Devlieger's study, 45% of participants reported poor or fair well-being [15], and similar studies reported a group of participants with persistent emotional distress and low well-being even many years after the injury [16, 18, 19, 20, 24]. Suicide causes between 5.8 and 11% of deaths post-SCI [25], suggesting very low levels of well-being for some people. SCI has a myriad of impacts on all domains of life, many of which do not emerge until well after the early rehab journey. Well-being is not just affected by the initial onset of SCI: stressors such as secondary health conditions, pain or hospitalisations may also affect well-being long term or cause it to fluctuate.

This body of research demonstrates that poor well-being is common, and good well-being is possible, post-SCI; providing further impetus to address well-being in SCI rehabilitation. However, it is clear that well-being is a complex phenomenon. What factors influence whether someone with SCI experiences good or poor well-being? And, importantly for those working in SCI rehabilitation, are these factors amenable to change? In this paper, we examine the factors that influence well-being outcomes from the perspective of people with SCI. We argue that a comprehensive understanding of these factors is critical to the intentional design and evaluation of rehabilitation interventions.

There is a large body of quantitative research about factors that predict, or correlate with, well-being of people with SCI. Such studies have found correlations between well-being and variables such as functional independence [26, 27, 28], sexual function [27] , physical activity [29], bowel and bladder function [30], marital status [31], socioeconomic factors [32], social support [28] and secondary health complications such as pain, spasticity, pressure injuries and constipation [29]. These studies contribute knowledge about what factors generally coincide with good or poor well-being of people with SCI, and some of these factors may be influenced by rehabilitation interventions. However, quantitative research does not provide an in-depth understanding of this complex phenomenon. Further, the results of these studies may not accurately reflect the lived experience and priorities of people with SCI. Quantitative studies often measure variables predetermined by (usually able-bodied) researchers whose judgements about what constitutes a 'good life' for people

with disabilities may vary greatly from the perspective of people with disabilities themselves [33, 34, 35, 36, 37, 38]. Such studies may overlook elements of well-being that people with SCI value, or overemphasize elements that are not important to them [36, 39, 40, 41]. Measures of well-being are often designed for the general population [42, 43], such as the Medical Outcomes Study Short Form (SF-36)[44]. These generic measurement tools have been criticized for containing items which may confronting, confusing or irrelevant to people with SCI such as the ability to walk [40, 45, 46, 47], or for missing items unique to SCI such as secondary health complications [40]. The SF-36 has been adapted to be more suitable for people with SCI (the SF-36-V [48]), and a suite of well-being measurement tools has recently been developed for people with SCI, in consultation with this population [40]. Use of such measures in future quantitative studies may enrich our understanding of what factors affect well-being of people with SCI, and may help researchers to evaluate well-being interventions in a way that is meaningful to this population. However, the current body of quantitative literature provides an incomplete answer to this question, making it difficult to implement or evaluate interventions to promote well-being.

A more accurate and in-depth understanding of what influences well-being should come from the experience and perspective of people with SCI. This is best achieved using qualitative methodologies, and there is a growing body of qualitative research about well-being post-SCI. Hammell [49] reviewed seven qualitative studies that sought the perspective of people with SCI about factors that influence their well-being (referred to as quality of life in that study). This systematic review with metasynthesis, conducted by a prominent researcher in the fields of well-being and SCI rehabilitation, identified nine determinants that could either enable or constrain well-being. A number of qualitative studies have subsequently reinforced and added detail to these determinants from the perspective of people with SCI [22, 50, 51, 52, 53, 54, 55, 56, 57, 58]. These determinants, defined in Table 2.1 and described fully in Appendix A, provide a framework for thinking about how rehabilitation interventions can address well-being outcomes for people with SCI.

Table 2.1.

Well-being determinants and definitions

Well-being determinants described in Hammell [49]	**Definition**
Sense of loss	Negative changes and psychological consequences from SCI
Body problems	Difficulties associated with impaired body functions
Occupation	"Anything that people do in their daily lives" [49] p131.
Responsibility and control	People with SCI assuming responsibility for their own lives; self-determination and decision-making
Values and perspectives	Values and priorities which inform the lives of people with SCI
Self-worth	A sense of being valuable
Self-continuity	Continued or restored sense of self and biography
Relationships	Relationships with family members, partners, friends, carers and peers; mutual support and contribution
Environment	Dimensions of the physical, economic, political and legal, social and cultural environment that either constrain or enable well-being

Well-being determinants include a *sense of loss* and *body problems*, which negatively affect well-being. Engaging in *occupation* is an important contributor to well-being, and being able to assume *responsibility and control* is valued even when people with SCI need help with occupations. Evaluating *values and perspectives*, rebuilding a sense of *self-worth* and *self-continuity*, and meaningful *relationships* also have a positive impact on well-being. Finally, various aspects of the physical, social, economic and cultural *environment* can either enable or constrain well-being.

The determinants described in table 1 are a promising framework for designing and evaluating well-being interventions. An important next step is to understand **whether, and how, rehabilitation interventions can influence these determinants in order to enhance well-being**. As argued above, it is important to seek the perspective of people with SCI about

issues related to their own well-being. This understanding may inform the design, implementation and evaluation of interventions and programs in SCI rehabilitation, in order to address well-being in a way that is meaningful to people with SCI.

2.1.1 Aim

This study synthesized qualitative research about well-being interventions for people with SCI. Specific aims were to explore the perspective of people with SCI about:

- *whether* well-being determinants were influenced by interventions,
- *how* these well-being determinants were influenced, and
- the *perceived impacts* on well-being when its determinants were addressed

2.2 Methods

2.2.1 Identifying and selecting articles

We conducted a systematic review of qualitative studies, reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [59]. A database search was conducted to locate studies that contributed to the research aims, in Medline, ADMED, Cochrane Database of Systematic Reviews, PsychARTICLES, PsychINFO, Embase and CINAHL. Search terms were: spinal cord injuries, spinal cord injur*, paraplegi*, tetraplegi*, quadriplegi* AND quality of life, personal satisfaction, wellbeing, well being, well-being, happiness, good life, flourish* AND qualitative, interview. A hand search of reference lists and citations supplemented the database search.

Studies were included that a) used a qualitative methodology; b) exclusively recruited people with SCI, of any cause; c) involved an intervention (defined as involvement with professionals, programs or services for people with SCI or disabilities) with the intervention provided to all participants; and d) sought to explore well-being (or a specific phenomenon linked to well-being). In order to contribute to the research aims, qualitative methods needed to facilitate an in-depth understanding of the perspective of people with SCI: we excluded studies that only used questionnaires and surveys with closed questions. For the same reason,

researchers needed to support their interpretations with participant quotations. Including the words of participants is also an important indicator of research quality, as this 'audit trail' is evidence that findings are rooted in the data [49]. Mixed-methods studies were included if the qualitative component met the above requirements. Only papers published in English in a peer-reviewed journal between 1996 and October 2020 were included. Systematic reviews were excluded, but reference lists of reviews were hand-searched and original papers were included if relevant.

The research team developed the inclusion and exclusion criteria together. These criteria were discussed and refined following an initial literature search. One reviewer (BS) conducted the final search and study selection. Reasons for rejecting studies were discussed and confirmed with a second member of the team (MV). Disagreements at this stage were resolved through dialogue and consensus.

2.2.2 Quality appraisal

We appraised the quality of studies using the Critical Appraisal Skills Programme (CASP) qualitative checklist [60]. This checklist is intended for use as a basis for discussion, and calculation of an overall score (or cut-off for inclusion) is not recommended [60]. Therefore, rather than being used in a prescriptive way [61], the checklist was used as a basis for team discussions. If serious or multiple methodological flaws were identified, dialogue and consensus was used to determine inclusion or exclusion from the review, and the checklist was used to document the decision-making process [62]. The only pre-determined 'fatal flaw' used as a basis for exclusion was the absence of participant quotations to support researcher interpretations. Including the words of participants is also an important indicator of research quality, as this audit trail is evidence that findings are rooted in the data [49, 61].

The process and results of study selection are summarized in figure 2.1.

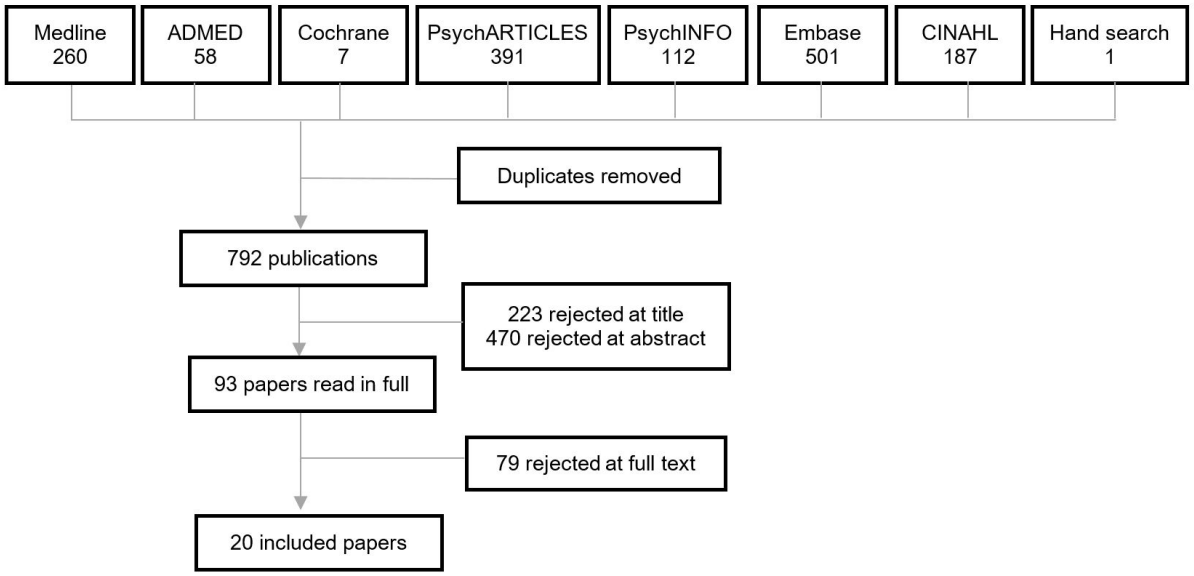

Figure 2.1.

Flowchart of study selection

841 original publications were identified. The titles of 239 papers indicated the study was unrelated to the research question or did not meet the inclusion criteria. Abstracts of 602 studies were read, with 488 studies excluded at that point. We read 114 papers in full to ascertain relevance when the abstract did not provide enough information, or where the study appeared to be relevant. Ninety-four papers did not meet the inclusion criteria were rejected at this point. Of these, six studies met most inclusion criteria but were judged to be of inadequate quality because they did not provide supporting participant quotes [63, 64, 65, 66, 67, 68]. Other reasons for rejection of full-text articles were: inadequate/unclear focus on well-being, participants did not all receive the intervention, or the study recruited people with conditions other than SCI.

2.2.3 Analysis

Framework synthesis guided our analysis. Based on framework analysis [60], framework synthesis is a method of analysing qualitative research that uses an existing framework as a basis for coding and categorisation of themes [69]. An existing framework was particularly helpful for identifying and categorising well-being related themes, because this phenomenon is broad and often poorly defined. We followed the five stages of framework analysis:

familiarisation, identifying a conceptual framework, indexing, charting and mapping and interpretation [70]. We designed an analysis framework based on the nine well-being determinants identified by Hammell [49], guided by the definitions in table 1 and more detailed description in Appendix A. Papers were initially read in full to gain a sense of the overall findings, and to confirm the suitability of the chosen framework. We then analysed the studies deductively, using the analysis framework. Concepts in the articles, including participant quotes and researcher interpretations, were coded by the relevant determinant/s. For example, the statement "*Being able to connect with people, learn through people, make friends*" was coded as 'relationships'. During this analysis, we also coded using an inductive strategy, to identify items that did not match with the determinants as defined. Coded concepts were extracted, attempting to retain as much of the original meaning as possible, and were grouped together for each well-being determinant. Further analysis identified sub-themes of each determinant, including whether and how the determinant was influenced, ways in which that determinant was influenced, and perceived outcomes of changes to that determinant. Relationships between the concepts and determinants were also analysed. Researcher BS performed the analysis. Because framework synthesis involves coding using a pre-defined strategy, researchers MV and SC independently reviewed 30% of the studies to verify the coding strategy was being applied according to the framework. Team discussions and consensus were used to resolve any discrepancies in coding, and to confirm findings that did not fit within the framework as originally defined. For example, we discussed whether existing character strengths should fit within the 'values and perspectives' category or whether it warranted a separate category.

2.3 Results

Twenty articles were included in this review, and are summarized in Appendix B. The studies involved a range of participants with SCI, representing a variety of ages (17-77 y.o.) and time since injury (7 months to 37 years). Level of injury ranged from L4 (incomplete) to C2 (incomplete). Five studies only recruited people with tetraplegia (C3-C6); the other studies recruited people with both paraplegia and tetraplegia (n=13) or did not report level of injury (n=2). Interventions included education programs, facilitation of leisure and physical activity, vocational interventions, assistive technology for computer access and

environmental control, mobility training, and peer support. Describing the specific activities, valued aspects and limitations of these interventions is beyond the scope of this paper and these findings are reported elsewhere.

Five studies were mixed-methods, and one paper reported qualitative results from a larger mixed-methods study. The quantitative components of mixed-methods studies were not included in this review, but it is worth noting that only two of the mixed-methods studies used a randomised control design. Common methodological issues included a lack of critical examination of researcher bias, methods not being made explicit (e.g. in the form of an interview guide), and no discussion of data saturation. We appraised all included studies as having used a suitable methodology, methods and analysis, and we included findings from all studies in our analysis.

2.3.1 Findings

The key finding of our review is that people with SCI perceive rehabilitation interventions can influence well-being determinants. Appendix C shows the well-being determinants for which people with SCI reported positive changes. In each study, people with SCI described positive changes to a number of well-being determinants, with most studies reporting positive changes in at least six of the nine determinants. Interestingly, these changes were brought about by a wide variety of interventions, which included surgery, mobility training, peer mentoring, technology use and leisure activities.

People with SCI described the contribution of well-being determinants as life changing and healing e.g. "*I was healed from the inside out*"[71]. They shared the surprising discovery that life was not over [72]; that "*everything would be okay*" [73] and that life was full of opportunity and possibility ("*the sky was the limit and everything was possible*" [74]). They also talked about the lifting of their spirits [71, 74, 75], and renewed happiness and purpose (e.g. "*there's life after the injury … you know what? I'm happy… I can't wait to roll around, and get on with life*" [72]). Despite the challenges of SCI, people learnt that a good life was possible "*how not to just live with [issues related to SCI], how to live well with them*" [73].

The following section discusses how each well-being determinant was influenced, and the well-being outcomes people with SCI described.

A sense of loss

People with SCI described losses associated with their SCI, as summarized by one man with tetraplegia: "*I lost all my freedom, my health, my body, my dignity*" [76]. Participants talked about the impact of SCI on their ability to perform tasks, which were no longer possible, took longer, were more difficult, or needed to change. Participants missed valued occupations and roles, and felt frustration and disappointment in their changed abilities [76, 77]. They described the difficulties of being dependent on assistance of paid carers to assist with tasks, as well as the changed relationship dynamic and sense of burden when reliant on family and friends for help [78]. They also described a loss of identity and a struggle to accept a new identity post-SCI [72, 76, 79]. The losses caused by SCI had significant emotional consequences, with participants reporting sadness, depression, anxiety, frustration, fear, uncertainty, stress and despair [72, 73, 77, 80, 81, 82, 83]. There were also losses for family members and carers [82, 84, 85, 86]. The interventions themselves sometimes confronted people with SCI with their losses (at least initially) as they increased awareness about limitations and prognoses, involved a new way of doing things, and required people to engage with the public and a new community of people with disabilities [77, 78, 81, 83].

However, in contrast to Hammell's findings [49], participants in these studies were not preoccupied with loss. When participants discussed losses, they were usually describing a previous perception that had now changed. "*Becoming a quad… you lose confidence in yourself and you feel that it's all finished, so [participating in music groups] has given me confidence, knowing that it is not finished*" [77]. This finding would be in part a reflection of the included studies, in which participants discussed their experiences of an intervention rather than their broader experience of SCI. It is likely that there are many losses that participants did not discuss in the reviewed studies, and participants did report some ongoing losses. However, our review found that many people with SCI reported a reduced sense of loss, and, importantly, that well-being interventions may positively influence a sense of loss. Participants reported that their losses diminished as interventions influenced other well-being determinants, which improved their ability to perform valued tasks, reduced their need for care, restored healthy relationship dynamics, changed their values and perspectives, promoted adjustment and facilitated a more positive sense of self. Some interventions enabled people with SCI to share and process their losses, particularly with peers [73, 75, 77, 82, 86].

Body problems

Participants reported improvements related to a number of body functions including strength, balance, endurance, cardiovascular function and fitness, respiratory and voice function, sensation, weight, pain, energy levels, fatigue, sleep, falls risk, spasm, need for medications, and prevention of secondary health conditions [71, 76, 77, 79, 82, 83, 86, 87, 88, 89]. "*... if I wasn't doing all this, who knows what kind of shape I would be in*" [71]. Reductions in body problems resulted in improved function for daily tasks, improved participation, better capacity for socialisation, reduced strain and fatigue during daily routines, reduced reliance on carer assistance, improved mood, and reduced stress and anxiety [71, 76, 77, 82, 83, 84, 87, 88].

Interventions often targeted body functions explicitly, through accessible physical activity [71, 76, 79, 83], skills training , mobility training [83, 87], respiratory/singing training [77, 82], education [86], and surgery [84]. However, other interventions addressed body problems more indirectly. Engaging in enjoyable and meaningful activities (particularly leisure activities) enabled people with SCI to relax, and to temporarily escape from body problems and a sense of confinement, either physically, symbolically or by distraction [79, 82, 90]. Interventions that facilitated computer access enabled people with SCI to research body problems and their management, find information about opportunities for physical activity, and share and gain information about body problems with peers [75, 90]. Formal peer support services improved knowledge about body problems and their management, and the shared experience provided legitimacy and safety for conversations about intimate body issues such as bladder and sexual function [74].

A desire to improve body function was a motivator for many people with SCI to engage in interventions or physical activities [71, 83], and this was seen as a life-long task. "*It's a constant push, you know, you are constantly pushing yourself to get you know better and better*" [71]. However, body problems were sometimes a barrier to participation in intervention activities, including pain, fatigue, incontinence, side effects of medications and inadequate body function (e.g. poor grip strength) [83, 90]. Some interventions posed risks to the body or had adverse effects including injuries, dizziness, falls, pressure injury, pain, fatigue or exposure [77, 79, 83, 86, 90]. Involvement of rehabilitation staff often helped to reduce these risks and barriers, by planning ahead, modifying activities and equipment, flexible schedules, and providing assistive technology [79, 83, 90]. People with SCI often

reported that the benefits of interventions outweighed the risks/cost, and they did not usually view risk negatively. Taking risks and challenging their bodies was a source of pride and motivation [79], and this experience influenced other determinants such as self-worth and self-continuity.

Engaging in occupation

Engaging in occupation was often the key focus of the interventions, which addressed occupations through skills training, assistive technology, education, task modification and grading, improving body function and providing opportunities to try accessible activities. Increased engagement in occupations was significant to people with SCI. Many of the study participants were unable to do much for themselves, had few meaningful activities to fill their day, had little control over decisions and routines, and were reliant on assistance for many tasks. They reported that even small changes in their ability to perform occupations made a significant difference to their well-being. Interventions made tasks possible, easier, 'smoother', faster and more flexible. These improvements made it possible for people with SCI to do new things, do activities for longer, prioritize meaningful activities, have a routine, make choices, access information, perform life roles, participate in society, and contribute to others [73, 77, 82, 83, 84, 85, 87, 88, 89]. 'Doing' had symbolic meaning beyond the task itself: "*to think that you can do something for yourself… mentally it means an awful lot*" [80]. Participants described an increased sense of confidence, self-worth, security and freedom as they engaged in occupations. Emotional benefits included relaxation, joy, surprise, fun, and pleasure, not only from the occupation itself, but also from the experience of gaining a new skill and challenging expectations [71, 78, 79, 80, 82, 83, 84, 85, 87]. These benefits, in addition to the diversion and meaning that occupations provide, were seen as reducing or preventing negative experiences such as depression and stress, and assisting with coping and adjustment post-SCI [71, 76, 77, 79, 80, 82, 83, 84]. Increased autonomy in performing occupations often led to people working towards new or more challenging occupations [73, 77].

Increased autonomy in occupations also meant that people with SCI were less reliant on assistance from others. This resulted in a reduced perceived burden on, and changed relationship dynamic with, family members [76, 80, 84, 86]. Participants were more able to go out or be at home alone, which increased their community participation, privacy, sense of freedom and escape, as well as reducing burden on carers [78, 80, 84, 85, 86]. Increased

autonomy also impacted paid care, enabling carers to be less present or more efficient, and reducing care hours in some cases [84].

Responsibility and control

People with SCI reported well-being interventions improved their motivation, opportunity and capacity to assume responsibility and control in their lives. "*The [self-management] course taught me how to take control, you know of my care, and with the realisation that nobody's gonna look after you like you"* [73]. Participants described an increased sense of control over their lives, health, bodies and recovery, and an increased recognition of the need to take responsibility for these aspects of life [71, 77, 84]. Participants reported greater control over their daily lives as interventions (particularly those facilitating computer access) enabled them to manage their own routines and appointments, take notes, manage their finances, plan activities, and control their home environment [75, 78, 80, 90]. Responsibility and control were enhanced as interventions provided people with SCI with the awareness, confidence, language and skills to be assertive and advocate for their own needs [73]. Interventions increased the opportunity and capacity to make choices and solve problems [74, 80, 81, 85, 86]. However choices were limited for some people by limited opportunities and resources (e.g. lack of accessible recreation opportunities) [76].

Values and perspectives

People with SCI described changes in their values and perspectives as a result of well-being interventions: "*... changed my whole outlook on life*" [73]. People with SCI often described a negative outlook soon after SCI: "*My expectation before was that life was essentially over; it was 'you poor helpless cripple*'" [86]. These perspectives changed with time, and due to the influence of rehabilitation interventions. Perceived limits and potential were challenged as interventions raised expectations, enabled achievement of occupations not previously thought possible, and increased confidence and self-efficacy [77, 78, 79, 80, 81, 84, 88]. Participants reframed disability and their new identity as a person with SCI [73, 79]. Participants also perceived a change in the expectations and attitudes of others, as they challenged stereotypes and demonstrated their abilities to family, friends and the general public [78, 82, 84, 85, 86]. People with SCI consistently emphasized the importance of hope, which increased because of well-being interventions [71, 72, 77, 81, 83, 84, 88]. They described how hope provided a clearer sense of direction, more positive sense of the future, options and solid goals to work

towards, something to look forward to, sense of security, and a sense of being 'back on track'. Hope was almost universally described as contributing positively to well-being: "… *put in a better frame of mind … big part to play in managing someone's mental health… getting back into life really*" [81], "*there is still light*" [73]. However, people with SCI also valued realism and didn't want false hope [74]. Participants also described an increased ability to see positives in their situation [72]: "…*got me to turn around and look more at what I can do and why I should feel lucky rather than depressed*" and "*there's still a hell of a lot that we can be thankful for*" [73]. Interventions enhanced coping strategies and problem-solving, and facilitated adjustment and acceptance [73, 75, 76, 77, 81]. The attitude of participants towards the interventions themselves also changed, as their initial negative expectations were challenged, attitudes towards assistive technology changed, and as they persevered and changed habits to incorporate a different way of doing things [78].

Some interventions deliberately targeted values and perspectives through education and group activities [73, 81]. Values and perspectives were also influenced by exposure to peers with SCI, either through formal peer support services, incidental peer support, and through seeing others engage in occupations [71, 72, 73, 76]: this exposure raised expectations, and provided 'contagious optimism', motivation, an opportunity for comparison, increased knowledge of solutions and possibilities, and skill sharing. These factors were also influenced by the positive attitudes of others e.g. family members and rehabilitation staff [85, 86]. Experience, experimentation and achievement of occupations also helped to change attitudes of people with SCI and those around them [73, 75, 79, 81, 85]. Finally, people with SCI described how their own character traits and strengths influenced their well-being. They emphasized the importance of determination, persistence, patience, dealing with frustration, motivation, habits, goals, and intentionality [71, 76, 78, 90]. Interventions sometimes developed or strengthened these characteristics, but many were viewed as being pre-existing or innate, such as an existing 'strong mindset' [71]. These findings add to Hammell's list of values and perspectives, and expand our understanding of this category to include existing values and perspectives, not just changed or new ones.

Self-worth

People with SCI reported that interventions improved their sense of self-worth, as they increased a sense of confidence, competence, capability, self-esteem and self-efficacy [71, 73, 77, 79, 81, 82, 84, 87, 88]. "*I feel better about myself … I think [job seeking] has given*

me a purpose. I feel it's improved my feeling of self-worth" [88]. This acceptance included greater understanding and acceptance of limitations, a sense of self-compassion and improved body image [73, 83]: "*I want a more balanced life … I respect my body a lot more*" [73]. A feeling of being less 'needy' was described, which included less frustration and a reduced sense of being a burden [80, 84]. People with SCI also described a greater sense of dignity as an outcome of interventions "*it gave you some dignity back*" [83], and they valued being treated as a unique, worthwhile individual during intervention activities [71, 83, 86]. Being able to participate in occupations also contributed to self-worth, particularly occupations perceived as being meaningful, having the right level of challenge and risk, contributing to other people or society, or relating to valued life roles [71, 74, 77, 79, 80, 81, 82, 83, 84, 85, 86, 87, 88]. Relationships formed or strengthened during intervention activities also contributed to an increased sense of self-worth [71]. Improvements in body functions also improved self-worth and body image [88].

Self-continuity

Countering the biographical disruption of SCI [91], interventions were perceived to retain or restore self-continuity. Participants valued retaining a sense of personhood in the context of a hospital or institution [86], and interventions early after injury were important in retaining self-continuity [81]. Interventions facilitated self-continuity when they connected people with SCI to their pre-injury values, roles, experience and self-identity [81, 84, 85]. "*When you don't have to ask for help with certain things, 'cause you can manage by yourself – then, it feels more like it was before, really*" [84]. "*Emotionally [singing] makes you feel good, because it does feel the same as before [the accident]*" [77]. Experiencing a sense of 'normalcy' was important to many of the participants.. "*It took me a while to really believe, just in my own mind, that I was still me. I had a spinal cord injury, but life wasn't necessarily over. I still had all these opportunities to live yet*" [86]. Facilitating pre-injury activities is an obvious way to address self-continuity, and interventions which included pre-injury interests and activities were valued [77, 78, 80, 85]. People with SCI particularly emphasized the importance of previous leisure occupations [77, 85], which some saw as being underemphasized in rehabilitation [76]. However, engaging in all pre-injury occupations was not always possible, or of interest to, people with SCI. Participants discussed the importance of developing a new identity and engaging in new activities which take into account the changes and limitations of SCI [85].

Relationships

Improved relationships was a strong theme in the reviewed studies, and people with SCI perceived well-being interventions positively influenced their relationships in various ways. Intervention activities and related occupations provided an opportunity to socialize with others by doing a shared activity, 'hanging out' during the activity time, or participating in related social activities (e.g. going for a picnic after church) [77, 82, 85, 89]. Socialisation (particularly with peers with SCI) enhanced well-being by facilitating enjoyment, fun, a sense of community, connection and belonging, motivation, encouragement, celebration, acceptance, affirmation, and reduced social isolation [71, 76, 77, 79, 82]. Being able to perform occupations more independently affected relationships as this independence enabled people with SCI to get out more, fulfill important relationship roles, and interact with others in a more fun and spontaneous way [78, 83, 85]. Performing an enjoyable activity with others shifted the focus from SCI to a common interest [79]. Interventions that enabled computer and telephone access facilitated relationships through connection to support and socialisation with existing and new networks [75, 78, 80, 90]. However some participants reported a sense of exclusion and isolation when using social media [90], or found some social interactions confronting and painful [86].

People with SCI reported that interventions changed relationship dynamics, as increased autonomy resulted in a reduced sense of burden, annoyance, frustration, perceived need to apologize frequently, and sense of obligation [78, 80]. "*It's easier to socialize with people if they don't need to help me with things"* [84]. Some participants reported that these changes required adjustment on the part of family members, who were sometimes not accustomed to the person with SCI being assertive or not needing their help [73, 78]. Although relationships were important to people with SCI, they described the difficulties of having people around them a lot of the time, particularly carers they would not normally choose to be with. Participants valued being alone and having privacy; interventions facilitated this when they reduced care requirements [78, 80].

Environment

Similar to Hammell's findings [49], people with SCI in this review identified barriers and facilitators in the physical, social and economic environment which limited their ability to participate in activities that promote well-being. Environmental barriers included lack of

transport, inaccessible facilities and environments, few accessible opportunities nearby, lack of information about opportunities, accessibility and weather challenges for outdoor activities, stigma and low expectations of others, limited access to rehabilitation post-discharge, stretched resources and program capacities, lack of time and energy, high cost of activities and equipment, and limited personal and insurance funding [74, 76, 78, 83, 86, 89].

> "*I would really like to go but I cannot because either my physical condition does not allow me or it's too far away. Sometimes they organize nice meeting at [name of restaurant], but I would get home too late at night. I'm not able to [go to gatherings] in the winter because I almost never drive.*" [74].

Interventions addressed some environmental barriers through information provision, transport assistance, modifying the environment or tasks, managing risks, and enabling engagement in occupations from home or bed [75, 79, 85, 86, 89, 90]. Interventions enhanced well-being by expanding the range of physical environments available to people with SCI, who valued having increased opportunities to leave the bed, house or hospital [83, 85]. The opportunity to access (or even just see) outdoor, natural environments was particularly valued, and associated with positive emotions of fun, laughter, connection, escape, peace, calm [79, 88], and being in a "*whole other world*" [79]. However, it was clear that many environmental barriers remained, which would limit the ability of people with SCI to engage in well-being interventions or benefit from them outside of a research context.

2.4 Discussion

2.4.1 Implications for rehabilitation research and practice

Improvements in well-being were vitally important to people with SCI involved in the studies, but well-being outcomes are not usually the explicit focus of rehabilitation design or evaluation. Rehabilitation programs may miss opportunities to promote well-being if this is not a clear focus or priority. Further, important improvements in well-being may not be captured if it is not evaluated comprehensively. We recommend a shift towards a more explicit focus on well-being in intervention design and evaluation, in order to better promote

and measure outcomes important to people with SCI. The findings of this study can be used to design interventions with the intent to influence well-being.

A clear conceptual framework should inform the design and evaluation of rehabilitation interventions that seek to explicitly and comprehensively target well-being. The findings of our study may help inform the selection of such well-being frameworks, as we have synthesized the well-being outcomes important to people with SCI. These well-being outcomes relate to both subjective well-being (positive emotions, pleasure and life satisfaction) and psychological well-being (meaning, growth, autonomy, virtue and relationships) [92, 93]. These two conceptions of well-being, arising from the hedonic and eudemonic philosophical traditions respectively [94], have often been pitted against each other [93, 95, 96, 97]. However, our review supports a broad understanding of well-being that incorporates these two distinct but related conceptions [92, 93, 94, 95, 96, 98]. A broad conceptual framework, as supported by our findings, would drive a similarly broad approach to measuring well-being outcomes. Both subjective and psychological well-being should be the focus of well-being evaluation, in order to capture the range of outcomes important to people with SCI. These well-being outcomes may cross traditional disciplinary boundaries, suggesting a multidisciplinary approach to well-being research and intervention should be adopted.

The well-being determinants identified by Hammell [49] and later studies [22, 50, 51, 52, 53, 54, 55, 56, 57, 58] were addressed by study interventions, and changes in these determinants were perceived to influence well-being. The findings of our review explain and add depth to the importance of these well-being determinants, and support their relevance to the design of well-being interventions. Interventions targeting well-being should address some or all of these determinants (engaging in occupation, responsibility, values and perspectives, self-worth, self-continuity, relationships and the environment). Our study has described ways in which interventions addressed these determinants, providing important detail that may inform intervention design. In the reviewed studies, well-being determinants were sometimes targeted directly by an intervention, most commonly body problems, values and perspectives, and engaging in occupation. Changes in these determinants had a flow-on effect to other determinants e.g. reduced body problems impacted self-worth. Well-being determinants are evidently interrelated, and the impact of well-being interventions may be multiplied beyond just the targeted determinants. This finding adds support to the ‘value’ and importance of well-being interventions.

Our findings have further developed the 'values and perspectives' determinant to include character traits and strengths described by people with SCI. The field of positive psychology has recognized these character strengths as being important to well-being [50, 99]. These character strengths were reported in the qualitative literature published after Hammell's review (synthesized in Table 1), as well as in the intervention studies we reviewed. These findings add to the list of values and perspectives that influence well-being, and suggest that well-being may be influenced by pre-existing character in addition to the changes in values and perspectives that Hammell reported. Well-being interventions should include identification and development of helpful character traits and strengths.

Of all the well-being determinants, engaging in occupation appeared to have particular importance, and all of the reviewed studies influenced this determinant. Although people with SCI still needed assistance for many of their daily tasks, even small improvements in the ability to engage in occupations had a big impact on well-being. This review has identified characteristics of occupations people with SCI found particularly beneficial to their well-being, which may help inform identifying and prioritizing occupations to address in SCI rehabilitation. Occupations particularly enhanced sense of self-worth and identity when they related to meaningful life roles and self-identity, or enabled people with SCI to make genuine contributions to others. Returning to pre-injury occupations was important in facilitating a sense of self-continuity, although being unable to perform pre-injury occupations detracted from well-being, and engagement in new occupations was valued in its own right. Occupations that enabled people with SCI to socialize with others contributed to well-being, and participants particularly valued the opportunity to make connections with peers with SCI. The importance of participating in meaningful occupations early after SCI was emphasized, although people also valued engaging in new occupations many years post-SCI. Several studies in this review had an emphasis on leisure, and leisure interventions in these studies influenced the greatest number of well-being determinants. Leisure occupations were particularly beneficial in promoting well-being through the pleasure of the activities themselves, as well as by providing diversion from stressors, structure and meaning to the day (especially in the absence of employment), a sense of belonging, social interaction, and through the physical benefits of physical activity and relaxation. However, some people with SCI reported that these important leisure occupations were not prioritised during rehabilitation.

2.4.2 Limitations

The impact of SCI is diverse in terms of level and completeness of injury, which makes research with this population challenging. While a good range of participants were represented in the reviewed studies (including both tetraplegic and paraplegic level injuries), it cannot be assumed that the broad experience of a range of people with SCI will apply to a particular individual. Additionally, authors rarely stated the cause of injury, and it is possible that findings may differ between people with traumatic and non-traumatic SCI. Although we did not exclude paediatric studies, the reviewed studies only included adults with SCI. Further research is needed to gain the perspective of children with SCI about their well-being. All except six of the included studies were conducted in North America, and the voices of people with SCI from outside of that region may be underrepresented in our findings. In particular, findings about program availability, activities and limitations, which are likely to vary between contexts, may not accurately reflect the situation outside of North America. Our exclusion criteria also limited our ability to hear the perspectives of people with SCI from outside of English speaking regions, who are likely to have different interventions available to them, and whose values related to well-being outcomes may differ to the participants in our reviewed studies. Finally, it is possible that we missed some voices of people with SCI from studies that were not included in our review, including from studies that were excluded due to their recruitment of people with conditions other than SCI, or studies that were missed by our search process (e.g., if they described well-being using terms that were not captured by our search).

Various forms of bias may have influenced the analysis process. Although we used cross-checking and additional inductive analysis, there is a risk that the use of an *a-priori* framework may have unduly influenced the categorisation and interpretation of findings: it is possible that we categorised some concepts to fit the framework when we may have interpreted them differently had we started with a 'blank slate'. The background and perspective of the researchers may also have influenced analysis, both positively and negatively. The occupational therapy background of BS and MV provided a rich understanding of the 'occupations' determinant in particular, but this background may have biased us towards occupation-related findings during our analysis. We deliberately chose a broad analysis framework that would reflect the influence of various rehabilitation professionals, to avoid skewing our findings towards a single profession. This may have been

further supported by the diversity of expertise of our research team. For example, MV leads research on developing capacity in community, health and disability services to work more effectively across sectors and disciplines to increase the inclusion of people with disability. SC is an academic with lived experience of spinal cord injury, whose research has explored the journeys of people with SCI through loss and rehabilitation, examining factors that have enabled people to flourish.

Interventions were rarely described in detail in the reviewed studies. This level of detail is not always possible or a priority in published research, however the ability of clinicians and other researchers to adopt a similar intervention is therefore limited. One of the studies focused on the impact of performing an occupation (physical and leisure activities) while only briefly alluding to the intervention which facilitated that occupation [76]. While contributing rich data about the impacts of these occupations on well-being, the direct link between interventions and well-being outcomes was not as clear in that study. Further research is needed about valued aspects and limitations of well-being interventions, as well as research that describes well-being interventions in detail.

Methodological issues in the reviewed studies may have impacted findings. In many studies, a lack of critical reflection about researcher influence in many studies meant we could not determine whether or how biases were managed. Negative impacts on well-being (e.g. being confronted with loss) were rare and seemingly temporary, however it is unclear whether perspectives were sought about negative outcomes because many studies did not include a detailed description of methods (e.g. in the form of an interview guide).

Participants reported gaps and limitations in the current rehabilitation system, particularly the limited opportunities for well-being interventions and programs in a community setting. Many people with SCI reported that they wanted to continue with interventions beyond the study period, and that they wanted programs to be longer or more readily available. The findings of this review present a challenge to the current rehabilitation system, and it appears that people with SCI are missing out on opportunities to enhance their well-being. While our review has demonstrated that interventions can positively influence well-being, the lack of opportunity for people with SCI to engage in these interventions outside of a research context limits the applicability of our findings.

Most studies did not include a definition of well-being or apply a conceptual framework of well-being. Further, many studies explored an existing or previous intervention which was

not intentionally designed to improve well-being. Other researchers have noted an unclear or ill-defined understanding of well-being in rehabilitation research in general, and have described the challenges to conceptualizing well-being [13, 39, 100]. Ideally, we would have only included studies that used intentional, theory-informed well-being interventions. However, the dearth of such research broadened our inclusion criteria to all studies that intended to explore well-being outcomes. While the reviewed studies reported many benefits to well-being, these outcomes may have been limited by a lack of well-being conceptual framework informing the intervention design. Further research is required about the outcomes of interventions that have been intentionally designed to improve well-being, informed by clear conceptual frameworks. Our findings may inform the development of such interventions.

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2.5 Contribution of the systematic review to the thesis

The introduction to the systematic review strengthens the context established in Chapter 1, adding conceptual depth to the thesis**.** It also updates and refines a list of well-being determinants from the qualitative literature, which then framed the review's synthesis. I return to this list of determinants in the discussion chapter, where I examine its alignment with the case study findings, and propose its further development for use in program design and evaluation.

The systematic review findings advance the theoretical literature by showing how services can address these known determinants, and exploring the resulting outcomes, which are evidently interrelated. The findings reinforce the thesis premise: services can meaningfully influence well-being when they intentionally engage with the factors that shape it.

The systematic review revealed important themes, taken up by the subsequent studies. A central theme was the significance of engaging in meaningful occupations, including the breadth of the resulting impacts, and the characteristics of occupations that most supported well-being. This theme informed an *issue question* carried through to the discussion chapter, as I explore the case study findings through an occupational science lens. Other recurring themes, including peer interaction and support, staff approach, and the timing of services, also informed the case study analysis. The findings also underscored the potential of a range of disciplines to impact well-being, informing their further exploration through the scoping review.

The systematic review also brought to light gaps and unanswered questions. The scoping review sought to shed more light on how well-being can be defined and conceptualised, from a broader range of studies. The scoping review and case study also explored the unresolved question of whether programs achieve greater impacts when intentionally designed with well-being determinants in mind.

Finally, the findings highlighted the need for richer descriptions of program design and delivery to support transferability across services. The scoping review responded by examining program activities, valued elements, and limitations, including studies reporting negative impacts, to provide the necessary detail and nuance. The case study sought to provide rich detail about program design and delivery, considering a single program in depth while generating insights transferrable to other services.

CHAPTER THREE:

PERSPECTIVES OF PEOPLE WITH SCI ABOUT WELL-BEING SERVICES

This chapter presents an abridged version of the Author Accepted Manuscript of a published scoping review: Simpson, B., Villeneuve, M., & Clifton, S. (2021). *Exploring well-being services from the perspective of people with SCI: A scoping review of qualitative research. International Journal of Qualitative Studies on Health and Well-being*, 16(1), 1986922.

To avoid repetition of material presented in Chapters 1 and 2, the introduction has been removed and the methods section has been slightly amended. The core findings and discussion have been retained; these remain as per the published article apart from minor formatting adjustments to align with the thesis format.

3.1 Aims

The larger aim of this paper is to give service providers insight into how to improve the delivery of their services by identifying the experience and perspective of people with SCI about interventions targeting their well-being. The specific aims were to: **i) examine the extent and nature of qualitative research related to well-being programs for people with SCI; ii) describe how well-being is conceptualised in these studies, and whether/how intentional design for well-being was used; iii) describe specific activities, timing and context of rehabilitation services related to well-being; and iv) explore how people with SCI perceive and experience these services.** In collating this information from rich qualitative studies, the larger aim of this paper is to give service providers insight into how to improve the delivery of their services and maximise their participants' well-being.

3.2 Methods

We used a scoping review methodology, which is well-suited to exploring the scope of research activity [1, 2], particularly for an emerging body of research about a poorly-defined construct, which this appeared to be. We used the five stages proposed by Arksey & O'Malley [2]: 1) identifying the research question; 2) locating relevant studies; 3) selecting appropriate studies; 4) charting the data and 5) collating, summarising and reporting the results.

We used the search strategy described in Chapter 2, but selected studies using different inclusion criteria. Studies needed to include people with SCI of any cause or level, and of any age, but could also include people with conditions other than SCI. Included studies needed to relate to well-being, with well-being (of any definition) being an aim of the service or research, or linked to the reported outcomes. Because we wanted to explore how rehabilitation can affect well-being, we included studies that reported mostly negative impacts on well-being. We were guided by the World Health Organization's definition of rehabilitation as a "*set of interventions needed when a person is experiencing or is likely to experience limitations in everyday functioning*" aiming to enable "*individuals of all ages to maintain or return to their daily life activities, fulfil meaningful life roles and maximize their well-being*" [3]. We included studies in which participants discussed such a service, including services provided outside of an inpatient rehabilitation setting, or conducted by non-professionals. One area of contention was whether adapted sport should be considered a rehabilitation service: we included studies that involved entry-level adapted sports, but not elite sports. Included studies needed to have employed a qualitative methodology.

A flowchart of study selection is shown in figure 3.1.

We extracted data related to each research aim, and used reflexive thematic analysis to identify themes, using the methods described by Braun & Clarke [4, 5, 6].

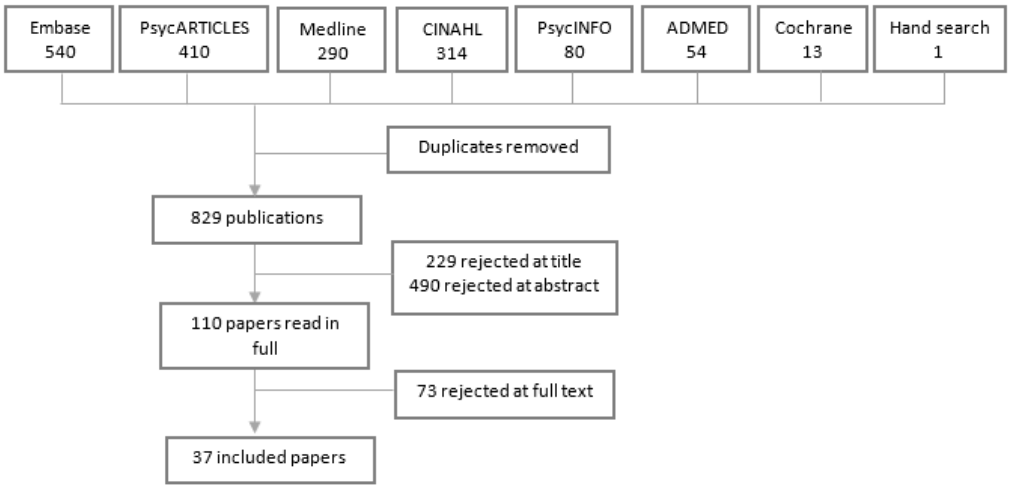

Figure 3.1

Flowchart of study selection

3.3 Results

Research aim i): examine the extent and nature of qualitative research related to well-being programs for people with SCI

Study characteristics are described in Appendix D. Of the 38 included studies, 28 used a solely qualitative methodology, one was a systematic review of qualitative studies, seven reported both qualitative and quantitative results of a mixed-methods study, and two reported only the qualitative results of a broader mixed-methods study. The quantitative component of mixed-methods studies mostly involved a single cohort pre-post design (n=5), and only one mixed-methods study involved a randomized controlled trial.

Four of the studies recruited people with other conditions, in addition to people with SCI. These other conditions appeared to all cause long term physical disability. Eight studies exclusively recruited people with tetraplegia; the other studies had a mix of people with paraplegia and tetraplegia (n=20), or did not report level of injury (n=9). Mean time post-injury in the studies was less than one year (n=1) 1-2 years (n=3), 3-5 years (n=5), 6-10 years (n=7), 11-15 years (n=5), more than 16 years (n=3) or was not stated (n=13). All the studies

involved adults, and no paediatric studies were found. Three of the studies included interviews with family members and health professionals in addition to people with SCI. The majority of studies were conducted in USA (n=14) and Canada (n=9), with other studies conducted in Australia (n=5), Ireland (n=3), Sweden (n=2), UK (n=2), Italy (n=1) and Switzerland (n=1).

Quality appraisal findings are reported in Appendix E. The most common methodological issues were methods (e.g. interview guide) not being made explicit, no discussion of data saturation, and a lack of reflection of how researcher biases may have influenced design, recruitment and analysis. Most studies did not report ethical, methodological or recruitment issues, which may have been because such issues did not arise.

Research aim ii): describe how well-being is conceptualised in these studies, and whether/how intentional design for well-being was used

The term 'well-being' was used in 16 of the included studies, but the most commonly used term was quality of life (n=21). Other terms used that appeared to relate to well-being included life satisfaction (n=5), social well-being (n=5), physical well-being (n=4), psychological well-being (n=4), subjective well-being (n=3), mental well-being (n=2), emotional well-being (n=2), flourishing (n=2), health-related quality of life (n=1), psychosocial well-being (n=1) and overall well-being (n=1). However in the majority (n=31) of the studies these terms were not defined. Some authors used multiple terms (e.g. 'well-being' and 'quality of life') and these mostly appeared to be used interchangeably.

Of the studies that defined well-being (or quality of life), four listed a broad range of well-being elements, relating to physical functioning, psychological/emotional resources and state, social functioning, independence and participation, and environmental accessibility [7, 8, 9, 10]. One study defined quality of life as the gap between desired and actual achievements [11]. Another defined quality of life using the World Health Organization's broad definition of health [12].

Some studies focused on a specific phenomenon they linked to well-being, including: occupations and meaningful activities [7, 13, 14, 15, 16], physical activity [7, 17], adaptive sports [18], leisure activities [17, 19, 20], peer mentoring [21, 22], goal-setting ability and self-efficacy [13, 23, 24], employment [12, 25], computer/IT access [13, 26], coping [27, 28,

29], choice and control [20], autonomy [30], social support [31, 32], social participation [33], music [33], and use of environmental control systems [34, 35].

Research aim iii): describe specific activities, timing and context of rehabilitation services related to well-being

Service activities are described in Appendix F, and the timing and context of services are shown in Appendix G. A broad range of service types were studied, carried out by a range of disciplines. We categorized the services based on who delivered them: adaptive recreation and sport providers (n=6), peers with SCI (n=4), nurses (n=4), occupational therapists (n=4), an occupational therapist and social worker (n=1), assistive technology services (n=4), physiotherapists (n=4), exercise trainers (n=3), vocational consultants (n=2), various rehabilitation professionals (n=2), a music therapist (n=1), a music therapist and social worker (n=1), and a surgeon (n=1). Most services were delivered by a single profession, although presumably some of these services were part of a broader multidisciplinary program. Two studies described a multidisciplinary service.

Services were often only described in general or vague terms, although mixed-methods studies tended to include a more detailed description of specific intervention activities. While a range of disciplines delivered the services, we have identified and categorised activities that were common to the services, including: structured education programs (e.g. workshops), facilitating engagement in occupations and activities (e.g. skills training, adapting activities, escorted outings, group activities), facilitating access to assistive technology (e.g. exposure, prescription, loan, training, modifications), psychological and emotional support (e.g. coaching, training, goal setting, goal pursuit, support groups), formal and incidental peer support and mentoring, addressing body function (e.g. mobility training, breathing training, electrical stimulation), liaison (e.g. integrating program into general rehabilitation, referral to other organisations), nursing care and surgery.

Research aim iv): explore how people with SCI perceive and experience these services

Valued aspects, limitations and perceived outcomes of the services are described in Appendix H.

Valued aspects included positive expectations of service providers, which raised the expectations of people with SCI about what was possible: "*She just kind of conveyed this*

feeling to me … that I was going to be able to do just whatever" [16] p.153. The personal characteristics of service providers were also important in facilitating a positive, supportive environment, and valued staff attributes included respect, recognising dignity and equality, warmth and friendship. "*she was so reassuring and she was so caring and so pleasant, and there to tell me, okay, I – I'm not alone*" [25] p.188. Peers with SCI were another source of positive expectations and hope: *"…opens your mind up to all the things you can do and the way that you can get around it*" [21] p.1980. Peer support (whether formal or incidental) was also valued for the connection, belonging and understanding brought about by interaction with people in a similar situation: "*It's a great way to have a bit of camaraderie and a feeling of group, a sense of being in a group or a community*" [33] p.241. People with SCI valued long term opportunities for continued gains and improvement (in a range of areas), even if these gains were seemingly small. They also wanted opportunities to challenge themselves and take risks, although the right level of challenge was important: experiencing too many difficulties was confronting and discouraging. Services that facilitated participation and autonomy in meaningful occupations were highly valued, including in both pre-injury and new occupations: *"…makes you feel good because it does feel the same as before [the accident]*" [33] p.240. Learning new skills helped improve autonomy, and people with SCI wanted practical and applicable information that enhanced this learning. They also valued having their own problem-solving skills recognised and enhanced: an important way to gain autonomy in the long term. Their own efforts, character and determination were also crucial: *"… what helped me the most was my own will to be independent*" [36] p.6. Connections with others were important, and services were valued when they facilitated interaction with peers, and provided opportunities to engage with significant others: "… gives me an opportunity to do something together that we both like" [28] p.152. People with SCI noted the contribution of supportive family and friends in facilitating participation in valued activities, and support of others (e.g. transport to clinics) was often crucial for being able to participate in services.

There appeared to be an important balance between setting positive expectations and facilitating achievement early after injury, while not overwhelming the person during the acute stages post-SCI. People with SCI expressed varying perspectives about preferred timing of services, and flexibility in delivery appears important (although not always provided). Discharge home was a challenging milestone, and people with SCI valued services in preparation for, and soon after, discharge. Community-based services provided soon after discharge provided structure, routine, and an opportunity to maintain or continue gains made

in an inpatient setting "*I am feeling like I am accomplishing something throughout the day*" [7] p.34. There did not appear to be a time that was too late to provide services, and gains were valued even many years post-SCI. However, opportunities to engage in services at this stage were rare. The physical environment of services was important to people with SCI. Opportunities to be in (or at least see) nature and the outdoors were highly valued: "*you get excited about nature, clouds and the currents …*" [17] p.42. An unpleasant, inflexible, impersonal hospital environment had a negative impact on well-being in one study.

Overall, people with SCI reported few limitations of the services themselves, but a common theme was a lack of opportunity to participate in well-being-related services. Some of the services were provided only during the study period, and people with SCI often reported they wished the services were longer or more available outside of a research context. Many people with SCI reported a lack of opportunity for accessible activities that promote well-being, particularly in a community setting or many years after injury. When suitable services were available, travel costs and logistics to access the services were often challenging or prohibitive. People with SCI were often made aware of community-based services by peers or through their own research, and there was a perceived lack of awareness of such opportunities amongst health professionals: "*But it seems there really isn't an awareness when you have to explain what you want and what you're going to do and they just look at you like 'really, you're going to do what?*'" [17] p43. Although a number of studies described services provided during inpatient rehabilitation, some people with SCI reported a lack of priority for such activities during their own early rehabilitation journey. Low expectations of health professionals and inflexible service delivery were limitations of inpatient rehabilitation reported by some study participants.

People with SCI reported a range of service outcomes, which related to both psychological and subjective well-being. Participants reported improved confidence and self-esteem, coping strategies, motivation, sense of identity, and normality. Improved mood, positive emotions, and sense of gratitude were also reported. "*I feel much more alive. Enlivened and engaged with what I'm doing"*[33] p.241. "*It just helped to show us that there's still a hell of a lot that we can be thankful for*" [29] p.9. A commonly reported outcome was increased hope, which participants felt was especially important to their well-being: "*I think that was the hope that actually even helped me to get better*" [25] p.188. People with SCI reported improved independence and autonomy in performing occupations, which brought about greater control choice, privacy, and flexibility in their day-to-day lives. Greater autonomy enabled people

with SCI to contribute to others and perform valued roles, and reduced their sense of burden on others, frustration and 'hassle': "*the more independent I will be and the more I can do for others … that's gonna make me feel so much better with myself*" [11] p.101. The subjective experience of performing occupations (of any kind) involved a sense of fun, enjoyment, flow, engagement, meaning, purpose, freedom, escape, diversion and relaxation: "*You create some endorphins, and you've got your circulation working better … it's really had an effect on my whole outlook.*" [18] p.509. Increased autonomy in one occupation often had a flow-on effect, with participants often setting new goals, trying new activities, and having greater motivation to participate in other rehabilitation activities: "*It gave me the motivation to stay with the rest of the therapy*" [28] p.152. People with SCI also reported improvements in relationships and a sense of belonging, as services enabled them to participate more in the community, provided new social contacts, and facilitated a sense of belonging. Perceived outcomes of a sub-set of the included studies are explored in more detail in a separate publication [37] [Chapter 2].

3.4 Discussion

A contribution of this scoping review is the synthesis of qualitative research from a variety of disciplines, which readers may not have encountered otherwise. People with SCI reported well-being outcomes from a range of service types, reflecting the multidimensional nature of well-being and the fact that its determinants are relevant to a range of disciplines. Well-being may be addressed from different perspectives, and it is important for service providers to recognise their own potential to influence well-being, as well as the contribution of other team members. Improving well-being can and should be a common aim, which may require rehabilitation professionals to broaden their focus beyond the discipline 'silos' that may still exist in rehabilitation.

We argued earlier that a more explicit focus on well-being may maximise the impact of services on the lives of people with SCI, echoing calls from prominent rehabilitation researchers [38, 39, 40]. One of our aims was to explore how well-being was conceptualised in the included studies, and whether the services were intentionally designed to address well-being. Most authors did not define well-being (or related term). In several studies, improved well-being appeared to be a finding rather than an aim of the service. Four studies included a

broad definition of well-being that appeared to be a helpful framework for service design and evaluation. However, we were not able to determine whether or how well-being frameworks were used to design the services because information about service design was rarely provided, possibly due to word restrictions. The question remains, does intentionally designing services to address well-being elements produce greater impacts on well-being? Or is well-being so broad that services can impact it without intentionally aiming to do so? Further research is needed to shed light on these questions, which our review seems to have highlighted. Such research may include evaluation of programs that deliberately aim to address well-being by targeting its determinants. A review of the quantitative literature would also be helpful, particularly in shedding light on the question of whether a more explicit focus on well-being produces greater well-being outcomes.

This scoping review has synthesised important insights from people with SCI about valued aspects of services. These insights may inform service design and evaluation. A key finding was the importance of the characteristics and approach of service providers, including respect for the autonomy and dignity of people with SCI. Services that facilitated autonomy and control were valued, and these influenced well-being in a number of ways. People valued having their own skills and strengths recognised and encouraged, such as problem-solving skills. These skills are important for self care and self-management after SCI, an important way people with SCI can manage the impact of their condition on well-being [41]. Psychological strengths and resources are an important well-being determinant [37, 42, 43]. Interestingly, we did not find any qualitative studies from the psychology literature. Such studies may provide valuable insights about how psychological strengths can be identified, recognised and nurtured to promote well-being. Recognition of the importance of the skills and behaviours of people with SCI is congruent with the literature about self care and self-management

Another key theme was the importance of positive expectations. Service providers who promoted high expectations and facilitated hope influenced well-being by countering the low expectations people may have initially held about the possibility of a good life. Hope was also important to people with SCI, and increased hope was a valued outcome of some services. Hope and positive expectations did not appear to relate to a potential cure for SCI (although some participants discussed physical activity as a way of taking advantage of a future cure). People found hope in a good life in the absence of a cure, and despite the presence of significant impairment. This finding is consistent with the social model of

disability; that environmental factors are a vital influence on well-being [44, 45, 46]. However, well-being can also be influenced by body functions, and people with SCI reported important well-being outcomes when body problems such as pain and fatigue were addressed. They also reported many persistent environmental barriers that limited their ability to participate in well-being promoting activities and services. Spinal cord injury challenges simplistic distinctions between the medical and social models of disability, revealing how well-being is embodied. It is always a product of the complex interplay between bodily function and the social environments [47, 48].

The importance of interaction with peers with SCI was another key theme, and this related to the theme of positive expectations. Being exposed to the life of a person with a similar injury raised expectations about what was possible. Peer interaction was also an important source of social contact, belonging and understanding. Several of the studies involved formal peer support services, and these services appear to strongly influence well-being, particularly soon after SCI when a person may be unsure about what life may hold. However peer contact was also provided incidentally by many of the services, and facilitating informal peer interaction may be an important way service providers can influence well-being. Although beyond the scope of this paper, this peer emphasis suggests spinal cord injury services should give more thought to the importance of coproduction in the design and delivery of programs [49, 50].

There appear to be limited opportunities for people with SCI to participate in services to improve well-being, particularly in the community or many years post-SCI. Rehabilitation services often end within several years of injury, with longer term follow-up often focusing on managing problems like pressure injury and replacing old equipment rather than improving well-being. Interestingly, the majority of studies in this review involved community-based services, with several provided to people more than 20 years post-SCI. These studies contributed valuable insights from people many years post-injury. However, it appeared that many of these services were provided for the purposes of research, rather than being available generally or in the long term. Several participants reported a lack of services available to them, or that they wanted services to be available beyond the study period. Ideally, services for people with SCI would promote sustainable change and autonomy, so that they are not required long term. Presumably most people with SCI would prefer to become independent of specialised services if possible, although ongoing body problems such as pain, and the effects of ageing with SCI, may necessitate some long term specialised input. But people with SCI did value services provided to them many years post-injury, and

reported well-being outcomes from such services. Some of these services involved learning a new skill e.g. a breathing technique, and trialing new assistive technology. If similar services are not provided outside of a research context, people with SCI might be missing out on exposure to new techniques and technology, especially when they are no longer involved with a formal rehabilitation service. Several of the community-based services were ongoing, involving adapted sport/exercise and recreation. It was clear that many people with SCI required long-term and specialised services to engage in these activities, presumably due to their needs (e.g. access requirements) not being met by mainstream services. However, gaps in such services were also reported, with participants reporting lack of services in their area, or limited program resources.

These gaps may reflect the significant funding and insurance limitations that constrain the provision of services to people with SCI. SCI service providers may need to be creative and resourceful in order to offer well-being services outside of a traditional rehabilitation context. Research about the feasibility and outcomes of such services may also expand our understanding of how well-being can be improved across the lifespan of people with SCI.

3.5 Limitations

The studies in this review predominantly included the voices of people with SCI from USA and Canada, and findings may most strongly reflect the intervention context in North America. We did not include studies published in languages other than English, so may be missing the perspective of people from non-English speaking countries, whose experiences of SCI, services and well-being may differ from those in this review. Some studies included people with a range of conditions, and we were not able to distinguish which findings specifically related to participants with SCI. However, services are not always limited to people with SCI, and further research about whether and how services can impact well-being of people with a range of conditions would be worthwhile. Our key finding about peer support would also be interesting to explore in the context of these broader services, where the concept of 'peer' may extend to people with different diagnoses and conditions.

Methodological issues in the included studies may have impacted our findings. Some studies did not report many negative experiences or outcomes, and the absence of interview guides

meant that we were not always able to determine whether this information was sought. The background and position of researchers is a potential source of bias, and for many studies we were unable to determine if and how biases were identified and managed. There did not appear to be much (if any) contribution of people with lived experience of disability as co-researchers [51]. The absence of this perspective may have been a source of bias in design and analysis.

Our own backgrounds and perspectives have influenced design and analysis. SC is an academic with spinal cord injury, who has researched factors that affect the flourishing of people with disabilities. MV and BS have an occupational therapy background, which contributed expertise about (and a bias towards) occupation-related findings. MV's research is characterised by large-scale collaborations that cross disciplines and sectors and that privilege the voices of those typically marginalised within research. The distinguishing feature of this research is our intentional application of inclusive models and participatory methodologies to bring people who do not normally work together to solve complex problems through cross-sector collaboration and co-production.

3.6 Conclusion

This scoping review has identified qualitative studies from a broad range of disciplines, who seek to address well-being from a variety of perspectives. A strong conceptual framework of well-being is mostly lacking in this body of literature, despite calls for a more explicit focus on well-being in rehabilitation services. Despite this, people with SCI reported a range of well-being outcomes. Valued aspects of services included a positive and empowering approach of service providers, the opportunity to participate in and gain autonomy in valued occupations, and peer support and interaction. However, many people with SCI reported a lack of such services available to them, particularly after inpatient rehabilitation.

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3.7 Contribution of the scoping review to the thesis

The scoping review enriched the conceptual understanding of well-being, including validating the decision to use 'well-being' as the central term given its widespread use in the field. It reinforced the relevance of broad definitions and frameworks that incorporate multiple influencing factors, which some studies adopted and made explicit.

The programs sometimes targeted well-being specific influencing factors, implying some degree of intentional design in this literature. The finding that well-being can be targeted from multiple angles, through a range of service activities, and across disciplines validated the choice to study a broad, multidisciplinary program that targets well-being in non-traditional ways as a case. The review also informed the case description in Chapter 5 by providing insights about terminology, the need to capture a wide scope of program activities (e.g., liaison), and the impact of less formal elements like peer interaction.

At the same time, the review suggested that many programs may influence well-being only incidentally, reinforcing the need to investigate a program intentionally designed to do so. In the discussion chapter, I examine the findings through the lens of well-being theories, and consider whether the program's holistic design may have contributed to the strength of the impacts.

Synthesising valued aspects of services also identified themes to explore further through the case study. The findings reinforced some of the systematic review themes: the value of engaging in occupations, learning from peers, and accessing services both early and later post-SCI. Additional themes identified by the scoping review include autonomy, the influence of well-being enhancing environments, the need to manage and promote risk, and the potential of co-designed programs.

Finally, the scoping review highlighted barriers and limitations that affected services in this literature. This theme is taken up by the case study, which explores how barriers in the program's context influence its approach and impacts, and by the discussion chapter, which considers persistent barriers in the thesis context.

CHAPTER FOUR:

CASE STUDY METHODOLOGY AND METHODS

4.1 Stages of case study research

This chapter builds on Chapter 1, which introduced case study methodology. Design of the case study followed the stages proposed by Stake [1]; the first of these stages (conceptualising the topic) was outlined in Chapter 1. I now describe how I approached the subsequent stages:2) selecting and defining the case and its boundaries, 3) data collection, interpretation and analysis, and 4) reporting – acknowledging the iterative nature of case study (and qualitative) research means these stages overlap [1, 2, 3].

4.1.1 Selecting the case

Case study research is defined by its focus on the singular and particular, so selecting the case is a foundational and influential step [1]. This decision is informed by the purpose of the research: intrinsic case studies often arise from a researcher's genuine interest or curiosity about a specific case, while instrumental case studies are chosen for their ability to illuminate a broader issue [4]. Both purposes applied for this study. Pragmatic considerations also influenced the decision [1, 5]: existing connections within the organisation and the location of the site made the program accessible, facilitating the extensive and on-site data collection required.

4.1.2 Defining the case

The Sargood on Collaroy program was defined as the *unit of analysis* for this case study: the 'bounded system' that is being studied as a case [1]. This encompassed the facility, activities, human and material resources, systems, procedures, and policies. The *case context* included the physical, institutional, policy and socio-historical contexts surrounding the

program, considering the external factors influencing program design and implementation [2, 6, 7]. *Temporal boundaries* – the timeframes in which the case is studied [7] – were established to ensure data collection covered an adequate period of time and captured a range of activities during different seasons. Data were collected intermittently over a three-year period, beginning approximately three years after the program's establishment, with observations conducted at various times of the year to account for seasonal variations in activities [1, 3].

4.1.3 Data collection

Ethical approval was obtained for the study through the University of Sydney Human Research Ethics Committee (Project number 2019/989). Ethical issues that were reviewed and informed the design included potential for coercion during recruitment, identification of participants, and researcher safety.

A defining feature of case study research is collecting data from a range of sources to gain a deep and holistic understanding of the case [5, 8]. The multiple data sources also served as a means of triangulating the findings and identifying areas of alignment and divergence [1, 5, 7].

An important consideration was my position as the researcher in relation to the case. Case study research is naturalistic, aiming to minimise interference while still acknowledging the researcher's influence on the data [1, 9]. A key challenge during data collection was balancing proximity and non-interference. For example, during observation I sought to minimise disruption while avoiding the kind of detachment that might convey scrutiny or coldness. This raised dilemmas – such as whether to engage in conversation during activities or accept an invitation to a social activity afterwards.

Some interpretation occurred during data collection rather than these being separate, sequential stages [1]. For example, while conducting observations I recorded detailed information but also noted my reactions and impressions. These impressions informed my early interpretations of the data, which were developed further during discussions with my supervisors. These early interpretation guided subsequent data collection as I sought opportunities to explore them further – through conversations with program staff or by

arranging to observe another session, for example. This iterative, integrated process allowed me to explore and develop ideas and refine my understanding of the case over time.

Multiple perspective interviews

I interviewed multiple stakeholders about the program: a characteristic method in case study research for understanding a range of perspectives, and to obtain information that cannot be directly observed or found in documents [1, 10]. Recognising perceptions differ between individuals, I sought to interview people with SCI who participated in the program, a full range of program staff, and its leaders. I also hoped to interview significant others of people with SCI who had engaged in the program too, or might have been impacted by it.

Interviews provided insights into stakeholder interpretations and experiences – particularly valuable for exploring the subjective questions central to the study. I also sought to uncover *emic* issues: topics important to stakeholders that may not have been identified by the researchers [1]. I therefore used a semi-structured interview format, involving open-ended questions on key topics, and the opportunity for interviewees to elaborate and bring up other topics as relevant [11].

An interview guide (Appendix I and J) supported this semi-structured approach. The questions in the guide targeted the topics of interest identified in the earlier stages of research. Interviews were flexible, with questions asked in a natural order rather than adhering strictly to the guide. Active listening and probing were used to clarify and explore responses. Participants were given an opportunity to add or elaborate on any topic at the end of the interview. Interviews typically lasted 45-90 minutes and concluded when all key questions were addressed and participants had shared everything they wished to.

The approach to recruitment was based on the most convenient, practical and ethical means of promoting the study to the intended stakeholder interviewees. Participants with SCI were recruited via study flyers and posters displayed at the facility, and those interested contacted the research team via email or an online form. Staff were informed about the study via email and contacted the researchers directly if they wanted to participate. A person in a governance role known to the research team was invited to participate via email. We encouraged interviewees with SCI to invite significant others to be interviewed, although this recruitment method did not result in any new participants. Details of recruited participants are presented below.

Participants were provided with a Participant Information Statement (Appendix K) and consent form (Appendix L) and gave consent by signing the paper or electronic form, or via recorded verbal consent. Interviews were conducted face-to-face, by telephone or via video conferencing, depending on participant location and Covid-19 restrictions, which were in place for much of the data collection period.

Interviews were audio-recorded and transcribed. Transcripts were reviewed alongside the recordings to ensure accuracy and to gain an overall understanding of the data prior to analysis.

Interviews: People with SCI

Twelve people with SCI were interviewed. Demographic details (using pseudonyms) are shown in Table 4.1, with proportions of ages, level of injury, time since injury and funding in Figure 4.1. Eight participants were male (67%) and four were female (33%). Most participants had stayed at the program as 'guests', usually multiple times. One had not stayed overnight but regularly engaged in the community program as a gym member.

Interviews: Staff

Twelve staff members were interviewed, with the following roles: Manager (3), receptionist (2), occupational therapist (1), adaptive recreation specialist (2), exercise physiologist (1), spinal clinical nurse consultant (2) and guest attendant (1). This sample represented all key staff roles.

I also interviewed a person with SCI who has held various governance and advisory roles, including as an advisor and ambassador during its inception and design, and governance roles in two of the organisations providing program oversight. I've attributed his quotations to the perspective he was speaking from at the time (i.e. program advisor, board member). He also shared some insights as a guest of the program; when quoting him from that perspective, I used the pseudonym 'Ben'

Table 4.1

Demographics of Interviewees with SCI

Pseudo-nym	Age	Gender	Level of injury	Time since injury	Funding	Program involvement
Angela	60s	F	Paraplegic	5-10 years	NDIS	Multiple 1 night stays
Sian	30s	F	Tetraplegic	10-20 years	NDIS	5-6 stays of 7-10 days
Stewart	50s	M	Tetraplegic	5-10 years	icare	Multiple 1-2 night stays
Alan	70s	M	Tetraplegic	1-2 years	Self	Community program: gym and EP
John	40s	M	Tetraplegic	20-30 years	NDIS	5-night stay
Rob	50s	M	Paraplegic	10-20 years	icare	10 stays of 3-7 days
Adam	20s	M	Tetraplegic	5-10 years	icare	12 stays of varying lengths, including several courses
Ryan	70s	M	Tetraplegic	40-50 years	Self	15-20 stays of up to 3 weeks, Weekly EP
Lisa	50s	F	Paraplegic	3-5 years	NDIS	2 stays: during home modifications and for a course
Tom	50s	M	Paraplegic	20-30 years	NDIS	5-10 stays, including facilitating 2 courses
Marcus	20s	M	Tetraplegic	3-5 years	icare	3 stays
Carrie	50s	F	Paraplegic	30-40 years	NDIS	1 stay

NDIS: National Disability Insurance Scheme; icare: motor vehicle and workplace accident insurer; EP: Exercise physiologist; MVA: Motor vehicle accident

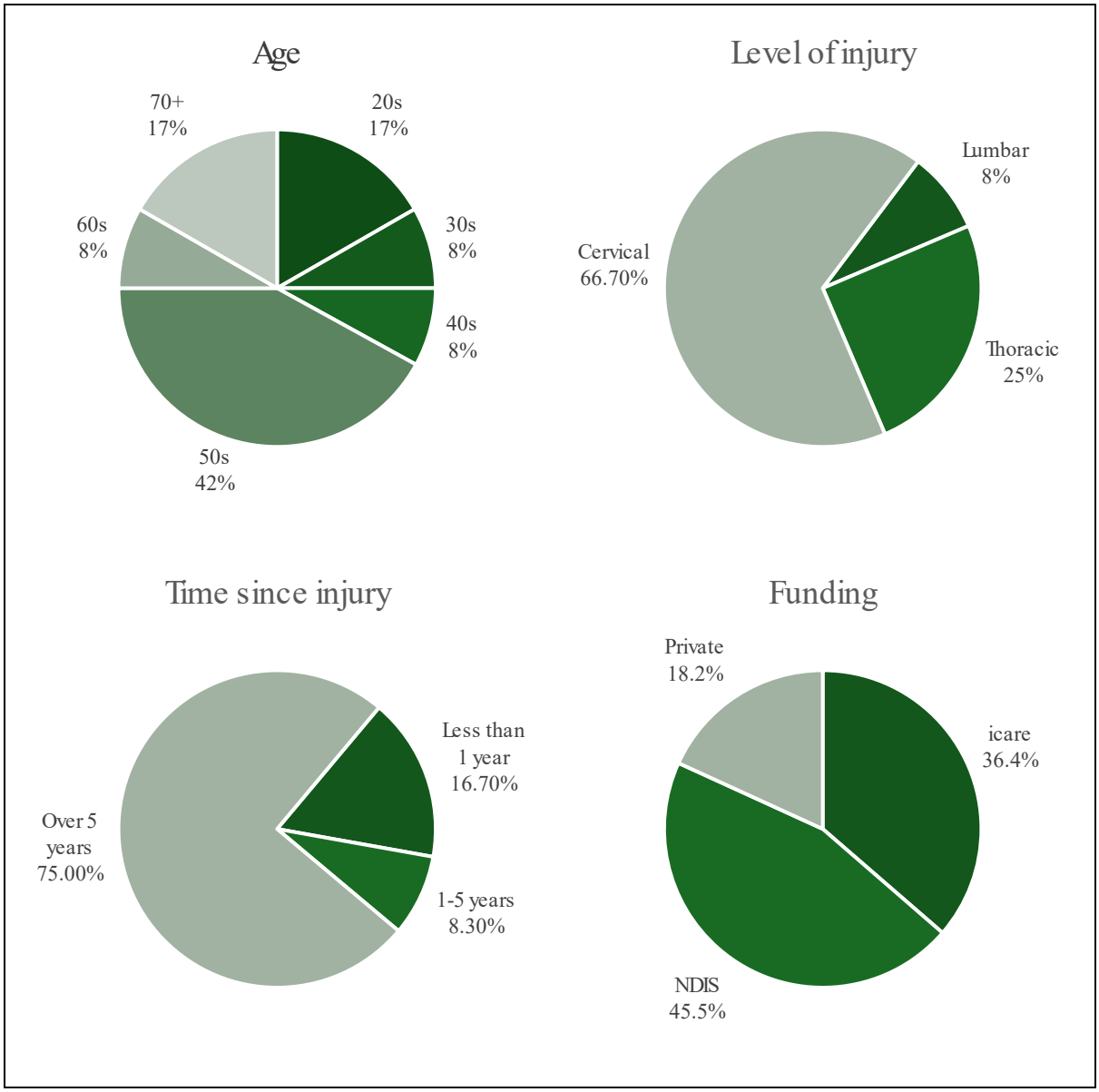

Figure 4.1

Breakdown of Demographics of Interviewees with SCI

Document review

I reviewed some key documents in the early design phase to help define the case and its boundaries, and establish areas of interest for interviews. The well-being focus was also confirmed by these documents, which indicated well-being was a central focus of the program, and described significant well-being impacts. Documents reviewed in this

planning phase included web pages, blogs from previous guests, social media posts and an internal evaluation framework.

I then used document review as a primary data collection method. Reviewed documents are listed in Appendix M; these included internal program documents, an intranet site, the websites of the program, stakeholders and related organisations, annual and financial reports, booking form data, media articles, social media, third party blogs, policy documents and local government publications.

The documents served as triangulation for data collected in interviews and observation, and provided additional information not easily observed or discussed in interviews [8, 11]. Policy and procedure documents offered insight into decision-making and program delivery. Website testimonials, social media posts, blogs and media offered additional perspectives of people with SCI, and – importantly – their significant others, whom I was unsuccessful in recruiting for interviews. Documents also provided additional and historical perspectives about program design (e.g. from former staff members), the perspectives of other stakeholders (e.g. governing bodies and benefactors), funding policies (e.g. insurer documents) and other organisations in the program context (e.g. local government projects).

Management staff provided permission and access to internal documents. They identified suitable documents after I explained the scope and purpose of the document review, and I also requested specific documents as the need arose. It is likely other internal documents were not offered, such as those deemed irrelevant or commercially sensitive. As such, the internal documents reflect the organisation's selection of materials to share, and what I thought to request.

I sought publicly available documents from the websites of key stakeholders, including the websites of the program, the larger organisation that administers it, and a governing body. I reviewed all pages of these websites. I also systematically searched for on-line documents using the Google search engine, using the search term “Sargood”. This yielded ten pages of search results, and we screened all results for suitability. Due to the unique nature of the search term, most of these on-line documents were relevant and included in our review. I followed links from these websites to identify additional on-line documents. I conducted this search again towards the end of data analysis to check for new documents.

I reviewed the program's social media sites (Facebook and Instagram), including text, photos, videos and comments. I also searched these platforms using "Sargood" as a keyword and hashtag to identify posts made about the program by other accounts. I followed these accounts to keep abreast of new data.

I also conducted targeted searches of stakeholder websites to identify relevant information that may not have been captured by the search engine (e.g. disability action plans), to locate key documents that were expected to be available but were not in the search results (e.g. annual reports), and to explore findings from other data sources.

Most documents were downloaded or saved in pdf format for coding and analysis. I watched all on-line videos that appeared relevant from the title or description (e.g. news clips), and took notes and transcribed pertinent quotations. I returned to some of these videos when I recalled they had discussed one of the themes, and transcribed additional excerpts related to these. This was a pragmatic, but admittedly unsystematic, way of using video data. The excerpts were coded together with the other document data.

An exception to the coding strategy was the program's intranet site: a substantial and important source of procedures and training materials that could not be downloaded for coding. I gathered key information and noted analytical observations as I accessed the site, and an excerpt from these notes is included in Appendix N to illustrate this approach. I recorded key information about program elements and resources, such as equipment lists, and sought specific details to confirm and extend what I had gleaned from other sources. I also noted my impressions of program design and delivery, including the specialisation and complexity evident throughout. Later in the project, I re-examined the site to validate the findings and obtain more detailed information about important themes, such as risk management.

Observation

Observation added to the "richness of detail, time, place, multiple happenings and experiences" [2] p556, as I built a deep understanding of the case. This richness is a hallmark of case study research [1], allowing for a more detailed and nuanced understanding of the program and its context. Observations also served as another means of triangulation [1], and I sought to observe activities that would both enrich and challenge the data gathered through other methods.

Program managers helped identify relevant and data-rich opportunities for observation, and I also strategically sought opportunities that would fulfil the above purposes. For example, I observed a snorkelling outing after identifying water sports as particularly impactful.

I observed a range of program activities including team meetings, recreation sessions and outings, individual therapy and gym sessions, group demonstrations, courses, and interactions in certain spaces e.g. the common kitchen area. I observed all areas of the facility (including guest rooms, common areas, outdoor areas, staff and meeting rooms, games and activity rooms) and important locations in the local context (e.g. the surrounding suburb and recreation activity sites), noting their features. I also examined program resources, such as equipment storerooms.

I made detailed notes during and after the sessions, which recorded my observations and impressions. I typed up the handwritten notes after each session, which was an opportunity for further reflection [11] as well as digital conversion. These notes were then coded alongside the rest of the data. I was grateful for the level of detailed throughout the data analysis process, which enabled me to explore the themes that emerged. In addition to coding and analysis, I drew directly on the observation notes to generate vignettes, which are discussed under ‘reporting’ below.

On reflection, the document review could also be considered a form of observation, as it involved examining images and videos that complemented on-site observations and enriched my understanding. However, I did not record formal observation notes during those instances, which in hindsight limited the depth of analysis these materials could have contributed. In a more expansive design, participatory approaches like photovoice [12, 13] could have also contributed observations from the perspective of other stakeholders. Given case studies’ emphasis on multiple data sources and perspectives, using photovoice as a structured visual observation within case-study research would be worth further exploration.

4.1.4 Data analysis

The overall approach to analysis was reflexive thematic analysis as described by Braun & Clarke [14, 15]. Its flexible and iterative nature was a good fit for case study research; it supported analysis of, and triangulating between, three data sources and multiple perspectives. The flexible, reflective approach allowed me to categorise the data, identify

patterns and relationships, and interpret themes in a way that reflected the complexity of the program and methodology. Rather than trying to eliminate bias or pursue objectivity, it provides a framework for acknowledging – even embracing – the perspective of the researchers throughout the analysis and interpretation process [14, 15]. The key is critical reflection and detailed, transparent reporting: aspects I therefore emphasise in the sections that follow. All data were analysed using this inductive, iterative approach. Separate rounds of deductive analysis were also conducted to address some of the research questions, as described below. Although coding and interpretation were integrated throughout the data analysis process, reflecting the iterative nature of reflexive thematic analysis I discuss them separately below for simplicity.

Coding

I read each transcript in full two times, to check for transcription errors and get an overall sense of meaning. Data were then coded using NVivo software [16]. The large amount of data from various sources (interview transcripts, documents, and observation notes) was imported into a single project for coding. To support this approach, I created separate coding categories that corresponded to each research question and coded all three data sources within this structure. There was some overlap between the categories, like when an interviewee described an outcome and how the program contributed to it in the same anecdote. Excerpts like these were coded in both categories, with the full quotes retained to provide context.

I first coded the data using an inductive strategy: creating codes throughout the process to represent key themes and concepts, then refining and organising them into a hierarchical structure. I dragged and dropped relevant text segments into these codes and sub-codes. For example, I coded the text segment, “I’m already sold, but it's things like that: the personability of it, or just how friendly the GA's are. Some of them are super considerate” under the sub-code *staff attributes and approach*, which was categorised under the code *staff*. This approach allowed me to efficiently categorise the data and identify patterns and relationships within it. I expanded, combined or removed some codes as clear themes and patterns emerged.

Developing the theory of change also demanded a more deductive, structured approach to analysis, which was adopted in a separate round of coding. [7, 17], The *theory of change*

was used as an analytical framework [18, 19], where relevant concepts such as *aims* and *assumptions* formed the top-level codes under which I categorised information about the program's design and delivery. This analysis informed and provided structure for the rich program description, including the program logic. I also examined how this deductively-analysed data related to the inductive findings, such as how the program elements related to the reported outcomes.

Interpretation

As discussed above, interpretation occurred throughout the research process, including during data collection. But it became most prominent as I developed the coded data into themes, considered their meaning and implications, and explored relationships between them. The approach was somewhat tailored to each research question.

For research question one, data analysis worked towards development of a *program logic* [20] and comprehensive description of each program component. This process involved identifying program components, such as intended immediate, intermediate and long-term outcomes, and examining how components fit together, such as how the intended outcomes relate to each other, and how the activities contribute to them [21]. At this stage, the analysis focused on detailing, categorising, and mapping relationships between components, rather than interpreting their meaning. The focus was on describing the program as it is intended.

The second research question was about reported outcomes. This question required an inductive approach, where I grouped common ideas and gradually refined the coding strategy and analysis to develop themes. I then explored relationships and alignment between the ideas, including between guest and staff perspectives, reported and intended outcomes, potential interactions or reinforcing effects among the reported outcomes, and how they contributed to the program's overarching aim of promoting well-being. This process enabled both an inductive identification of themes, a deep engagement with a range of data sources and perspectives [14, 15], as well as a more systematic interpretation of the reported outcomes in relation to the program logic.

Research question three, which explored how the program achieves its well-being outcomes, required deeper interpretation. *The theory of change* provided a useful guiding framework, as it seeks to create a map of "what a program seeks to do and how it seeks to do it" [21] p. 110. Consistent with this framework and the sub-questions, I identified *mechanisms* through

which outcomes were achieved, *assumptions* and principles underpinning these, *operational factors* influencing delivery, and *contextual* supports and constraints [20, 21]. Further analysis enabled me to explore the contribution of these aspects to the program outcomes and triangulate between data sources, such as whether the perspective of interviewees with SCI validated the assumptions made by program designers.

Writing the thesis developed the analysis and interpretation further: the task of expressing the findings clearly and ever more succinctly, and considering their order and structure, was another opportunity to refine their meaning, develop themes further, and connect ideas. Preparing abstracts and presentations promoted a leap forward in distilling the ideas and considering their implications for different audiences. Finally, the discussion chapter required a new level of interpretation, as I explored how the findings illuminated the *issue questions* raised by the background literature and reviews.

To support reflexivity and deepen the interpretative process [14, 15], I engaged in regular team discussions. These discussions were not aimed at eliminating bias, as Yin advocates [7]. They were instead guided by my epistemological standpoint (discussed below), and Stake's recommendation to use team discussions as an opportunity to think deeply about the findings and reflect critically on my assumptions and interpretations – recognising bias is inevitable [1, 10]. Each member of the research team brought their own unique perspective to the analysis, which enriched the interpretative process and helped identify themes that were most significant or meaningful in the context of the research questions. Following Stake's approach, we devoted more time to reflecting on and critically examining the stronger assertions and more important themes [10].

A distinctive feature of case study research, as opposed to other qualitative methodologies, is the use of multiple data sources and perspectives. Reflexive thematic analysis supported the analysis of, and comparison between, these sources and perspectives, as the data moved from categories to integrated, interpreted themes. The multiple data sources supported interpretation. By comparing and cross-referencing insights, I aimed to identify coherence in the emerging themes and assertions. Divergences between data sources were not viewed negatively but rather as a natural outcome of differing perspectives. These discrepancies were treated as valuable insights, prompting further interpretation to explore the underlying reasons for the disparities and their potential implications.

Quantitative analysis

Booking forms yielded a small amount of quantitative data about guest demographics, including ages, gender, level of injury and funding sources, which were relevant to the program description. Program staff provided this deidentified data from a two-year period in a Microsoft Excel spreadsheet, and the software was used to calculate means and percentages. Open-ended text from this spreadsheet (e.g. goals of the stay) was analysed in the same way as other documents.

4.1.5 Reporting

The findings of the case study are reported across five thesis chapters, which broadly align with the research questions. I followed the guidance of Stake and other proponents about the distinctive style for reporting case study research.

This includes the use of vignettes, which are designed to offer readers a sense of vicarious experience [1, 4] and illustrate key points through a narrative style of reporting. Anticipating the inclusion of vignettes, I asked staff interviewees to share stories that stood out to them or exemplified their perspectives. I also drew directly from observation notes to craft them.

The use of participant quotations is central to both case study and qualitative reporting [1], so I included these as much as possible. The reporting requirements of these methodologies posed challenges: to provide detailed and contextual information [2, 10], preserve participants' authentic voices and language [10] and represent multiple perspectives, while being succinct, avoiding repetition and maintaining privacy. To balance these considerations, I tried different reporting approaches and refined them iteratively. The final strategy I adopted is outlined below.

To maintain clarity and flow, I reported most quotations as concise 'snippets' within the text, while supplementing these with longer quotes that illustrated key points. Instead of reproducing several similar quotes to show a recurrent theme (my initial strategy that became repetitive and unwieldy), I explicitly noted, then summarised, ideas that were commonly expressed. I left participants' quotes unedited to preserve authenticity, even though this affected grammar at times (e.g. shifts between third and first person). I also retained the terminology used by interviewees or in documents (e.g. 'capacity-building',

‘independence’) when reporting the findings, including in the intended outcomes in the logic model. I explore how these terms were used in the subsequent findings chapters, and reflect on them critically in the discussion chapter.

The research questions guided decisions about which quotes to include and emphasise in each chapter. I prioritised the voices of interviewees with SCI about experiences of the program and its outcomes (Chapter 6), and drew more on staff perspectives when describing the program (Chapter 5) and developing the theory of change (Chapters 7-9). However, each chapter also considers alignment with other data sources, such as how guests experienced the program components described by staff.

I also incorporated the perspectives of people with SCI and significant others who shared their experiences online, though these sources carried less weight in data analysis and were less prominent in reporting. Social media posts were generally given precedence over website testimonials and media articles, as they are voluntary, uncurated, and reflect what people chose to share with their networks.

Recognising the source of a quotation influences its interpretation, I made the data sources explicit. I grouped in-text snippets by their source and identified them as a group (e.g. “staff provided additional insights about this principle…”) rather than repeating the source for each one. I provided a source for all longer quotations, attributing these to either a “staff member”, a specific staff role when this added necessary context, or the guest pseudonyms from Table 1.

Citing the source of documents needed its own strategy, to provide an ‘audit trail’ [11] while maintaining readability. While in-text quote snippets were identified as a group (e.g. “on-line testimonials”), I attributed longer quotations and specific details to the document they came from, using endnotes to distinguish these citations from literature references.

4.2 Epistemological standpoint

Underlying my choice and use of qualitative case study methodology are assumptions about the nature of knowledge and how we gain and make sense of it. This section outlines my

epistemological standpoint and theoretical perspective that influenced the study, alongside reflections on my personal stance.

Case study research can be conducted from different epistemological standpoints [2]: I adopted a constructivist understanding that meaning is created by those who experience the case [22]. This perspective also acknowledges reality is experienced differently between people and across time, which informed the decision to seek multiple perspectives and observe the program over an extended period. Constructivism shifts the power balance of who can hold and generate understanding [3] – and the research enabled people with SCI to contribute to the generation of knowledge about issues that affect them.

Constructivism also underpins the study's theoretical perspective – interpretivism – which influenced the use of qualitative methods. I was primarily interested in people's subjective experiences and the meanings they attached to these [5], and a constructivist, interpretivist paradigm was best suited to the research questions – although I acknowledge this stance would have influenced the kinds of questions I was interested in exploring in the first place.

This stance partly explains the study's closer alignment with Stake than Yin – the two main proponents of case study research – who differ in their epistemological and theoretical standpoints. Stake describes qualitative case study design from the same constructivist, interpretivist perspective, whereas, although Yin acknowledges that case study research can be conducted from different standpoints, his approach is most closely aligned with a realist orientation [7] and is often described as positivist [4, 8, 22, 23]. This orientation likely explains Yin's preference for a more rigid, structured approach to case study design in the pursuit of rigour [7, 17]. Stake, on the other hand, believed "knowledge is constructed rather than discovered" [1] p. 99.

Aligned with this position, I did not seek to uncover universal or concrete truths, and was less concerned with rigour in the positivist sense. The case study was a process of interpreting knowledge constructed by program stakeholders, which is then communicated to readers, who in turn construct their own understanding as they interpret what they read [23]. This meant I prioritised reflexivity, detail, context, and transparent reporting. I describe this approach in more detail when discussing perceived and potential limitations below.

My professional background also influenced my choice of methodology and methods. As an OT, I have had the privilege of hearing many stories as I became closely involved in

people's lives. Like Simons, I am drawn to people's stories and to "giving them a voice in understanding the contexts and projects in which they are involved, and finding ways to share these with a range of audiences" [2] p. 456. Qualitative research was therefore a natural fit. As discussed in Chapter one, my professional background also sparked my interest in the program as an intrinsic and instrumental case study, considering the concerns and questions raised by my work experiences.

The supervisory team contributed methodological expertise in participatory methods, qualitative and case study research. They also brought varied disciplinary perspectives, contributing a deeper understanding of occupations as well as a complementary, social scient lens. My supervisors also had specific content expertise related to participation, inclusion, flourishing of people with disability, and virtue ethics. Importantly, one member's lived experience of SCI shaped the research in practical and conceptual ways, influencing the questions I asked and the interpretations I considered.

4.3 Limitations

I now address potential and perceived limitations associated with the qualitative case study methodology, specifically concerning generalisability, rigour, bias, subjectivity, and logistical challenges. For each of these areas, I challenge certain objections, outline the steps we took to critically assess others, and acknowledge the inherent limitations of the study.

4.3.1 Generalisability

Proponents of case study research acknowledge a potential critique: a single case can't produce statistical generalisability. They note, however, that this is not the intention of case study research, nor the primary aim of many fields of inquiry [22]. A single case can also produce insights inaccessible through studies focused on the typical or generalisable, through its capacity to explore novelty and complexity in depth [1].

Whenever I was concerned about the transferability of the findings beyond my intrinsic interest – concerns that admittedly faded once the themes developed – I was reassured by Simons: "If we are able to capture and report the uniqueness, the essence, of the case in all

its particularity and present this in a way we can all recognise, we will discover something of universal significance" [2] p. 466.

The contribution of case study research lies not in representativeness, but in rich, context-specific insights that support alternative forms of generalisation. The analysis and reporting in this study aimed to support *analytic generalisation* [17] through transferrable principles for practice and program design, as well as *naturalistic generalisation* by providing thick, contextual description so readers can judge what may transfer to their own contexts [10].

Stake also notes the role of *tacit* knowledge – understanding gained through intuition and experience – as a valid way of making sense of complex human phenomena, and a potential strength of case study research [10]. This study contributes to tacit understanding by providing narrative-driven accounts, exploring program complexity, and elevating participant voices – allowing readers to engage with the case as if they were present.

4.3.2 Rigour

Another potential pitfall of case study research is a lack of rigour [4, 5, 17]. Hyett proposes a list of quality indicators for a case study that can enhance rigour [4] within the reflective, interpretive approach proposed by Stake [1]. These indicators These indicators informed the study design: I selected multiple data sources to address the research questions and enable triangulation, and sought cohesion between methodology, theoretical frameworks, and design. They also guided the reporting, where I prioritised clarity, detail and transparency. As recommended, I provide clear assertions supported by relevant quotations, a detailed case description, contextual information, and a sense of story and vicarious experience [11]. I also include a reflexive statement (above), enabling readers to consider how our positioning may have shaped design and interpretation, and judge the coherence of the approach.

Maintaining this coherence required balancing rigour with my constructivist, interpretive stance. The goal was to provide a rich, credible account of the case that invites understanding and interpretation, rather than claiming objectivity or asserting certainty. This explains many of the approaches outlined in this chapter.

For example, I used triangulation to explore whether multiple sources reinforced the findings – while recognising the inevitability of divergent perspectives and valuing these for the insights they offered. Rather than using data to confirm or refute propositions or draw firm conclusions [8], I explore 'issue questions' and acknowledge the findings as interpretive assertions – recognising both their limitations and contributions .

I aimed for a similar balance when planning and reporting the use of online sources, which Yin argues should be treated with scepticism [17], but which I also recognised as contributing additional perspectives [11]. The source of quoted data is made transparent, enabling readers to consider the merits. At the same time, I did not treat on-line data sources as a homogeneous category – a simplistic approach that overlooks important contextual differences – and developed a hierarchy of sources based on likely reliability.

4.3.3 Researcher bias

As with any research, the position of the researcher can introduce bias at every stage: from conceptualisation and data collection to analysis, interpretation, and reporting. A constructivist, interpretivist stance means that researcher positioning is acknowledged, even embraced as a strength, rather than minimised in a misguided attempt to eliminate all bias in case study research [1]. The recognition and management of the influence of researchers was another reason reflexive thematic analysis was adopted in this study.

Yet potential biases should also be critically examined, and case study research carries particular risks. Prolonged and intensive engagement with a case, often on-site, can lead to investment in, or attachment to, the case in ways that influence analysis and interpretation [2]. Being granted privileged access to the case may also produce a sense of obligation, which can inhibit frank examination of limitations or less positive findings. These risks applied to this study and were magnified by my existing connection with some program staff. While these connections facilitated access – a key logistical requirement of case study research [1, 5, 11] – they also introduced likely sources of bias that needed to be acknowledged and managed.

To maintain some detachment and avoid any risk of coercion, another team member recruited and interviewed participants known personally by me. Team discussions were also crucial to gain additional perspectives on analysis and interpretation, and to help me critically examine my own.

4.3.4 Subjectivity

Qualitative, case study research may also be criticised for being subjective. I certainly acknowledge the subjectivity of this study – but do so unapologetically. While some types of research questions do require more systematic or objective approaches, this study investigates inherently subjective phenomena – notably well-being – from the perspective of those who experience them.

Following Simons, subjectivity here is an "intelligence that is essential to understanding and interpreting the experience of participations and stakeholders" [2] p. 459. These stakeholders are who Lonergan identifies as 'subjects': knowers whose lived experience and judgments are part of how valid knowledge is produced; in other words, these 'subjects' are the basis of 'subjectivity'. And for Lonergan, that is precisely why subjectivity is not the opposite of objectivity: when our subjective operations are carried out authentically, with careful attention, intelligent inquiry, and responsible judgment, they yield the most reliable accounts of complex human phenomena [24]. Hence his line that "genuine objectivity is the fruit of authentic subjectivity"[25].

Given this view of subjectivity as an interpretive intelligence, qualitative methods, with reflexive thematic analysis, were the most fitting. Within that frame, I also expected differing perspectives amongst informants: while I examined the data for patterns, I didn't seek consensus or view divergence as a limitation.

Qualitative case study proponents do argue for discipline, reflexivity and transparency, though [1, 2, 5]. In pursuit of Lonergan's "authentic subjectivity" I aimed to approach the case with responsibility, attentiveness, intelligence and reasonableness. This included critically examining interpretations and assertions within the research team, especially where claims appeared significant or contestable. I also adopted a critical lens to examine alternative explanations for findings [5], which was supported by the lived and professional expertise of the supervisory team. I invited broader perspectives and tested the resonance of

my interpretations by sharing the findings with a range of groups, including at national and international OT conferences, and with fellow disability research students, hospital OTs, and the Sargood on Collaroy leadership team

4.3.5 Logistical challenges

Case study researchers face logistical challenges as they manage a large amount of data from various sources [2, 5]. When overwhelmed by the amount of data and the growing number of themes, it helped to remember this is an inherent feature of case studies, which generally "proliferates rather than narrows" and leaves the researcher with "more to pay attention to rather than less" [26] p24. I learned to embrace the complexity and came to recognise the importance of continually returning to the data: repeatedly 'zooming in' to explore themes in detail, then out again to consider their more holistic meanings and connections to each other.

The volume of data and broad scope of findings can also make it challenging to produce readable reports that aren't unwieldy [2] or too long for publication. I managed this by primarily reporting the findings as thesis chapters rather than published articles – reserving some 'issue questions' for later publications that can be more succinct and target a specific audience.

I also kept the thesis tightly aligned with the scope and focus described in chapter 1. Deciding what to include was an iterative process, which helped refine the final version of the thesis, but which meant that I needed to set aside some early iterations that I had made significant progress on. I also reassured myself that having too much to say isn't a bad thing for a PhD program: the challenge was tightening the focus and maintaining coherence.

Another challenge in case study reporting, which involves a large amount of descriptive and contextual detail, is maintaining the anonymity of participants [2]. While all participants were deidentified, they come from a small worlds. On one occasion, I changed some non-essential details in a story that involved a combination of distinctive factors that could have identified the person with SCI. Staff members are also potentially recognisable, especially when there are only one or two of them working in a particular role. I generally attributed their quotes broadly to a "staff member", and if their role was relevant to the point being made, I kept this as general as possible (e.g. "manager"). The small risk of being recognisable was acknowledged in the Staff Participant Information Statement.

By managing these limitations, the methods provided the most coherent and rigorous basis for examining the program and its outcomes – the findings of which are presented in the following chapters, starting with an overview of the case.

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CHAPTER FIVE:

INTRODUCING THE CASE

This chapter introduces the case study program, addressing research question one:

What is the structure, design, and purpose of this novel program?

a. **What are the key program components (inputs, activities, outputs, and intended impacts)?**
b. **Is well-being intentionally embedded in the program's design, and if so, how?**
c. **What is the socio-historical, institutional, policy and physical context of the program as a bounded case?**

The chapter serves the intrinsic aims of the case study by offering a description of the program's novel and distinctive features. It also lays the necessary foundation for the subsequent chapters, whose richer description and analysis require a basic grasp of the program components. I offer an overview that aims to provide enough context without being overwhelming. The chapter is therefore likely to prompt additional questions; I trust these will be addressed in later chapters as the account becomes more detailed and analytical.

The chapter describes the program as designed and intended. I therefore draw primarily on descriptive information from the document review, considering how the program is described and communicated 'on paper'. Observational data also permeates this chapter, providing a richer understanding of the program and how its elements fit together.

I start by attempting to define the complex and unique program, considering how it is described by stakeholders. I then present an overview and program *logic model*, which visually represents the various components and how they relate. The components are then described in more detail.

5.1 How stakeholders describe the program

Sargood on Collaroy is a purpose-built, accessible facility for people with SCI in Collaroy, a beachside suburb of Sydney, Australia. The program includes short-term accommodation for people with SCI and their family and friends, an adapted recreation program and clinical services.

As an apparently world-first program, it defies easy comparison to traditional services and is challenging to describe. As a staff member explained:

> *"I think part of the problem is that there's nothing like it. So you have to break through people's preconceptions around what it can be and is. And if you just give a simple answer, I think they can miss the point of what it is."*

Simple descriptions are sometimes necessary though, especially when promoting and explaining an unfamiliar model like this. Figure 5.1 highlights key phrases used by various stakeholders to succinctly describe the program in documents and interviews, offering insight into their language and priorities when distilling its nature into short phrases.

These phrases highlight novelty, innovation, relaxation and a break. Disability-related aspects of the program are also mentioned, including clinical support and learning. The blend of hospitality and clinical service provision is a distinctive feature of the program and a theme that runs throughout the findings, captured by the branding company as "part luxury holiday resort and part trustworthy, highly specialised clinical facility."[1]

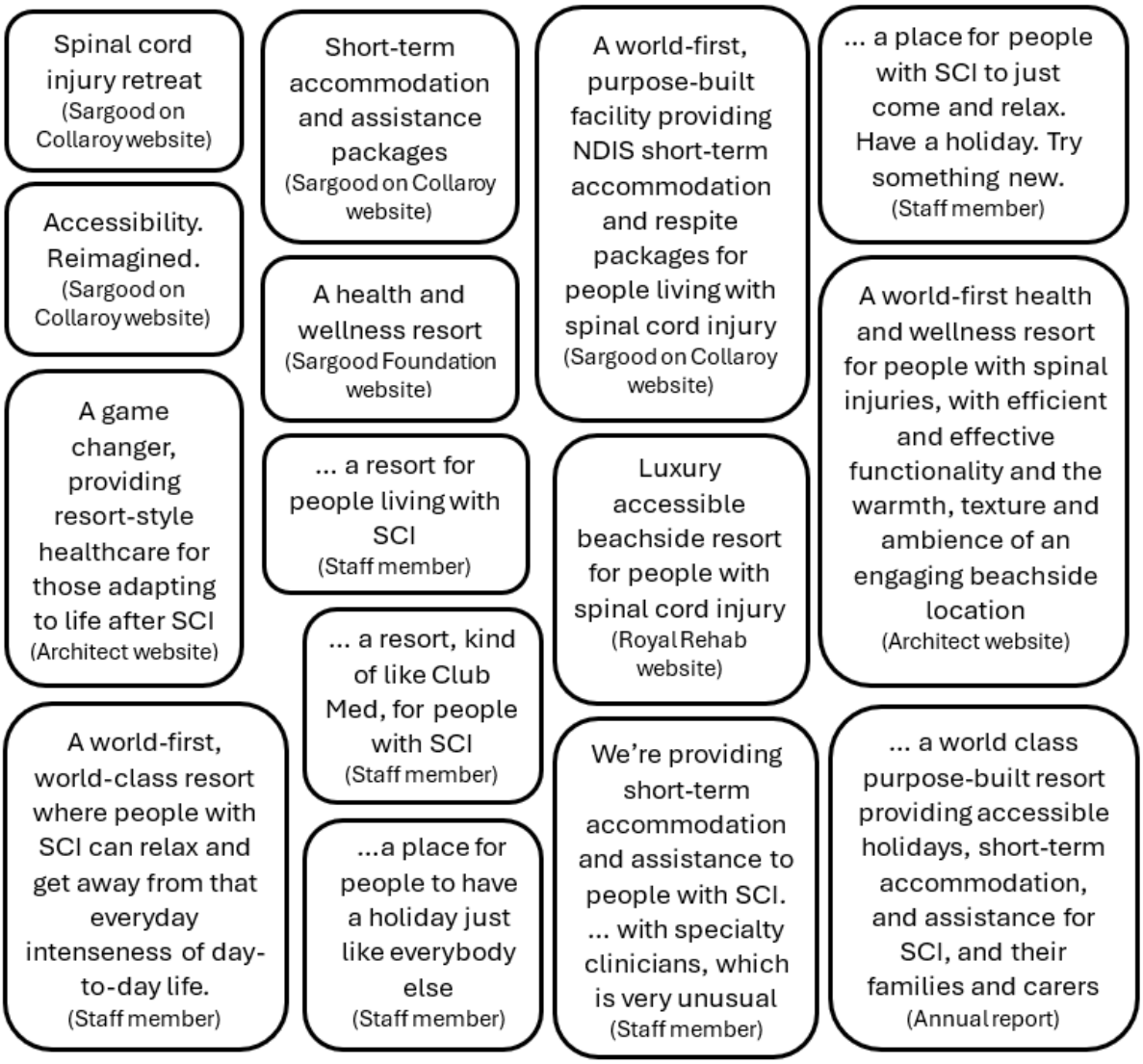

Figure 5.1

Phrases used by stakeholders to describe the program

A longer description on the program's website offers a more detail about its scope, aims and target beneficiaries:

> *"We aim to provide an environment of refreshment and inspiration for guests and their families, while promoting social integration, activity and support. This holistic approach aims to help people living with spinal cord injury to be happier, healthier and prepared to tackle the next big thing in their life. This might involve returning to school, study or work after their injury, maintaining social networks or starting a*

family. It is a combination of our equipment, our expert clinical knowledge and the overall environment of facilitating change at Sargood on Collaroy that helps us in our ultimate goal - to provide improvement to the lives of those with a spinal cord injury."[2]

This description identifies a range of aims that are in service of the overarching well-being aim, which I discuss further below. Importantly, the program's goals extend beyond people with SCI to benefit their family members and friends as well, a notable distinction from many other programs.[3] The dual focus on hospitality and clinical services is again clear here, with the "holistic approach" evidently requiring the inclusion of both elements.

This blend presents a challenge when describing the program to others. Staff and program advisors also highlighted an intriguing promotional dilemma, where "you've almost got to have two pitches: one for the guests and one for the funder." While familiar terms like 'hotel' 'resort' and 'holiday' may capture aspects of the program and appeal to guests, they communicate a level of luxury and mainstream appeal that may be off-putting to funders. I return to this dilemma later in the thesis but note that more recent public-facing documents, like the description above, avoid these terms and instead emphasise the program's aims and broader purpose.

5.2 Program overview and logic model

A program logic in Figure 5.2 provides an overview of the program components and their relationships. The structure is inherently complex, and the following sections unpack each component in turn, reproducing the relevant section of the logic for ease of reference.

The program logic is presented in the traditional sequence that represents the way programs are delivered [1]: *resources* that support the program *elements* and their related *activities*, which lead to *intended outcomes*. As required by case study research, the program *context* is also included: surrounding the other components [2].

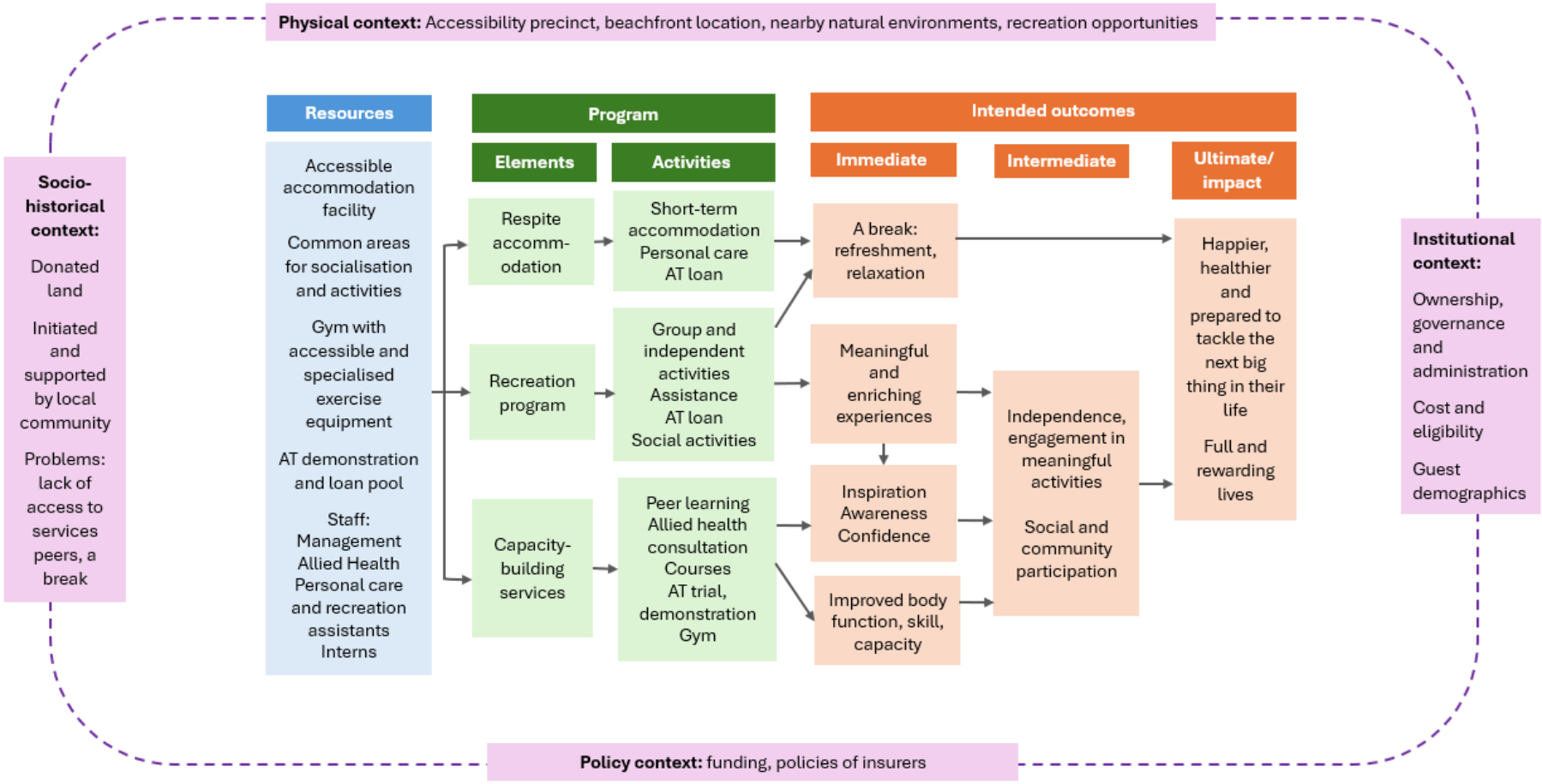

Figure 5.2

Program logic model

The discussion of the components departs from this sequence, considering the logic of the program's design [3]. I begin with the socio-historical context that conceived the program, followed by the intended outcomes that shaped its design. Next, I describe the three core program elements, their related activities and their contribution to the intended outcomes. I then identify the combined resources that support these elements and, finally, return to the program context, describing the physical, policy, and institutional contexts that bound the case.

5.3 Socio-historical context

The waterfront site's history is marked by strong support and funding from the local community and partnerships with health and disability providers, who sought to use the property as a "place of healing".[4,5,6] Frederick Sargood offered the house and land in 1915 to provide a refuge for injured World War I servicemen, then donated the property in 1918 to the Citizen's War Chest Fund. Over subsequent years, ownership of the site was transferred between various service providers; it has served as nurse's accommodation, a convalescent home for children suffering from tuberculosis and polio, and a day centre for people with intellectual disabilities.[7,8,9] The land eventually fell into disuse and was rezoned for high-rise residential development.[10] In 1999, the Collaroy Community Group (later renamed the Sargood Foundation after the site's original benefactor) was formed to preserve the site's intended purpose.[9] The group raised $20 million AUD to acquire the land and construct a facility for people with spinal cord injuries, with a broad aim of offering services for people with SCI, with a broad "mission to support people with spinal cord injury on their pathway to independence", as a program advisor with SCI explained.

A range of identified or assumed problems influenced the design. First, many people are disconnected from services beyond the first few years, as these become less available or appealing. They may therefore miss out on support for rebuilding a good life, managing ongoing issues, and becoming aware of new opportunities and possibilities. Second, people may be poorly connected to peers with SCI after inpatient rehabilitation therefore lack a valuable source of social connection, support and learning. Third, the many barriers to people with SCI staying away from home or engaging in recreational activities limit their opportunities for breaks, positive time together with their loved ones and enjoyable activities.

Program designers sought to address these problems by creating an innovative program that offered both hospitality and clinical services, and was accessible and appealing. The vision was to use the site as a state-of-the-art facility where people with SCI and their families could stay and learn together.[3,9] Royal Rehab, a disability and rehabilitation service provider, were awarded the tender to operate the facility, with a pitch for purpose-built accommodation with care services and equipment.[9,11] A co-design approach included understanding and addressing the needs of people with SCI, drawing on the perspectives of a core advisory group and numerous focus groups.[4,9,12]

5.4 Intended outcomes

Improved well-being is the program's ultimate intended outcome, or impact. The overarching aim is that people with SCI live "full and rewarding lives"[13] and are "happier, healthier and prepared to tackle the next big thing in their life."[2] Targeting well-being is inherently broad, and the overarching aim is addressed via more specific intended outcomes (Figure 5.3). These are classified as immediate (aims of a stay), intermediate (aims beyond their stay, or outside of the program), and ultimate (the overarching aim and intended impact).

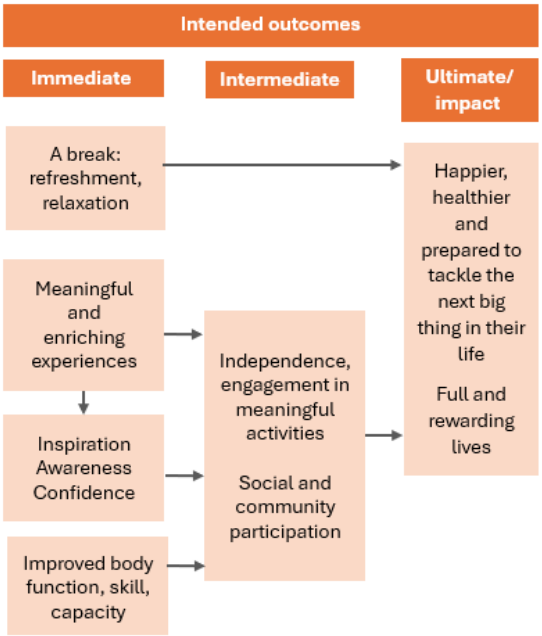

Figure 5.3

Section of program logic showing intended outcomes

The immediate outcomes fall into three distinct but, as I'll show, interrelated groups. Having a break is an intended outcome for people with SCI and their family and friends, where they can experience "respite, refreshment and relaxation" and "fully participate in meaningful and enriching experiences" during their stay. It also aims to provide inspiration, awareness and confidence, and enhance body functions, skills and capacity. These, alongside the meaningful and enriching experiences, are also in service of the intermediate outcome: independence and engagement in meaningful activities outside the program, and enhanced social and community participation – enabling people to "participate in their local community in an active way" as a program advisor with SCI explained.

The vision "refresh, learn, connect"[4,14] also functioned as a guiding statement, shaping decisions alongside the intended outcomes in the program logic. There is also a broader aim: to be a "showcase for innovation and connection".[4] These ideas align with the themes identified in the case study findings, and I return to them at times in the upcoming chapters.

5.5 Program elements and activities

The program includes three core elements: respite accommodation, a recreation program, and capacity building services. I now describe these elements, including the related activities and their relationship to the intended outcomes.

5.5.1 Respite accommodation

The program offers respite accommodation for people with SCI and their families (Figure 5.4), offering a break, refreshment, and relaxation, in service of the overarching aim of happier, healthier lives. The respite accommodation involves three related activities: short-term accommodation, personal care services and assistive technology loan.

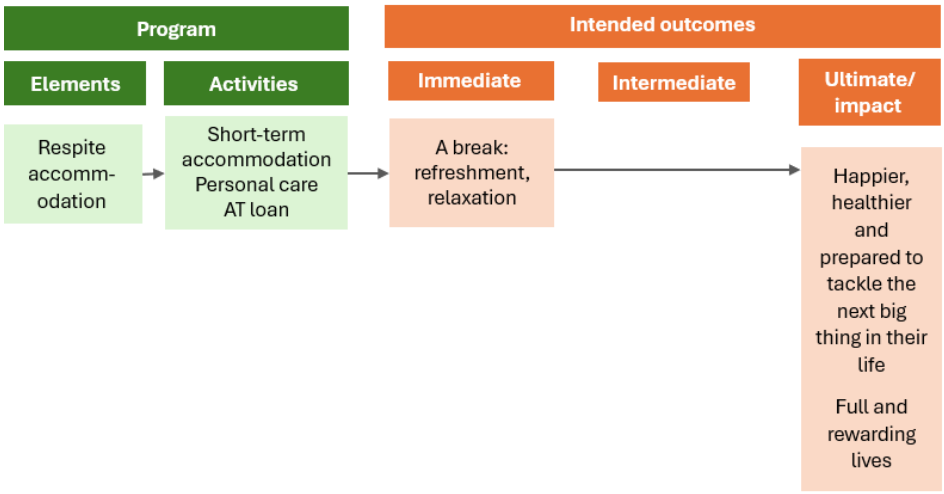

Figure 5.4

Section of program logic related to respite accommodation

Short-term accommodation

A central activity is short-term accommodation for people with SCI and their significant others, for stays up to four weeks, in a refreshing, relaxing environment. There are various reasons people seek short-term accommodation. Most want a break away from home in a pleasant location, often with family and friends or to visit family or friends nearby.[15,16,17] As intended beneficiaries of the program, significant others are able – in fact, encouraged – to stay with or visit the guest with SCI, at no extra cost.

Short-term accommodation may also address disability-related needs. People with recent SCI can take weekend leave from the nearby acute and rehabilitation spinal injury units (5.6% of guests).[18] Some stay while attending Sydney-based specialist services not available where they live, such as a driving assessment,[15] when recuperating from procedures like wound surgeries, or while their home is being modified. The program has occasionally been able to host large groups of people who all need accessible accommodation, like wheelchair sporting teams.[19,20]

Personal care services

The program offers personal care assistance for activities such as showering, dressing, toileting and transfers. This service is provided by guest attendant staff and is overseen by a

spinal Clinical Nurse Consultant. Prospective guests provide detailed information about their care requirements during the booking process. A team meet weekly to discuss upcoming bookings: a complex and specialised discussion that impacts room and equipment allocation and rostering, and which features in a later vignette.

Assistive technology loan for personal care

Guests can borrow assistive technology (AT) to meet their specialised personal care needs during their stay, shown in Table 5.1. This means they do not need to transport several bulky items: a common barrier or source of stress when staying away from home. People can select from a list of AT when they book their stay and staff may follow up with the person to clarify their requirements, given the importance of getting these details right. AT requirements are part of the weekly team discussion (above), to ensure that all items can be made available and that rooms can be allocated and set up appropriately – some of which can only accommodate certain beds, for example. The program also rents AT from local suppliers when required.

Table 5.1

Personal care AT available for loan and trial

Self-propelled shower commodes with various back supports, seat surfaces and apertures	Pressure mattresses (foam and air)
Shower chairs	Slide transfer boards
Over toilet aids	Call pager activated by pillow switch
Padded toilet seats	Electrically adjustable beds with control via handset, switch or voice
Grabrails in bathroom (modular, adjustable system)	Scanning bed controller with switch, App or voice control
Ceiling track hoist installed in each room	

5.5.2 Recreation program

The recreation program is where the hospitality and clinical streams of the program intersect: the enjoyable activities are part of the resort-like environment, require the planning and support of clinicians, and contribute to a range of intended outcomes (Figure 5.5). As well as offering “full participation in meaningful and enriching experiences”, the recreation program

often contributes to the refreshing and relaxing break. The activities also promote inspiration, awareness and confidence, which are intended outcomes shared with the capacity-building services (below), and important themes explored in later chapters.

The recreation program is optional but popular, and includes a range of group, independent and social activities. The program provides AT and assistance to facilitate the activities.

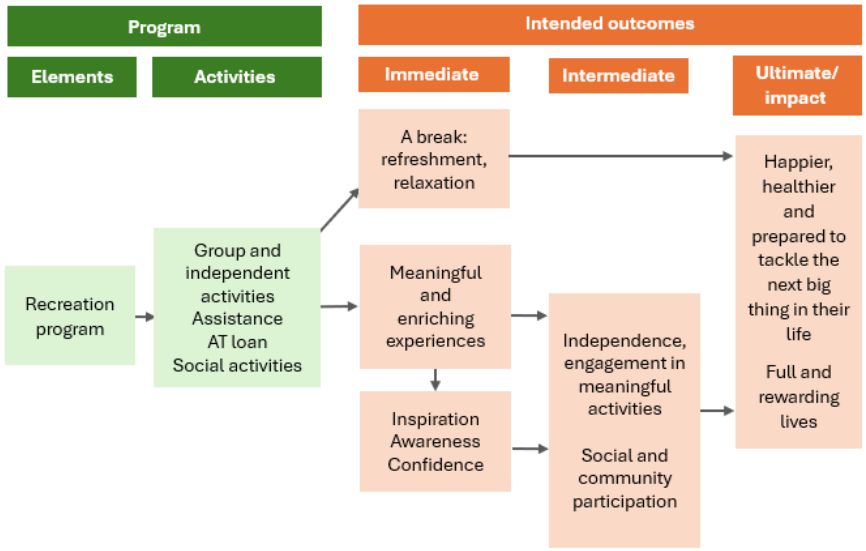

Figure 5.5

Section of program logic related to the recreation program

Group and independent recreation activities

Guests may choose from a weekly schedule of recreational group activities. Table 5.2 lists routinely offered activities, which include sport, outdoor recreation, gaming, and hobbies. Families and friends can also attend these activities, but they usually need to provide their own transport due to limited space in the wheelchair-accessible van.

Table 5.2

Recreation Activities offered by the program

Surfing	Whale watching
Swimming in ocean pool and ocean	Remote controlled sports
Exploring beach and rock pools	Cooking
Bush exploring (adapted hiking)	Farmers markets
Kayaking	Gardening
Video gaming	Bowling
Virtual reality gaming and experiences	Pool
Fishing	Yoga
Snorkelling	Photography
(Hand) cycling	Paint ‘n’ sip
Mountain biking	Dungeons and Dragons
Sailing	Ceramics
Water skiing	Terrarium-making
Tennis	Shooting
Golf	Indoor skydiving
Indoor rock climbing	Attending local festivals and events

The scheduled program sometimes draws on external adapted recreation programs, such as the nearby *Sailability* sailing program. Logistical support is provided for these external activities, including transport and additional helpers. The recreation program also utilises local mainstream recreation facilities, such as tennis courts and a fishing charter.

In addition to the scheduled group program, guests and their families are supported to engage independently in activities nearby, like exploring the local rock pools. Staff offer suggestions and advice about local options and can provide activity-related equipment such as snorkels.

Loan of assistive technology for recreation

Many of the recreation activities require AT, and staff have scoped and sourced a range of equipment that enable people with various levels of function to engage in these activities. For example, Wave Jets (jet propelled surfboards) enable people with limited trunk and arm function to catch waves without paddling with their arms. Guests can also borrow AT for

independent recreation activities if they are ready for independent use, such as hand cycles and off-road wheelchairs. Recreation AT items are listed in Table 5.3.

Table 5.3

Recreation AT available for recreation program, loan and trial

Beach/sand/pool wheelchairs – manual self-propelled
Batec motorised wheelchair attachment
X8 all-terrain wheelchairs (modified joystick and chin control options)
Hand cycles
Adapted kayak with trunk support and hand controls
Recumbent mountain bikes with hand controls and power assist
Wave Jet (jet propelled surfboard)
Strong arm fishing rod holder
Snorkelling equipment
Chin or adapted joystick operated remote controlled cars and boat
Virtual reality systems
Video gaming systems with adapted controls (switches, chin/mouth control)
Drone with modified hand joystick
Wheelchair-accessible van, with equipment trailer
Portable hoist attached to van trailer

Assistance for activities

Physical assistance for the recreation activities is provided when required. Staff are rostered on to the group recreation program to provide an adequate ratio of support, and rostering is flexible to accommodate guests who sign up at the last minute – something that is actively encouraged despite the logistical complications. This support may include getting ready for an activity (e.g. putting on a wet suit), accessing the accessible van, transfers (e.g. onto a beach wheelchair), mobility (e.g. assistance using the pool ramp), and physical support during the activity (e.g. to float in the water). Staff also occasionally a company guests on their independent recreation activities, to provide additional support and training to use a new AT item, for example.

Social activities

The weekly schedule also includes social activities, which enable people with SCI and their loved ones to socialise with other guests and staff in an enjoyable environment. Social activities have included sunset drinks and barbecues on Friday evenings, and weekly afternoon tea and scones. A monthly social lunch has recently been introduced in partnership with a peer support organisation, which is offered at no cost to people who are staying at, or can travel to, the program.[21]

Community-based recreation services

Recreation services are extended to people with disability who are not able or eligible to stay overnight. Most of the recreation activities listed above are offered to people with disability through a fee-for-service community-based program, which includes AT and assistance.[22] A 'roadshow' program gives people with disability in regional areas a chance to try recreation AT.[23] The program has also partnered with others to run community-based recreation events, including adaptive surf days[24,25].

5.5.3 Capacity-building services

Capacity-building services are the final core element, and the program's main 'clinical' aspect. As shown in Figure 5.6, the capacity-building services seek to foster inspiration, awareness, confidence, improved body function, skills and capacity. These are key to the intermediate intended outcomes beyond the program. An interviewee with SCI recognised these aspects when asked about longer-term aims of the program: "I would say, increasing capacity or independence or confidence."

Allied health consultations, courses, AT trial and demonstration and the gym program are specific capacity-building activities that target these intended outcomes.

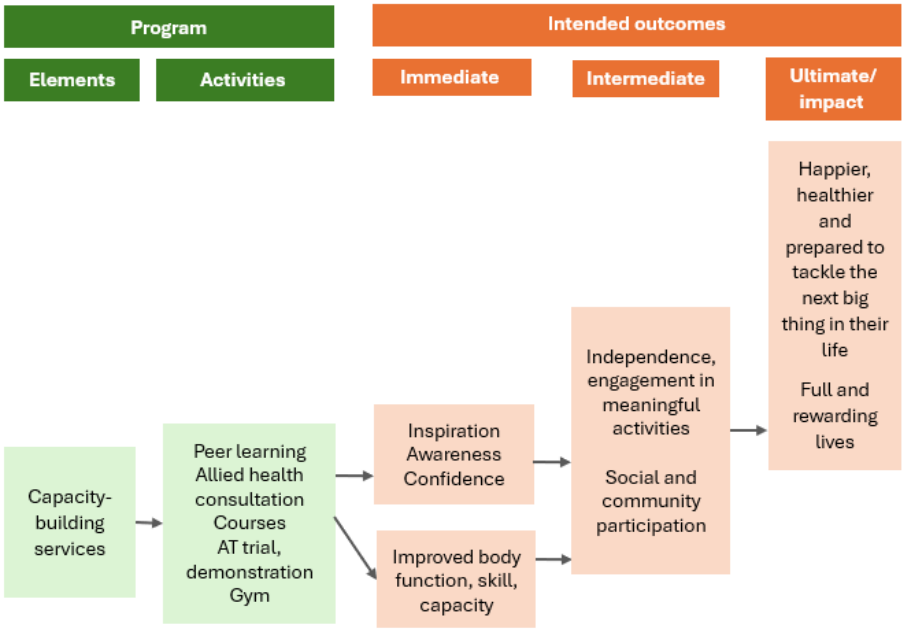

Figure 5.6

Section of program logic related to capacity-building services

Peer learning

A program advisor with SCI explained an important early intention was to facilitate a "learning community of peers". While not a formal program element, peer support is integral to the program and is fostered intentionally. As well as enhancing the social aspects of the program, peers make an important contribution to the capacity-building aims as they inspire, challenge, support and teach one another. For this reason, I located peer learning in the program logic as one of the capacity-building activities. However, peer interaction, support and learning permeate all three program elements and the "learning community of peers" is explored later as a key mechanism through which the program achieves its outcomes.

Opportunities for peer interaction are built into many of the activities discussed so far. One of the intentions of the short-term accommodation is to gather peers together. This includes connecting people with recent and established SCI, and connecting family members with others in a similar situation. The recreation program adopts a group format to enable peers to have fun together and challenge each other, and peer interaction is the primary purpose of the social activities. Courses and themed stays connect people with similar interests (e.g.

mountain biking) and demographics (e.g. ‘Golden Oldies’ retreat, Kids’ Camp) – explored below.

Allied health consultation

The program offers one-on-one consultations with in-house allied health staff. People can request this during the booking process, or may seek these services spontaneously or informally when they become aware of a new possibility during their stay. Allied health staff may provide advice, skill training, AT trial and customisation, and referral. Consultations focus on activities in which guests would like to gain independence (e.g. computer access), more specific skills (e.g. transfers), body functions (e.g. fitness) and/or problems (e.g. pain). Focus areas identified in interviews and booking forms are listed in Table 5.4.

Table 5.4

Examples of Activities, Skills and Problems addressed by allied health staff

Activities	**Skills / body functions / problems**
Video gaming, virtual reality, drone flying	Walking, gait
Outdoor recreational activities	Chair/floor/vehicle transfers
Hobbies	Standing
Cooking	Wheelchair skills
Environmental control	Pain
Computer /tablet access	Strength
Bowel and/or bladder management	Range of motion, stretching
Toileting	Balance, postural control
Dressing	Fitness
Sex and intimacy	Pressure management
Working	
Studying	
Gardening	
Holidays/travel	

Courses and camps

The program offers diverse courses and 'camps' that target specific skills, activities or demographics, listed in Table 5.5. These enable people to focus intensively on an area of interest such as intimacy or work, together with their loved ones and/or peers. Courses may be facilitated by program staff (e.g. surfing) or an external facilitator (e.g. Dungeons and Dragons, 3D printing, SCUBA). External training organisations may also host their existing courses at Sargood (e.g. *Neuromoves* exercise program[26], *Skills for Independence* peer-led course). For these courses, the program provides the accommodation, personal care and logistical support. Courses are generally offered at no extra cost to the participant, apart from general expenses (e.g. SCUBA certification), which are self-funded. However, courses that involve more intensive support (e.g. mountain biking) may require a higher support package, explained under 'cost and eligibility' below.

Table 5.5

Courses offered by the program to date

RAIDaptive SCUBA diving	3D printing
Mountain biking camp	Photography
Golden Oldies' retreat	Paint n Sip
Kids' camp	Pottery
Families camp	Neuromoves
Sex and intimacy couple's retreat	Making Strides
Surfing	Intensive exercise
Water skiing	Working and studying with SCI
Fishing	Full body yes! Wellness retreat
Indoor skydiving	Career and study workshop
Meditation	Sydney art experience

AT demonstration and trial

In addition to the personal care and recreation AT, the program provides opportunities to explore a range of AT solutions people may not have seen before (Table 5.6). This is an important part of the inspiration and awareness the program aims to offer.

Exposure to new AT happens in various ways. Videos play on TV screens in the common area and bedrooms, where guests can see AT in action and hear interviews with peers who use it. Staff show various devices at courses and during scheduled demonstrations (e.g. a weekly home automation demonstration). Peer interaction can also raise awareness about AT options.

The program also supports people to trial and acquire AT for longer-term use, in pursuit of the longer-term independence and participation aims. Guests can access trial AT via a range of sources – the recreation program, in-house equipment loan pool, AT systems installed in the facility (e.g. home automation, Handimove hoist), and from local suppliers.

Table 5.6

AT items for demonstration and trial

Custom holders for hand/mouth painting
Thermomix cooking device
Wheelchair accessories e.g. Lap Stacker carrying strap
Electric urinary leg bag opener
Kettle tipper
Home automation system accessed via voice, touch screen, switches, and/or proximity sensors
Adjustable kitchenette benchtops
Handimove hoist
Loop+ pressure sensing mat
Video gaming systems with adapted controls (switches, chin/mouth control)

Gym program

Guests can access an accessible gym and equipment during their stay, discussed under resources below. Gym staff are available to set up a program, and physiotherapy and exercise physiology (EP) staff can provide one-on-one consultations, at an additional cost. Locals with any disability can also pay to access this program.[27]

5.5.4 Resources

This section discusses the resources that support the three program elements, which draw on the same set of resources in different ways.

Accessible accommodation facility

The accessible facility is central to the program: it hosts the short-term accommodation, and is a 'hub' from which the recreation program and capacity-building services run. To attract people to the program and make it easy to stay, program designers incorporated an unusually high standard of accessibility and quality into the design.

All areas of the building and property are wheelchair-accessible, with threshold-free access throughout, large circulation spaces, low pile carpet and wide doorways.[28] The facility contains seventeen bedrooms, which are equipped with electrically adjustable beds, ceiling hoists, kitchenette with adjustable bench height, and a large wheelchair accessible bathroom with an adjustable, modular railing system. A home automation system is installed in each bedroom, providing control of the motorised doors, blinds, lights, air-conditioning, beds and entertainment system. The system is tailored to a wide range of access methods for guests with various levels of hand function, including app, switch and voice – including the recent addition of voice control for the adjustable beds.[29]

Aligned with the aims of providing a shared break to loved ones, the rooms are designed to accommodate families. The rooms are spacious and can accommodate three to seven people with fold-out sofas and portable beds. This distinguishes the program from regular hotels, which charge larger groups extra for the additional beds, space or rooms required, and respite facilities, which don't accommodate family members at all. Adjoining rooms can be combined into two-bedroom apartments to accommodate larger families (at extra cost to the

guest) or support workers. Most rooms come with an electric king-sized partner bed, which enables people with SCI to sleep beside a loved one.

A lift provides access to the three levels of the building, and a custom-designed sensor-controlled system has recently been installed to allow people with no arm function to control the lift.[29] Light switches and windows are at wheelchair height. There are also staff offices, meeting rooms, training room, equipment storage and an undercover parking area.

Common areas for socialising and activities

Common areas include a kitchen and dining room, lounges, games rooms, courtyards and a large patio area. These provide a venue and equipment for activities (e.g. gaming), host learning activities (e.g. adapted cooking and AT demonstrations) and promote social interaction between guests.

Common areas follow the same 'gold standard' of wheelchair accessibility, including height-adjustable benchtops, raised dining tables and wheelchair-accessible garden beds. Even the doll's house provided for younger guests is wheelchair accessible, with an access ramp for the wheelchair-using Barbie doll.

Gym with accessible and specialised equipment

Like at many other hotels, guests can exercise during their stay. The facility has an accessible gym, with equipment that can be accessed while seated in a wheelchair. The resistance machines are pneumatic and operated using a Bluetooth wristband, eliminating the need for manual weight adjustments for those who wouldn't be able to reach or manipulate these. Community members with any disability can also join and access the gym regularly.

The gym also offers a venue and equipment for the capacity-building services, and includes specialised rehabilitation equipment (e.g. a body weight supported treadmill, ceiling hoist) for this purpose.

AT demonstration and loan pool

AT supports all three program elements, which draw on a large AT demonstration and loan pool. For ease of reference, AT items were listed under the relevant program elements instead of this later section. However, there is some overlap between the categories. For example,

someone might trial personal care equipment they are considering purchasing, not just to meet their needs during their stay.

Clinical staff thoughtfully scoped and sourced this AT to suit the specialised needs of people with SCI, and to fulfil the program aims.

The loan pool includes specialised AT that addresses SCI-related needs, like high backed tilt in space commodes, which would not be easily accessible via other equipment loan or rental schemes. Some of the AT features are important for safety (e.g. postural support) and for preventing complications like pressure injury. Many of the items support people to do activities while seated and via hand controls (e.g. hand cycles). Some have modified hand controls for people with reduced grasp (e.g. straps) or offer supports to reduce the arm strength required (e.g. jet-propelled surfboards, power assist recumbent mountain bikes).

The loan pool includes various sizes and features, so items can be chosen or customised to suit the needs of guests with SCI. For example, there are a range of widths and control options for the off-road wheelchairs, including adapted hand and chin-controlled joysticks. To enable multiple guests to participate at the same time in popular or group activities, there are duplicates of some items.

There are AT systems installed that people cannot easily trial otherwise, including home automation in a demonstration space and in each bedroom. The ‘Handimove’ hoist was installed because the full system is not available to trial elsewhere, enabling some guests to explore the rare possibility of independent hoist transfers.

The demonstration and loan pool also includes custom-made AT systems (e.g. chin-operated remote-controlled car) created by program staff to increase the activities available to a wider range of guests. 3D printing facilities enable staff to create customised AT solutions for the loan pool and individual guests.

Although probably not considered AT, there are also items that support the recreation program, including a wheelchair-accessible van and equipment trailer (with attached hoist) to transport guests and their equipment and facilitate transfers in the community, and standard recreation equipment like snorkels.

Staff

Management roles include a resort manager (with a hospitality background) and clinical managers (with allied health backgrounds).[30,31] These leadership roles reflect the dual hospitality and clinical streams. Reception staff provide administrative and guest support.[9,31] Allied health staff, who have many years' experience in SCI rehabilitation, include an occupational therapist, adapted recreation specialists, spinal clinical nurse consultants, physiotherapists and exercise physiologists.

There are also guest attendants, a unique role that combines personal care assistance, support for recreation activities and hospitality-related tasks (e.g. preparing guest rooms). Guest attendant staff are supervised by the clinical nurse consultant and are trained in supporting the needs of people with SCI (e.g. bowel care), including spending time at the inpatient spinal unit run by the same organisation.

The program implemented an internship program in recent years, where people with SCI are employed and trained in project roles, based on their background and interests.[32,33,34] Two interns have since been employed permanently as a project officer[35,36,37] and in a maintenance and peer support role.[35]

The consumer advisory group continue to provide advice at scheduled meetings with management staff, and provide ad-hoc advice about new initiatives and plans.

5.6 The context

I now return to the program context: an important aspect of case study research. Figure 5.8 adds this final component of the logic model, represented as a purple boundary surrounding the other program components. The social-historical context was discussed at the start of this chapter, and I now describe the physical, institutional and policy contexts.

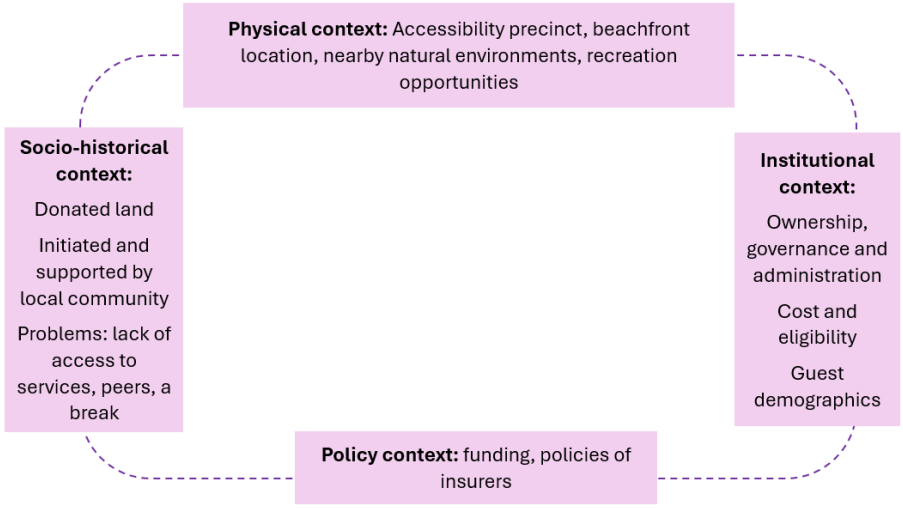

Figure 5.8

Program context section of logic model

5.6.1 Physical context

The facility is close to community facilities such as a lookout, park, playground, ramp-equipped ocean pool and pathway to the beach. The Collaroy village centre is approx. 300m away, with cafes, restaurants, and basic facilities like a post office and pharmacy. Nearby wheelchair-accessible bus services provide access to other beaches and the city. The local area is unusually wheelchair accessible. The facility is located next to an 'accessibility precinct', designated by the local council in 2012 as a priority area for improving access by people with disability.[38,39] Accessibility upgrades to the precinct have included a waterfront pathway to the nearby golf club, upgrades to the accessible toilet bedside the ocean pool, a 'Changing Places' toilet with adult hoist and change table, ramp access to a lookout spot, and a wheelchair accessible playground.[40,41,42]

Collaroy is in the Northern Beaches region of Sydney, which is a 30km stretch of suburbs and natural features such as beaches, lookouts, bushland, lagoons and parklands. The major tourist precinct of Manly is approximately 20 minutes away, while Sydney city is about 45 minutes by car or an hour by bus and ferry. The nearest airport is around an hour's drive away, or can be reached via a relatively lengthy public transport journey involving two train transfers and a bus.

5.6.2 Institutional context

Ownership, governance and administration

The facility is owned by The Sargood Centre,[43] an entity with three stakeholders: icare (the insurance provider of lifetime care and support for motor vehicle-related catastrophic injuries in NSW), a private benefactor, and the Sargood Foundation.[9,13,44] The program is operated by Royal Rehab, a not-for-profit provider of rehabilitation, housing and disability services.[30]

The resort manger reports to the Royal Rehab executive team and board. The boards of the Sargood Centre[45] and Sargood Foundation[46] also oversee program activities. There are several people with SCI involved in these governance roles, one of whom I interviewed.

Cost and eligibility

Guests (or their insurer) are charged for the program, and at the time of data collection there were three cost packages available. The 'support package' includes accommodation, recreation program, one hour/day of occupational therapy or clinical nurse consultant consultation, and equipment loan. The 'high support package' and 'very high support package' add personal care assistance to this offering (6 or 12 hours/day of 1:1 support respectively)[47].

Figure 5.9 shows the support packages utilised by guests.[18] 44.6% of guests used the 'support package, which does not include scheduled personal care. 20.8% of guests requested a package that offers up to 6 hours/day of personal care. 34.6%, just over a third of guests, required a very high level of care of 6-12 hours/day.

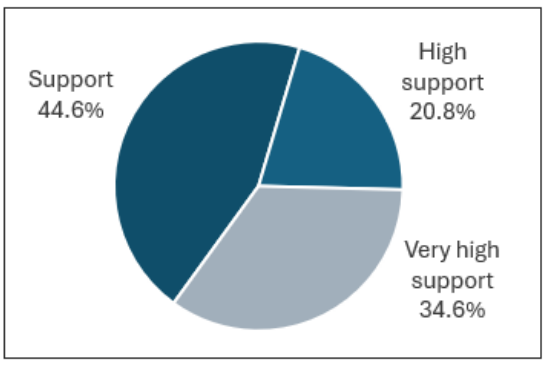

Figure 5.9

Support Packages utilised by guests

Guest demographics

People with permanent, non-progressive spinal cord injury (and their family and friends) can stay at the facility. Around a quarter of guests come alone, a quarter with their family, and half with a partner.[48] Figure 5.10 shows the demographics of guests with SCI who booked stays.[18]

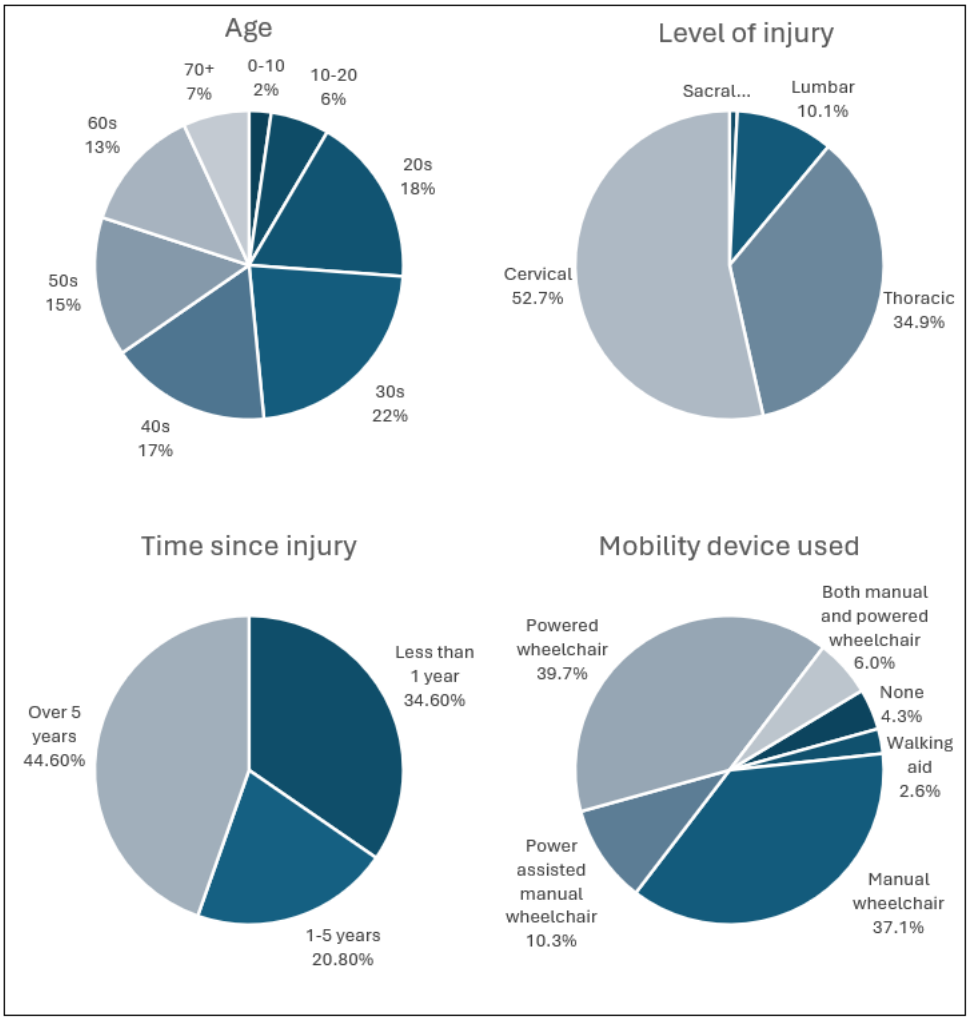

Figure 5.10

Guest Demographics

70% were male. There was a roughly even spread of ages, with slightly fewer guests in the 0-20 and over 70 age brackets. A little over half of guests had a cervical level injury. Of these, 31% had an injury of C4 or above suggesting a reasonable proportion of guests have very little functional upper limb use, although the data do not specify level of injury completeness. The large majority (93%) of guests used a wheelchair for mobility.

Level access and adequate circulation space would be particularly important for the 39.7% of guests primarily use a powered wheelchair. One third of guests sustained their injury within the previous year, and would therefore have been relatively new in their journey. Just over 20% of guests had been injured 1-5 years prior, and 44.6% had been living with a SCI for more than 5 years.

Some guests reported secondary complications of SCI, with 5% reporting a current pressure injury, and 29.5% prone to autonomic dysreflexia. 6.8% of people with SCI had an additional traumatic brain injury or memory loss of some form.

The demographics of interviewees with SCI roughly aligned with the broader guest demographics reported here. The interview group had a similar proportion of people aged 30-50 and 60-70, although the specific age breakdowns within those brackets varied. The study and did not recruit people under 18 years. The interview group had a slightly higher proportion of people with injuries at cervical level (66.7% compared with 52.7%) and sustained more than five years prior (75% compared with 44.6%).

5.6.3 Policy context

Funding

Figure 5.11 shows the funding sources for guests' stays.[18] Stays are most often funded through disability insurance, mostly though Australia's National Disability Insurance Scheme (NDIS) (53.4% of guests) or the state-based motor vehicle insurance program, iCare (38.5%).

The Sargood Foundation, which provided seed funding and the initial impetus for the program, continue to provide some ongoing funding. They source donors for quality improvement projects and specialised equipment, and may also fund stays for people without insurance funding (1.8% of guests in this sample), particularly aiming to support people who

are over 65 and ineligible for the NDIS. They also offer grants to assist with travel costs to get to Sydney.[49,50]

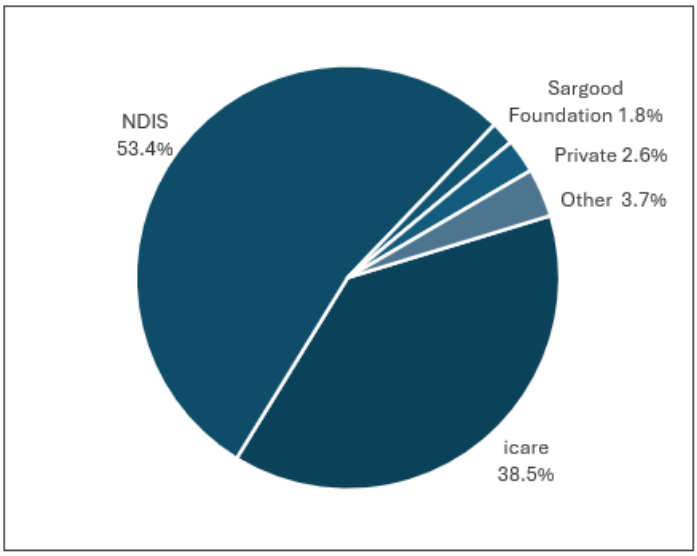

Figure 5.11

Funding Sources for Guests

Funding has sometimes been granted by other organisations such as a state-based SCI association[51] and occasionally through competitions.[52,53] A few guests (2.6%) fund their stay privately. Guests can also opt to privately fund an upgrade to a premium ocean view room, or a second room for family, friends or carers if they cannot share their room.[54]

Policies of insurers

A stay at is generally categorised by insurance funders as respite or short-term accommodation, which is something they'd routinely consider for funding. icare recognise the broader benefits of the program to independence and well-being, and they will routinely approve 28 days per year for their participants with SCI,[55] considering this as a holiday. At the time of data analysis, NDIS funded stays under the 'respite and short term accommodation' funding category, but this policy changed a couple of months prior to thesis submission. The fee structure is under review at the time of writing to align with the new funding policies, which are discussed later in the thesis.

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CHAPTER SIX:

REPORTED OUTCOMES

This chapter addresses the second research question:

What are the reported outcomes of the program?

a. **How do the reported outcomes align with the program's intended outcomes?**
b. **How do they relate to each other?**
c. **How do they impact well-being?**

It draws primarily on the guest interviews. Although data were analysed inductively, the reported outcomes show strong alignment with the intended outcomes. To demonstrate this alignment and provide a clear structure for the chapter, the intended outcomes inform the main chapter headings and the order in which the outcomes are discussed.

The chapter begins with the break offered by short-term accommodation, followed by a discussion of how the recreation program offered the intended 'meaningful and enriching experiences'. Outcomes related to independence and engagement are then discussed, starting with narrower, immediate outcomes of inspiration, confidence, awareness, improved body functions, and skills and capacity. The longer term impacts on independence and meaningful activities outside the program, and enhanced social and community participation, are then described. The chapter then turns to how these outcomes appear to impact well-being directly, and by improving outlook and life satisfaction.

The themes in this chapter begin at a fairly descriptive level, as required by the research question. Relationships between the themes are developed as the chapter progresses, and the findings are interpreted further in the theory of change that follows in Chapters 7-9.

6.1 The break offered by short-term accommodation

> *"They're about trying to get people out of the house, giving them a good, beautiful environment where they can come and have a break, have a holiday, and still have access to all the necessary equipment or staff that they need."* (Stewart)

Having a break emerged as a prominent theme, highlighting its significance for people with SCI and its successful achievement through the program. I now describe related sub-themes.

6.1.1 Refreshment, relaxation and reprieve

> *"The mental bit: I think that's why I go, as much as anything ... It's a holiday. It's wonderful. We all need that break."* (Angela)

Interviewees often said taking a break was a valued aspect of the program and important to their well-being. Many used the word 'holiday' and described typical holiday-like experiences such as relaxation and escape.

They viewed these experiences as essential to anyone's well-being, and valued the program's efforts to address the SCI-related barriers they faced. They therefore interpreted this as reducing inequity rather than offering a luxury: as Rob explained, "it's to remove structural inequalities in society … we can't just pop and stay somewhere … prohibitively expensive, complicated to do, risky." Taken together, these accounts suggest that the 'break' was understood not simply as rest, but as a restoration of equity and access to experiences that are ordinarily taken for granted.

In fact, the challenges of SCI meant having a break was even more important for some. The program offered a reprieve, where "guests feel calm and relaxed in a world that is sometimes hard," as one website testimonial put it. Another guest shared on social media how she "felt at peace for the first time in years." There were a couple of on-line stories from people who "got to take a holiday from the hospital", which offered a reprieve from the hard work and time apart from family.

Addressing SCI-related needs was essential for a genuine break, because travelling away from home was often a source of more stress otherwise. Interviewees contrasted the program to their usual experiences, describing a place where "you know everything is taken care of already … It's just delightful … It helps your wellbeing." The information on the website and

their previous stays reassured them it is “all accessible, and it's not a hotel that you've got do a bucket load of research on it to make sure.” Knowing this, and having care and equipment taken care of, meant “you don't have to stress about anything … you don't have to do any of the extra disability-related annoying things ... It's just a holiday." The expertise of the staff also eased the usual worries when travelling away from regular carers: “Having everyone there that knows what they're doing, the stress that that takes away is also really important.” Across participants, the removal of these additional practical and emotional burdens appeared central to the experience of having a ‘genuine’ break.

Interviewees also appreciated the program “making it easy for loved ones to come and they also get a break.” For families coming to terms with a recent SCI, this may be especially important, as a wife of a person with SCI shared on-line: “we were finally living again not just recovering ... relaxed, free, us again as a family.” People with established SCI also valued positive time together with their loved ones. For example, Lisa was able to regain a lost experience of sleeping beside her husband: “And I hadn't realised that I was missing that so much... we both realised it was the first time in three years that we've slept in the same bedroom.”

Interviewees relayed that family carers valued “a total break from that low level caring”. But the need to have a break from the person they cared for was notably absent from our findings – although it’s important to note we didn’t hear from family members directly. Nevertheless, a clear theme was the appreciation for a shared break, and the opportunity to spend positive time together. People with SCI, too, needed to “have a break from the grind” of everyday life with disability, and the stressors of managing and receiving care.

The program also offers a reprieve from daily life by providing something special or outside the usual routine. As a staff member reflected, many guests come to “experience something different from their everyday lives”. Guest interviewees appreciated the program offering “things to do that you might not have any opportunity to do outside of Sargood,” associating this out-of-the-ordinary experience with being “on holidays” where “it's good to get out and do things”.

6.1.2 A sense of 'normality'

> *"To feel normal – it can never be underestimated. It's so nice to go … I'm not having to fit in to the environment: the environment is fitting me. That is very normal. It's a normal life, like having a holiday … You know that lovely feeling?"* (Angela)

While the program offers a reprieve from everyday life, it also paradoxically provides a sense of 'normality'. Angela (above) emphasised the value of feeling normal, which appears defined by her pre-injury experiences and the non-disabled ease in well-matched environments. Similarly, Sian found normality in a hassle-free holiday; being free from "extra disability-related annoying things" made it feel like "just a holiday". The word "just" reflects the simplicity she valued, where she could enjoy a trip "like anybody else would," with the spontaneity of "being able to just be like, 'I'm just going to pack up, go on a holiday.'" 'Normality' appears to be defined here by the absence of effort, where environments and routines no longer require adaptation or negotiation.

Angela also found normality in the appealing aesthetics and touches like the herb garden, which fostered a sense of dignity, especially compared to the usual offerings for people with SCI. She explained these "have a different look, and it reinforces that somehow you're a patient, whereas at Sargood you're a client." She objected to this different standard for wheelchair users because "a chair is just a physical thing … it's not who you are."

The local community also played a role in creating a sense of normality. Interviewees noted locals seemed used to interacting with wheelchair users and responded in a relaxed, unselfconscious way. For Rob, this meant his experience in the community was "normal, it's easy, and that's how things should be". He captured the paradoxical nature of normality: where "elsewhere you might be a freak," in Collaroy "you're normal, completely normal, and that's really quite strange". Lisa made similar observations, noting her usual experience is "I change people's behaviour" when others hurry past or avoid her, whereas "at Collaroy I changed the behaviour, but usually it was because somebody said hello." This suggests that normality was not only shaped by physical accessibility, but also by social interactions that reduced self-consciousness and difference.

6.2 The meaningful and enriching experiences of the recreation program

> *"I'm on holidays. It's good to get out and do things. I know some people do go to Sargood and they don't do the rec activities. They just want to relax … But I always like to do the things, because I don't have the opportunity to do those usually."* (Sian)

The fun activities added to the holiday-like experience: "they do a lot of great activities… it's supposed to be a holiday." John compared it to a "nice, relaxed resort" with an activities program, which he found "really cool" as a wheelchair user. While acknowledging some people prefer quieter holidays to "do your own thing," he embraced the activities, returning home "on a high" and wanting to go back.

Several guests described barriers to participation outside the program. Sian listed the supports she needs, including help changing in and out of a wetsuit, "one-on-one rec support" during the activity, modified equipment, and help with showering and dressing afterward. She explained that her motivation to participate stems from the rare access to this support: "without the Sargood full team of support, then I can't really do that sort of activity. So that's why I'm like, 'I'm going to do all of them.'"

Recognising the benefits and barriers, the recreation program aims to facilitate "full participation in meaningful and enriching experiences". In this section I describe specific ways in which these experiences were "meaningful and enriching".

6.2.1 Positive emotions and engagement

> *"Those power assisted mountain bike things – they're a blast, like 'wow, This is fantastic!' I went out to West head and it's really quite a rugged fire trial and I loved it. I like nature. And it's very difficult to get to otherwise."* (Rob)

'Fun' was a recurring theme, and appeared to capture more than simple enjoyment, encompassing a range of positive emotional and engagement experiences across participants. Staff described striving to provide "five days of fun, every day of the week" andshared about the many smiles they'd witnessed, that represent these emotions: "You just have to look on our social media and watch some of the videos and see the smiles on faces when someone's catching a wave for the first time." The emotions staff observed ranged from happiness to

exhilaration: “For some, it's the biggest smile in the world. For others, it's smiles, tears, hugs, high fives, and fist pumps.”

People shared similar emotions in online testimonials, like “we were on cloud nine throughout our stay!”, “had an absolute ball,” and “the best thing I’ve ever done”. They highlighted a sense of “freedom and exhilaration,” and an escape where “I kind of forgot that I had a spinal cord injury” and experienced something “totally different”. This sense of fun was evident throughout the program, based on my observations as well as interview data. Staff described a sense of fun and freedom in the building itself:

> *“Sometimes you can barely hear yourself on the phone … they’re hustling and bustling. The kids are zooming through on their wheelchairs … racing each other up and down the hallways … hilarious.”*

But it was the recreation activities that most strongly elicited this sense of fun, as well as a broader range of positive emotions. Interviewees reported various emotions, often tied to enjoyment, pleasure and exhilaration: “I come back on a high” and “it was really fantastic!” On-line testimonials had a similar range of positive emotions: “pure joy… fully uplifting,” “such a great feeling,” “unreal… surreal feeling,” “an awesome feeling,” and “fully uplifting”.

For some, these emotions were rare, as they reflected “we were all smiling and laughing, which we haven’t done in a long time,” and “they were my first tears of joy since this crazy part of our life started.” A wife gave an emotional testimonial about seeing her husband with SCI having fun, saying “it was all too much for me. I broke down in tears of happiness.”[1] In an online video, a guest shared the enjoyable problem of water getting into her snorkel mask because she “was smiling so much”.

Natural environments were also a source of positive emotions, which Tom described as “beautiful and serene and very good for my well-being”. A mother shared on-line her joy at seeing her children playing together in the nearby “beach, the beautiful walks and the rock pools,” and her child with SCI being supported to try snorkelling for the first time – “which he absolutely loved”.[1] Being in the water was especially enjoyable for many people, who described the experience on-line using superlatives like “indescribable”, “out of this world”, “thought I’d died and gone to heaven” and “one of the greatest moments of my life”. Water sports like surfing give a sense of “adrenaline”, and “that rush … just awesome”.

While adding to the sense of fun and exhilaration, natural environments also often provided a sense of calmness and contentment. While often exhilarating, interviewees said being in the water could also be deeply relaxing: “a whole other world” where they could experience “the calming effect” and “that feeling of weightlessness and mental clarity”. People explained online how this stood in stark contrast to their usual experience, where “my body’s so heavy, everything’s hard to move,” whereas in the water it’s “like you weigh nothing” and “there is immense relief to be found in the weightlessness of just floating”. One guest expressed the joy of floating for the first time in 14 years in a social media post:

> *“The kind of float where every muscle is relaxed, my head back in the water, hearing the water rippling amongst the splendid silence, looking up to the sky and marvelling how good life is.”* [2]

Indoor activities like pottery and terrarium-making were another low-key source of enjoyment and were an alternative to the more physical outdoor activities. These indoor activities suited Adam, who has high-level SCI. He sometimes gave outdoor activities a go, including a failed surfboard attempt that ended with him asking staff to “’just throw me at the waves. … if a big wave comes, just push me into it.’ And I was just getting thrown around and I had time of my life doing that.” He found this experience exhilarating but not worth the logistics to do regularly.

In contrast, he reflected on the “passive enjoyment” he found in indoor activities, which were easier to access. Nevertheless, even these still mostly involved “sitting and watching and telling someone what to do,” and while he “can still get enjoyment out of that,” it is “not as much enjoyment as someone who can physically do”. Adam had a pragmatic, accepting attitude, describing himself as “fairly patient and understanding with activities like that,” and thoughtfully articulating the complexities of engagement for people with high-level SCI. He found enjoyment by focusing on aspects that brought meaning, like coming away with “something tangible or nice”, spending time with his partner, and seeing her enjoyment.

Still, Adam most appreciated the active engagement of “mentally challenging activities,” like cooperative or strategy games, because they “activate my problem-solving skills or give me a different outlet to express myself creatively, or a different mindset on how to think”. These activities also create “a level playing field,” because “it’s mental and imagination – it’s not requiring your arms. Everyone’s in the same position.” Adam also enjoyed new activities that harnessed the little movement he had available, in his head and neck.

Adam appreciated staff "trying new ways to get other people involved" by opening up new activities for people with high level SCI. The adapted controller for the RC car was created for this purpose, as was a Dungeons and Dragons course, to which two staff reached out separately to invite Adam. The occupational therapist designed and fabricated a custom paintbrush holder for Adam's participation in the Paint and Sip course, which had additional features not found in off-the-shelf mouthsticks like adjustable brush angle and size, and a mount so he could pick it up and put it down independently. These efforts enabled the more active, fulfilling engagement Adam enjoyed.

While many of the experiences were temporary, they were still highly valued. Interviewees recognised that some enjoyable experiences are limited to special occasions. Tom shared an example of kayaking, an activity he doesn't get to do outside his routine of work and parenting, but "loves" when he has the opportunity. A staff member explained the significance of facilitating these transient positive experiences, noting "we all go on holidays and have a temporary high… so if we're able to provide even just that, that's enough to better someone's life."

6.2.2 'Firsts': lost and new experiences

> *"A lot of great firsts were achieved whilst I stayed at Sargood in Feb and I can't wait to get back there to make many more firsts and some seconds!"*[3]

This social media quote encapsulates a key finding: the program was the first opportunity for many people to engage in lost and new experiences. Several interviewees said it was the first time they'd returned to valued pre-injury activities like kayaking, fishing, being in the ocean, and mountain biking. People could also try new activities they might not have attempted otherwise and, as John expressed, "to come across a facility that is accommodating to allow you to go do those things is awesome."

People also shared testimonials on-line about regaining something they thought was lost or impossible: "not in my wildest dreams would I ever get to do that again," and "you find it hard to imagine how it would work or how you would have that opportunity once things change physically." A mother shared how the program offered experiences her child with SCI might not have had, regardless of her injury:

"There's a lot of skills that [child with SCI] has gained that she most likely would have never had a chance to if she had been able to walk. She would never have probably gone sailing, never tried kayaking…and I think that freedom is what a lot of people find at Sargood on Collaroy."[1]

Getting back to a valued activity, even when done differently, can provide a familiar experience and restore a sense of identity. For example, Ben recalled "quite fondly" his experience of adapted surfing which, although "it's not quite the same kind of surfing, lying down on a jet-powered surfboard," still brought back familiar sensations: "it's still a phenomenal feeling to get out there at the ocean and feel free and catch a wave."

Another person shared on social media their experience of getting back to mountain biking. While it had changed in some ways – "my solo mountain biking days might be over" – the experience was familiar and valued: "the sense of freedom, the power of accepting help from others, and doing it with two of my mates made for the perfect afternoon."[4]

A wife similarly shared in a newspaper article how her husband with SCI was able to reconnect with the sensations related to his "water baby" identity, which included "swimming, fishing, bodysurfing and even barbecuing. All of these experiences are available to him now at Sargood." A social media post shared a similar experience: "Surfing was everything to me before, so to have this back has given me part of my identity back, which has increased my quality of life."

6.2.3 Positive shared experiences

"I loved coming with my kids. I loved my kids being able to come out in the surf with me … I got an awesome video that I was able to show other people once I'd left, but probably the most special thing was to have my wife and kids there with me and experience that" (Ben)

People with SCI appreciated the opportunity to enjoy experiences with their family and friends. For John, a stand-out aspect of the program was that "it was inclusive so that my travel buddy was able to join in on the activities". Tom shared several examples of "good fun family time" with his daughter, including exploring rock pools, kayaking, sailing and going "up to the Palm beach lighthouse on the X8s, and [she] rode on my lap for a lot of that."

Several guests from outside the area appreciated the accessible place to stay near friends and family in Sydney, fostering relationships that might suffer without this contact. In an online testimonial, the wife of a person with SCI who visited from an international location shared how the program made it possible for their family to visit Australia – something she had previously thought was impossible:

> *"One of my selfish and internal fears I had as a wife of a new quadriplegic was the idea of never seeing my Australian family again. Travelling to and from Australia with kids had always presented its challenges, but adding a quadriplegic to the mix was more than I thought I could handle"*[1]

The facility sometimes served as an appealing venue for hosting special events with loved ones, which was an opportunity for memorable shared experiences. Adam shared how staff went out of their way to make one moment special: "[The manager] overheard us talking about how I proposed … he ran down and grabbed a bottle of champagne and brought it up and gave it to us." Ryan shared a similar example: "we had a birthday party, we had a glass of wine, we were singing and carrying on, and one of the girls who worked there was on the piano."

Shared moments can be particularly impactful for young people with SCI. While I didn't interview young people, staff relayed examples they had observed, such as a teenager with SCI whose "friends don't know what to say, how to react … but when you see them getting out and just having a swim with their mates down at the beach, all laughing and having a great time: you can't put a price on that."

Sadly, these kinds of experiences were otherwise uncommon for some people. Anecdotes about shared experience sometimes ended with statements like "which we'd never been able to do before" and "for the first time in ten years". Staff members also reflected on,

> *"... the number of people that have come who have said, 'It's the first time we've been able to have a swim together while on holidays. Normally, I have to sit up on the footpath while my family's down on the beach enjoying themselves.'"*

Children with SCI may feel this sense of exclusion especially acutely. In an online testimonial, a mother expressed appreciation for the program being "so much fun, and 100% accessible so we can do things as a family, and no one has to be left out." The program,

therefore, “is an absolute godsend” in a “heartbreaking” context where her son with SCI is often excluded.[1]

6.3 Outcomes related to independence and engagement

I now explore the intended outcomes that surround the aim of fostering independence, engagement and participation beyond the program, shown again in Figure 6.1 for reference. I begin with the immediate outcomes then explore the increasingly broader impacts.

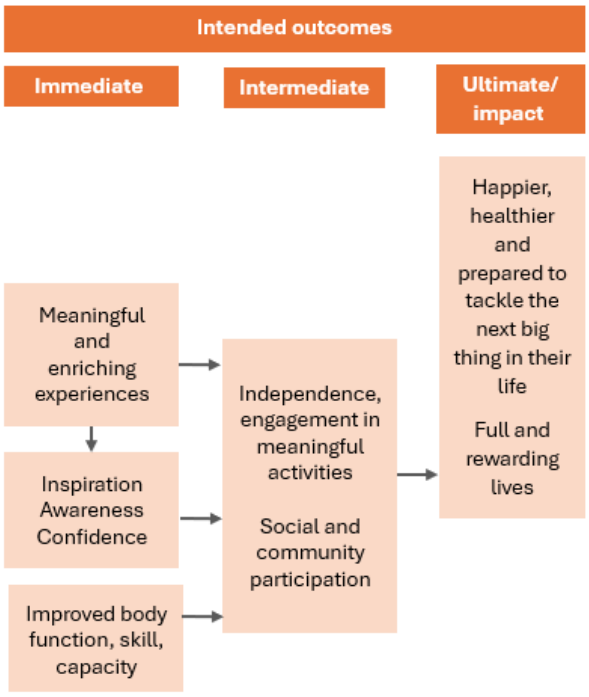

Figure 6.1

Section of program logic related to independence and engagement

6.3.1 Inspiration and confidence

> *"They feel invigorated when they leave. They've stepped out of their comfort zone and they feel alive again … They've embraced their fears … they've got this adrenalin rush and they're like, 'When can we come back and do it again?'"* (Staff member)

Inspiration and confidence were key themes in the case study, and these played a crucial role in promoting broader engagement beyond the program.

The recreation activities were especially powerful sources of inspiration and confidence. Guests described these as "not just enjoying activities" in the moment, but as contributing to long-term changes and new opportunities. Because recreation activities are fun and risky, they motivated – and required – people to step out of their comfort zones. They often involved initial apprehension, especially when they were risky and had not been attempted since the injury. Interviewees shared how it "took a bit of courage to say, "yep, I'll have a crack at that" – particularly for activities like entering the pool or surf "for the first time in decades," which could feel "intimidating" or "shocking".

Recreation activities could also bring up difficult memories. John shared an example of trying snorkelling after having sustained his SCI in the water and explained the importance of having "that emotional support" when "doing an activity for the first time that might have caused your injury". He appreciated the staff providing "that shoulder to talk to or guide you through that activity to achieve it" – a theme I explore further in Chapter 8. Staff members also shared examples of supporting people to go back into the surf after having sustained their injury in a similar location, and,

> *"… it's been absolutely life changing for them because they can kind of put it – put the [original spinal cord injury] in that place of, 'yes it happened in the water. But I can still have a life and still have a swim or a surf.'"*

Despite initial apprehension, people usually appreciated the opportunity "to try something new and get out of my comfort zone," and said their experiences were ultimately positive: "I felt nervous but again, I really liked it." Rising to a challenge instilled a sense of pride and more positive emotions, like the initially reluctant guest who staff said came back every day "with a big smile saying, 'That was the best day'… she had a grin from ear to ear." Crucially, this also built confidence.

For some guests, staying away from home was challenge itself. Carrie approached her first visit thinking, “I’ll test the waters, see how I feel, see if I want to go back.” A staff member, similarly observed that some guests initially “just want to come here and see what it's about”. A board member with SCI noted that staff are mindful of this apprehension when away from home, and intentionally work to “put people at ease and help people come out of their shells a little bit in terms of being more self-confident and ambitious”.

6.3.2 Awareness of solutions and possibilities

> *“I wanted yell to the rooftops about how good the place is, to be exposed to the equipment and touch base.”* (Carrie)

One of the intended outcomes is that people with SCI become updated and aware of new possibilities and solutions. Interviewees with SCI appreciated this, including those with long-term SCI who “have been out in the community post-injury 30 years and are out of date”. They valued updates about new resources and opportunities: “I love whenever I go back, I'll just try and book in a catch-up with [the CNC] and see what's happening.” For some this was a highlight: “that's where I do think Sargood is just awesome”.

Lisa, whose injury was relatively recent, also had gaps in her knowledge that she wouldn’t have thought to ask about, because “I just hadn't realised what was possible or what was missing or available.” She emphasised the important role the program played in raising her awareness of possibilities, where “I had no idea that it would provide me with so much that I didn't even know I needed.”

This new awareness may be about activity options, and guests also valued staff and peers offering “ideas of some other things I could or should do”. For example, Adam “wouldn’t have thought ‘I can control an RC car,’” without this being suggested as an option. Being exposed to new activity options further sparked his curiosity about what else he could try: “So now it’s like, ‘what else is around?’” This makes the program refreshing: “it helps give it a new breath of life when we go there.”

The program also raises awareness about new AT, as Carrie alluded to in her opening quote. The loan pool of recreation AT provided exposure to new possibilities, with one guest noting “they’ve got so much kit there – different hand cycles, different power wheelchairs, kayaks

and surfboards with motors and all sorts of things you just wouldn't normally get an opportunity to try."

Guests valued not just being updated about what is available, but also an opportunity to properly try these options. For Angela, this meant,

> *"I know now what works … I would recommend Sargood for people coming out of hospital, before they go into accommodation … before you make any decisions go and see what you do need, and how it works for you."*

People particularly appreciated being able to trial AT in a home-like setting over an extended period, helping them understand what might work (or not) in their own homes, and compare multiple options. Lisa explained, "I tried four commodes while I was there … being able to try a few while I was there made a huge difference in knowing the questions to ask or what to look for". She also appreciated having access to clinicians when weighing up these options, "because the nurse and the OT told me why this worked or why this didn't work and what to watch out for".

It was also a rare opportunity to try AT systems like "automatic doors … all those sorts of things I don't normally have". Tom appreciated this opportunity because he was "trying to build a house" and wanted it "automated as much as possible". He appreciated learning what worked, like being able to "open the blinds in the morning… turn the lights off when you want," as well as understanding the limitations: "I found Alexa to be absolutely useless."

The limitations of voice control may be annoying, even amusing, for a non-disabled person. Yet this is no minor insight for someone with SCI, who has few alternative means of controlling systems like these, and whose safety and autonomy depend on them. Informed decisions about how the system will be controlled can be critical prior to installation because they often fundamentally shape the choice of system, and specialised access methods are difficult, sometimes impossible, to retrofit.

6.3.3 Improved body functions

> *"She really knew spinal mate. You can tell within 10 seconds, the way they get a hold of you. And I said, 'I want to kneel.' 'Yeah, no worries. What else do you want to do?' And she took me to my absolute limits and allowed me to experiment and check things out. So I brought that home with me."* (Ryan)

The program addresses body functions through allied health consultations and gym programs, with common goals listed in Chapter 5. Like for Ryan (above), these services facilitated meaningful improvements in body functions, which often had broader impacts on skills and capacity (discussed next). The reported outcomes reflected the complex reality of SCI, where functional gains like kneeling may be possible for some people through improving residual strength, strengthening unaffected muscles, and/or learning to do things in a different way. I observed a gym session where the encouragement, support and adaptation of an expert staff member enabled a person with incomplete SCI to make significant gains in their walking ability.

That was the only walking-related example in the data, and most reported outcomes related to more specific functional gains, or a reduction in body problems like pain. For the interviewees, the majority of whom had tetraplegia and longstanding SCI, these were highly valued and impactful outcomes.

The gym program also helped guests maintain "good health" and prevent and manage secondary complications. They valued the opportunity to work on body functions such as "my heart and lungs … girth control … protecting my joints and building up muscle". Guests also appreciated the emphasis on "lifestyle things" like making "smart choices that will prevent you from having stuffed shoulders".

Gym staff said even simple solutions could address long-standing issues, like showing people "a couple of stretches that reduce neck pain that they've had for years and years … and they're like 'wow that feels amazing, I can't believe I wasn't shown this in the past.'" People also reported psychological benefits from exercise, as a guest shared online: "exercise helped me focus on improving my physical strength but also made a big impact on how I was feeling mentally."

Key to these outcomes was the clinicians' SCI-related expertise. As Lisa noted,

> *"They know exactly what my capacity could be. And I trust them. So I get more results out of an hour and a half at Sargood than I do anywhere else."*

Guests also confirmed the adapted gym setup was "essential" in different ways to the outcomes, which are both general and SCI-specific. They said it provided opportunities equivalent to "an able-bodied person going to a gym" by meeting their specialised needs. They reported this opportunity was rare elsewhere, including in hotel gyms. More

problematic, however, was “trying to find a gym” to exercise in everyday life. In contrast, Ryan was impressed that “every piece of equipment in there is for somebody with a spinal injury… wow!”

Some people lived close enough to access the gym regularly, but most could only access these services during their stay. Nevertheless, staff said even temporary services often had longer-term value, especially when people were set up to continue with the program at home: “They are able to come here and catch up on a few things and to sort out a few issues and take that home.”

Short, intensive bursts of therapy can also produce meaningful, long-term outcomes, as seen in the earlier examples. An EP relayed another example of a guest who “lived rurally, so his closest access to physio and spinal cord injury services is a few hours’ drive from home.” While he “didn’t really know what to expect” on his first stay, he ended up visiting the gym, where “his whole plan for the first week changed” and “he ended up spending two hours in the gym with me every day”. This unexpected access to services yielded important outcomes, where “by the end of the week, he went from not really knowing how to exercise at home, to trialling and purchasing equipment that will give him the best access that we can get to exercise at home.”

Guests also appreciated the opportunity to discuss body functions with the CNC. For example, one guest shared how a new medication for recurrent urinary tract infections “cleared it all up straight away. And I’m like, ‘what the heck? What is this new thing?’” Carrie similarly benefited from this up-to-date and practical advice:

> *“In half an hour, as [CNC] does, she brought me up to date with the latest way to manage infections and … I walked out with a handful of notes, bottle of tablet, a card with where I’ve got to order my stuff.”*

Carrie also reflected on the importance of trustworthy information about managing her health as she ages, especially being “the first generation” to grow old with long-term SCI:

> *“I'm 30 years in a chair. I've now got to try and get to 80, being in a chair for 60 years, and stay healthy. So I know that I need to be on top of my health and I know that I'm getting to a point where the usual avenues – GP – is not enough. I need to age with my disability, and I need to be up to date. So I’m looking forward to*

booking back into Sargood … and have another meeting with the CNC and that I know... you're being told the right information."

Helpful advice about managing body functions also came from peers. Ryan shared an example:

"There's a bloke up here and he's five times stronger than me … He can push for miles, but he uses a motorised chair. And I said, 'what the hell are you doing?' He said, 'I'm saving my shoulders. … I've increased my exercise, so I control my shoulders through my exercise' … I've come around to his attitude these days."

Some options need careful thought. For example, colostomy, an alternative means of bowel management, was reported by some guests as positively impacting their participation and well-being, but may be confronting to consider. A staff member shared a story of a guest who was supported through this decision-making process by the sensitive advice of peers and the CNC.

> A recent story is one of [CNC's] clients that she's been working with a lot: she's probably stayed 8, maybe 10 times. Her bowel care goes for 8 hours of her day. So she's up at 10 o'clock in the morning and she wouldn't finish bowel care occasionally til 4 o'clock in the afternoon. That was normal. We condensed it to about 4 hours … And slowly, slowly, slowly chipped away. And she just had a colostomy done. And we've had her speak to people here who've had colostomy bags, we've had her talk to so many different people: 'This will change your life. You won't have to sit on the toilet for four hours, you'd be out in the community.' And she's got it done.

6.3.4 Improved skills and capacity

"I think their outlook or their context for everything they do is increasing capacity or increasing quality of life. That's just where they operate from." (Lisa)

Guest interviewees appreciated the opportunity to "learn some skills" they could use in their daily life, recognising "it's not just a holiday place, it's a place for education and support." As well as the functional gains in the gym (above), guests gained capacity in a range of skills and in various ways. For example, Ryan shared his plans to,

"... go to Sargood to learn how to surf. I'm going to sail, to learn how to dance. I'm going to start with – well, they don't teach driving – but I'm going to start with learning some of the tricks of driving."

Peers make an important contribution again here, as they can provide particularly helpful advice about practical skills. Lisa appreciated the opportunity to "observe, learn, see how they adapt things". Ryan shared an example of teaching a skill to a fellow guest, reflecting on how meaningful it was for him to be able to contribute in this way:

"... we were having a meal together ... and she nearly dropped to the floor and said, 'oh my God, how do you do that?' And her lesion was very similar to me, and I said, 'what do you mean? Haven't they shown you how to bloody eat?' ... And I said, 'this is what you do'. She couldn't believe it ... It's very emotional for me ... something as simple as that, that made such a difference to her life."

Guests also learn skills from allied health staff. For people like Lisa, access to on-site clinicians offered a rare chance to work on skills like transfers, with gratifying results:

"I've only done Sargood four months and I've gone from being stuck in a wheelchair and carers doing everything, to, 'Dear [Lisa], please practise manual transfers'. ... that's a bit of a change."

She light-heartedly added an unexpected benefit of trying new things at the program: "I'm good at ceramics now too!"

Lisa attributed these gains to the staff's experienced and positive approach to problem-solving, explored in Chapter 8. This countered her own low expectations ("I'm going to deteriorate") and those of other health professionals ("I was told my arms were too short, so I couldn't do manual transfers"). In contrast, program staff offered practical suggestions like "put your hands more forward … or use blocks," and encouraged her that she could "practice more, build up the strength". This experience was a revelation to Lisa, who had "never looked at it from that point of view, that I could get stronger… So it was life changing."

Courses are another avenue for developing skills. Lisa shared her experience of the *Skills for Independence* course, where she made gains in "wheelchair independence" and "being responsible for the conversations around you … setting up your environment to win".

AT was another crucial enabler of capacity beyond the program, when guests went on to purchase the AT they had seen or tried there. While staff don't complete funding applications they can provide a letter outlining the outcomes of equipment trials to support an application by the person's usual therapist. Carrie shared her experiences of having basic items declined by her funder, and her expectation the program would lend more weight to her applications:

> *"Next time I need a piece of equipment, I'm just going to go to Sargood, stay, test the equipment and pay to get a proper report that hopefully NDIS won't knock me back on. Because how can they possibly knock me back on a piece of equipment that's being prescribed by an expert? So I've struggled up till now to find people … that can write proper reports that NDIS will fund."*

Guests are sometimes provided with custom AT solutions to take home. CAD design and 3D printing is a useful means of manufacturing solutions in-house, offering "rapid prototyping" for testing and refinement, and a low-cost method of producing products for individual guests. For example, a guest shared on social media how "the OT was able to help design and 3D print joysticks specifically to my hand function so I can fly drones a lot easier."[5]

6.3.5 Independence and engagement in meaningful activities outside the program

> *"Now I play golf at least once a week… and I'm a member of my local golf club … it's a huge outlet for me, and its life changing to my mental health as well."* (Ben)

Some of the outcomes discussed so far are meaningful in their own right, as they address troublesome issues and contribute to an improved outlook. Many are meaningful because of their contribution to independence and engagement in meaningful activities beyond the program, and the discussion now broadens in scope and extends in time to consider these impacts.

As alluded to throughout the chapter, this intended outcome was successfully achieved for many guests, who emphasised the program "does impact people's lives, not just while they're there". One person shared in a media article, "my independence increased tenfold. It's taken a while but I'm now doing everything I used to do."[6] Interviewees shared many examples of activities they'd continued with in their everyday lives.

A recurring theme in these stories was initial low expectations, having an opportunity to try the activity, realising its significance and feasibility, and being equipped to continue it. This process mirrors the program logic, which underscores the importance of well-conceptualised and explicit aims, a topic I return to throughout the thesis. An anecdote shared by a staff member illustrates the process:

> *"He thought that because of his function, [mountain biking] was something that he wouldn't be able to do again. And he trialled mountain biking while he was here and found that that's actually a viable option for him. So we linked him in with somebody near home who can help him purchase some of this equipment to continue doing that hobby that he enjoyed before."*

Many of the examples related to recreation activities, as Sian observed: "a lot of people that go there discover rec activities that they can then go and do in their lives." She shared examples of a person who "discovered surfing, and he was going to do that when he went home … And another lady decided that she wanted to do hand cycling. So the rec guys were helping her put together a quote for the NDIS so that she can get a handcycle."

Several guests also made gains in their ability to travel. Interviewees shared how the supportive facility was "the perfect stepping stone," that got them "at least part of the way there" as they pursued more challenging travel goals. An on-line testimonial shared a similar example: "I've gone from the woman who wouldn't leave the house, to the woman who's planning an overseas trip!"[1]

The following vignette summarises a CNC's story about guests who used their stay as a trial run before expanding their travel options. They gained skills and confidence, and worked out what they truly needed when traveling to more challenging locations.

Having a clinical basis here gives people a breather and eases their worries, especially those traveling or holidaying for the first time. They know that if anything goes wrong, someone will be there to help. We've been that confidence-builder for many guests. For instance, some guests come to us first because they want to go on a cruise but aren't sure what to expect. They use their stay here as a test run, asking us about equipment, medications, and preparations.
We discuss their experiences, what they've learned, and what they need to take with them. Guests have told us that being here is a safe environment where they can figure out and prioritise what they really need for their travels. Many have said they used us as a testing ground and ended up loving it so much that they returned just to stay here again. Initially, they came to enjoy Sargood and prepare for future travels, and they found comfort in knowing they had the resources and support they needed. But the main reason for coming was to be able to step out of their comfort zone afterwards.

While less common, there were examples of people going on to explore new vocational options, like an online testimonial from a person whose experience at a 3D printing workshop helped him realise, "there is a lot more vocationally and recreationally that I can do regardless of my injury", including "thinking about a potential career in drafting".[1]

Interviewees also valued improvements in their basic daily routines and personal care, such as learning "how to do my own bowel care, which I never thought I'd be able to do". Staff shared several examples and their impacts, such as a teen boy whose "parents used to have to travel with him [to sporting competitions]… now the person who travels with them with the team just needs to give him five minutes of assistance and otherwise he is fine on his own."

A staff member noted these seemingly small gains can have a large impact on independence, as well as instilling a sense of hope for future improvement:

> *"Little things can make all the difference: like being able to feed yourself with modified cutlery, that can make a world of difference to your independence … If we can give them that support and encouragement to meet those small goals, it kind of gives them that – hope, I guess – that they can continue on that journey of becoming more independent."*

Most interviewees with SCI had a high level of disability and still needed a lot of assistance in everyday life, though it's noteworthy this was not foregrounded in their discussions and seemed an accepted or inevitable aspect of living with SCI. While some of these interviewees still used the word 'independence', what they valued was not doing things without any help, but being able to participate in meaningful activities by any means.

For these guests, the availability of skilled support was a crucial factor in their participation outside the program. As Rob noted,

> *"Everyone seems to think, 'but I'll get beach chairs. Or a ramp at the pool'... Well, that's not much good to me, I can't use it by myself. Someone else has to be there."*

The program facilitated access to this support by training caregivers and linking people to local services. However, access to skilled assistance was still limited for many people. While some activities were viewed as a holiday-only experience, this barrier was a reason some people did not participate in activities they would have liked to outside the program.

6.4 Enhanced community and social participation

As well as independence and engagement, the program sought to enhance social and community participation more broadly. Many of the activities described above would contribute to this aim, since they involve being in the community, joining clubs, and interacting with others. Ben's earlier example illustrates this link: engaging in a recreation activity, even in a modified form, enabled him to be part of a valued community. As he reflected:

> *"Yes, I happened to catch some waves lying down rather than standing up. But while I was out the back waiting for a wave with everybody else, I was just the same as anyone else out there."*

Participating in community-based activities would presumably also foster social participation with others in those groups, although this was not strongly evident or explored within the findings. Clearer findings about social participation related to loved ones and peers. The program also contributed to participation in an unexpected way – by becoming a valued community itself. I now explore these themes.

6.4.1 Changed relationship dynamics and roles

Independence and confidence appeared to have flow-on effects for relationships with loved ones, as they impacted relationship dynamics and roles. These impacts featured less prominently in interviews with people with SCI, but were evident in online guest accounts and staff interviews.

Shared, positive experiences can increase bonding, as highlighted in a website testimonial: "this trip has made our family bond refreshed and stronger." Resuming a shared activity can also restore a familiar and more equal dynamic. A staff member relayed an example of a young man with SCI who thought he'd never fish with his dad again, but when provided with an adapted rod and a drone "suddenly he's actually better at fishing than his dad". This experience meant "that bonding they used to do when he was much younger is being relived".

Relationship dynamics can also change when a person gains autonomy. In an online video, a guest reflected on how her family dynamics altered after her independent stay: "I always rely on my husband and kids to help me at home… now I've realised I can actually do it." Being more independent also brought moments of solitude and privacy, and she came to appreciate "it was actually nice being on my own … after my accident I was surrounded constantly by other people."[7]

Being able to contribute to a loved one can also shift relationship dynamics. A staff member shared a story of a tetraplegic guest making a cup of tea for his wife using the adapted kettle

> *"… and the wife just burst out crying. Since the injury her husband had never been able to make a cup of tea for her … someone to offer a gesture that they couldn't offer before … Now the effort's been put in and that meant more than a cup of tea."*

The program may also create opportunities for parents with SCI to fulfil this role in new ways, at least during their stay. A staff member described how "mum can have a sleep-in and then dad takes the kids out to head down to the gym or hit one of the tracks round here." They reflected on the value of this dynamic: partly "it's independence," but also "being allowed to parent" in a way that fits the holiday context: "doing things the kids want to do" and "enjoying each other's company whilst on holidays. It's nice, it's fun".

These experiences may be especially meaningful for families navigating relationship and role changes early after injury. A mother with SCI shared online her experience of visiting the

program during this phase, describing how it offered a reprieve from relationship stressors and created space for positive time together:

> *"When I had my accident … we all went through a big transition where we had to redefine roles … A place like Sargood is a total game changer for a family who are adjusting to a member having a spinal injury. It creates an opportunity to enjoy each other without the stress or responsibility of looking after their mum."*

6.4.2 Social interaction with peers

> *"Just being around people with SCI and going through different but similar journeys was great and having yarns with the people, their partners and families wheeling through."*[5]

The program provided opportunities for social interactions between peers with SCI, as well as with their significant others. Staff reported "lifelong true friendships" between guests or family members, who sometimes "tim[e] their stays" to be together again, and "often are back in touch outside of Sargood as well".

For some interviewees, social interaction with peers did not extend beyond their stays yet was still valued. This may have occurred in small but impactful ways, for example Alan appreciated "the free cup of coffee after [a gym session] … sitting on the balcony, exhausted," noting that "people are social animals". Social interactions happened in informal, everyday contexts. Interviewees highlighted opportunities like "the social drinks on Friday nights" and group recreation activities. Common spaces, such as "the courtyard area," "game room," and the kitchen and dining area, also encouraged connection, with families often "cooking… or sitting around the tables".

Courses are another avenue for peer interaction. Tom, a course leader, explained having participants staying together is an opportunity for "all the stuff that happens outside" the formal learning of the course. Prolonged time together is a chance for "the conversations that weave their way through evening sessions or breakfast or smoko or whatever". Angela relayed her own experience of a course where "most of us became quite friendly, which was nice. The sharing of stories." Some courses, like kids' camps, are specifically offered to encourage shared experiences. As one child with SCI said in a media article, "I can do a

bunch of things that I wouldn't be able to do at home, and I get to be around people who understand me."[8]

It is worth noting not everyone wanted to socialise with other guests with SCI, with some opting out of social and group activities – at least initially. Sian noted that some people "shy away from talking to other people with spinal cord injuries because they think … 'the only thing that we have in common is that we're both injured." She also reflected that some people with SCI "don't want to deal with other people in wheelchairs" – while observing that the program can help change these perceptions: "Once you get over that stigma … you do meet other people that you do get along with," and although "you're not going to get along with everybody that's there … you might find somebody that you see eye-to-eye with."

Sian's intuition was supported by the perspectives shared by a few other guests, who were reluctant to engage with peers if their injury was the only basis for connection, explaining "I don't necessarily want to socialise with people if [SCI] is all we've got in common," and "my first identity's not my spinal cord injury". But after their initial hesitation they were able to meet "some really nice people, I've socialised with," and ended up appreciating the social opportunities offered by the program.

6.4.3 A new source of community

> *"It's like a family in a way … the sense of community would be the most important [lesson for other programs]."* (Adam)

As well as facilitating participation in the broader community, the program created its own community – a place of support and connection people with SCI can enjoy and return to. For Adam (quoted above) the sense of community was the most valued aspect of the program – which was fostered by relationships with staff in his case.

The community also encompassed peers with SCI, and their loved ones. Social interactions often quickly deepened into understanding and support, and fostered the sense of community. For some people, this was an unexpected and significant program outcome. Carrie is a good example. Despite appreciating the potential of peer support, having volunteered for many years, she no longer experienced these benefits herself. She was now "by choice, out of touch," because she hadn't found an appealing way to stay connected. The program represented a significant reframing, offering a new and appealing context for peer support in

a space she enjoyed being in, meaning she could "have a small connection with the wheely community in a really pleasant environment" without being "an outpatient, or worse, an inpatient". Carrie explicitly linked this realisation to her well-being, and became emotional talking about it: "I just think the place is awesome. I've got a lump in my throat about it."

Other interviewees similarly described "a supportive place" where "it's easy to connect" and where they felt understood, valued and included by staff and other guests. These experiences were also common in on-line testimonials, where people said "they're like family to me now" and "it feels like we're part of a community that is outside of the hospital." This was valued because "when you're at home, you're kind of isolated so it's nice to be able to talk to the other guests."

Encountering this community added to the sense of 'normality'. A person with SCI shared in a newspaper article the unusual experience of being in the majority "because everyone's in a wheelchair, it's normal. I say to my husband, 'he's on my turf now.'"[9] It could also help people work towards a new norm, as someone shared on-line:

> *"Being part of this community and sharing a lived experience with non-judgemental and supportive staff helped me to let go of some trauma and begin to work towards the acceptance of the new normal."*[1]

The wife of a person with SCI reflected on the complexities of defining normality post-SCI, where the program helped them feel,

> *"... normal for once, and part of a new family. I'm not going to call it a new normal, because life with a SCI is far from normal, but we felt understood and didn't need to explain things to those around us."*[1]

6.5 Well-being impacts

The chapter now turns to reported well-being impacts, related to the overarching aims of people with SCI being "happier, healthier and prepared to tackle the next big thing in their life," and living "full and rewarding lives".

The outcomes explored so far contribute to this overarching aim, again demonstrating strong internal alignment within the program logic, and between the intended and reported

outcomes. Some of the outcomes, such as positive emotions, are *components* of a good life and impact well-being directly. Most of the reported outcomes are better understood as *determinants*, influencing well-being indirectly. I summarise their contributions to well-being below and outline theoretical foundations for these ideas in the discussion chapter.

Relaxation and refreshment from having a break contributed to a sense of renewal and restored a healthier balance of positive and negative emotions. The enjoyable, challenging recreation activities also significantly enhanced positive emotions, and built confidence. Engaging in these deeply missed activities also restored some of the losses of SCI, as they were a rare opportunity to relive pre-injury experiences, and represented their pre-injury identity.

People were also equipped to engage in similar experiences outside the program, and they had a greater scope of meaningful activities available to them. The program also fostered a sense of value and capability – more SCI-related losses – as people were treated with dignity, felt 'normal,' and gained skills, confidence, capacity and autonomy.

Relationships were enriched as positive, shared experiences enhanced bonds, and families experienced a reprieve from relationship stressors. Relationship dynamics and roles may have also been enhanced, as people with SCI gained autonomy and loved ones saw their potential in a new light. The program also offered new avenues for connection: with peers, in community-based activities, and as a valued community in its own right.

In addition to the outcomes already discussed, two well-being outcomes emerged strongly from our findings: improved outlook and life satisfaction. These arose when people became aware of new possibilities and were equipped to pursue them – building on earlier outcomes like inspiration, confidence, and engagement.

Improved outlook relates to a shift in perspective: seeing what is possible and what life can look like moving forward. Life satisfaction is closely linked to this idea but less future-oriented, capturing a renewed sense of vitality and wholeness in the present. I now explore these ideas as I draw the chapter to a close.

6.5.1 Improved outlook

> *"It gives you hope for 'there are things I can do. Wow, there are more things I didn't think of I didn't know.'"* (Rob)

People with SCI reported a "much more positive mindset," "positive thoughts" and improved outlook. Lisa described this particularly eloquently and emphatically when asked whether she thought the program impacted well-being:

> *"My technical answer would be, 'shit yeah'. They completely changed my world … It completely shattered [laugh] – which is a good thing – completely reshaped the way I thought my life was going to go. And for my husband and family: my parents were in tears every time they spoke to me when I was there, because I'd say, 'look what I've learnt, look what I've discovered' … they completely changed my view of what was possible and what my future looks like."*

An improved outlook was also evident in many on-line testimonials, with people sharing the program "makes you realise that there is so much still possible" and helped "change the image of myself in my head about what was now "normal" … what else I could be doing to make myself happy again".

This outlook stands in contrast to the negative expectations and despair reported early after SCI. Lisa compared her new perspective (above) to her earlier one, where "I hadn't realised how debilitating my experience of being in a wheelchair had been like, that my world had got so small … this really was as good as it gets and it's only downhill from here." The program transformed her perspective about the possibilities available to her: "I cried nearly every day [laugh] but more out of what was possible … I had no idea, having my eyes open to, 'if you want this, this is probably possible for you.'"

Lisa was one-year post-SCI, and I didn't interview people with a more recent injury. But other interviewees mused about how different their experience might have been if the program was available earlier in their journey: "Wouldn't it be nice to have had that for all your life?" People with established SCI shared similar sentiments in online testimonials as they reflected on their early days when,

> *"It's the mental anguish that you are not prepared for … It's a massive readjustment not only for the individual but for the whole family. I wonder how things would have been different for myself and my parents if Sargood was around back then… Thank goodness it is here now.*[10]*"*

Staff also provided insights about newly injured guests they'd worked with. They shared examples of people who had visited during their inpatient rehabilitation, who were "quite

depressed because they think, 'there's nothing I can do now.'" Visiting the program helped them realise "there's a lot of other things that they can do with their injury, and they can still have a life." This story from a staff member was illustrative of these kinds of examples:

> *"Two young boys, about 15, came and visited from [inpatient rehabilitation] … just for a stay over the weekend. We got them doing every single activity that they could possibly do. And they – their families really appreciated it. They were so happy that they could show their sons that there are things that they can do and there are things that they can look forward to and enjoy."*

Even interviewees who had been injured many years ago reported significant shifts in perspective – like Rob, who had been living with SCI for nine years and whose quote opened this section. Ryan also reported the program had "huge" psychological impacts 46 years after his injury, because it was "motivating, inspirational, confirming … simply showing that it's possible".

People with SCI of many years also expressed similar sentiments on-line, sharing how the program helped them "realise that I was able to do more than I thought" and "opened my mind to the fact there is still so much that I can do" even many years after injury. They said the program gave them "a new bucket list, a new plan of things to see and try" and "a motivational boost to get me moving again;" it "made me reset my goals and realise I was able to do more than I thought," and "has been my reminder that life has not finished; it has only changed."

Family and friends may also have their expectations raised about what is possible for a loved one with SCI. Lisa said her husband was deeply affected by his stay, where,

> *"He got to meet other spinal cord injury people, other people in wheelchairs, talk to allied health professionals, see how other people use their wheelchairs … And there was someone there who had a similar level injury, so it was kind of like, 'well, in theory, anything he can do, [Lisa] can do.'"*

Similarly, Sian said her father was "very impacted by Sargood" as he gained a greater understanding of the possibilities available to her:

> *"I don't know what he thought [before], but he definitely felt that life was okay … he was like, 'Oh my God, you can do this.' And he was just blown away by the*

accessibility, and he was like, 'We need to get you this in your house.' Yeah, he was very affected by it and he constantly talks about it all the time now."

Rob's opening quote used the word 'hope,' and the importance of hope after SCI is often emphasised. However, the term implies a level of intangibility, especially in the early context where things are uncertain and people may need to look forward to, or trust in, a different experience in the future. The improved outlook participants reported was more certain, immediate and internalised; it was grounded in what they'd witness and experienced, backed up by newly realised capabilities, and strengthened by growing confidence. This placed the future possibilities within reach, because many of the necessary conditions were already in place. Even when Rob used the term 'hope' he then shifted to the present tense. These insights suggest 'hope' does not fully encompass the outcomes reported here (though I explore its role in the discussion chapter) and underpin my decision to use the term 'improved outlook' instead. The immediacy of these possibilities may have also contributed to greater life satisfaction in the present – discussed next.

6.5.2 Life satisfaction

"Your life is more complete, Its more fulfilled … it makes your life more whole" (Rob).

Rob's quote above echoes the overarching aim to promote "full and rewarding lives," which would no doubt be gratifying to program designers. In addition to, or perhaps because of, an improved outlook about the future, guests reported an impact on their life satisfaction in the present. For Adam, this involved a "different mindset," and his experiences meant he could "get more enjoyment out of life" and "feel valuable, or valued".

Staff also relayed examples of where "it's changed their overall well-being and their mental health and how they view their lives and view the world now since the injury." "I've had few people say that their experience here at Sargood … changed their life, and maybe saved them?" A staff member talked about a guest with long-established SCI whose family member shared at his funeral that,

"… coming to Sargood was his favourite thing to do. His highlight, pretty much, to his life was having opportunity to come here and seeing what's possible for someone in a wheelchair. And that it's not the end: there's so many great things that are awaiting them."

The document review revealed similar testimonials of the program "changing people's lives and making them better," with one person saying the "impact on our life will last eternally". People used terms like "feeling alive," "made me whole again," and – the social media post that originally sparked this project – "helping me fall back in love with life". I conclude the chapter with a social media comment that captures the ultimate impact on well-being particularly effectively, and demonstrates the program can enhance the pursuit a good life, even decades after injury:

> *"'Living life to the fullest'.....that's something I have tried to do ever since becoming a para at the age of 12. Coming to Sargood on Collaroy put a whole new meaning to that some 39 years later."*[11]

Document sources of specific information and extended quotations

[1] Sargood on Collaroy website – Our satisfied guests

[2] @katford66 (20 January 2020). Facebook post

[3] Comment on Sargood on Collaroy Instagram

[4] @Sam Bloom (11 June 2025) Facebook post

[5] @Jake Briggs (20 February 2023) Facebook post

[6] Swain, S. (2017, September 16). *The world's first holiday resort for people with spinal cord injuries has opened in Collaroy*. Manly Daily

[7] Sargood on Collaroy Facebook post

[8] Clancey, D. (2023, n.d.). *Former governor-general praises special camp for brave children*. A Current Affair

[9] Swain, S. (2017, September 16). *The world's first holiday resort for people with spinal cord injuries has opened in Collaroy*. Manly Daily

[10] The Sargood Foundation website – About Us

[11] (5 September 2019) comment on Sargood on Collaroy Facebook post

Interlude

The last chapter outlined reported outcomes. The following chapters examine how these outcomes were achieved, using a *theory of change* framework.

I introduce these chapters with a vignette drawn from my observation of a recreation outing. The account illustrates how the themes from the previous and upcoming chapters are enacted in practice. Pseudonyms are used.

It seemed I'd chosen a great day to observe the snorkelling session. Even on a weekday, Shelly Beach was alive with activity: swimmers, snorkelling groups and families all taking advantage of the warm weather. The rec team had parked the van in the top carpark, because the accessible space closer to the beach was taken. Marty, who has incomplete tetraplegia, was being carefully guided down the steep driveway in his wheelchair by Finn, the recreation team leader, and Chloe, the recreation assistant. Andrew, a new trainee on the rec team, followed alongside, watching closely and stepping in to help when needed.

Finn then guided Marty into a custom-made steamer wetsuit and neoprene bootees, explaining these were for warmth while also helping with buoyancy and skin protection. Customised zips meant the tight suit could be opened up wider, making it easier to get on and off for someone who couldn't move much or stand up. Even so, it looked like a delicate process and Finn took extra care to protect Marty's skin and joints, and support him as he leant from side to side. Finn was training Andrew as he worked, carefully explaining why and how he completed each step. This explanation gave me useful insight too.

Once Marty was suited up, Chloe helped him across the sand in the beach wheelchair to the water's edge, and Finn and Andrew carefully helped him slide into the deeper water. Finn ran through arm movements he had taught in earlier pool sessions and established hand signals for communication. I thought about how intimidating this experience might be, especially for the first time. I could see how Finn's approach – calm, encouraging and vigilant – would be reassuring.

Marty, Finn, and Andrew snorkelled together, while I watched from the path (wishing I'd come equipped to swim too.) They stopped after about 25 minutes to prevent Marty getting too cold. Once everyone was dressed and warm, we sat at a picnic table together and chatted over coffee.

Marty was grinning and said, “That felt so good, it’s just so nice to be weightless.” He was keen to keep snorkelling outside the program, and I reflected on how this would be quite achievable for him. I’d been calling it ‘adapted snorkelling’ but it required less modification than I’d expected, even for someone with tetraplegia. Once Marty was in the water, it looked like anyone snorkelling with a buddy. Marty had evidently not realised this either, not having attempted it til now. I thought about how simple yet hard it was to overcome this barrier: ‘all’ it took was support, advice and skill training from people dedicated to opening up a new activity to people with disability.

Marty asked about buying the same wetsuit. Finn told him about the supplier they’d found and shared some tips for extra modifications, like adding a zip for easier access to his leg bag.

Marty and the team included me in their chat and were generous in sharing their experiences to help my research. Marty said he’d recently been interviewed by the CNC about his colostomy, keen to share the significant impacts on his quality of life. The interview was going to be added to the video reel for other guests, which includes a range of peer insights and AT updates. Finn told me about the first Dungeons and Dragons night, which they’d just put on as a new activity for people with limited arm function. It was a surprising hit, especially with quieter people.

As the session wrapped up and everyone started heading back to the van, Finn warned Andrew about a tricky lip on the footpath ahead and explained how to safely manoeuvre the wheelchair over it. The steep driveway back up to the van was another challenge, and Finn mentioned how he’d been advocating with the council to install more accessible parking spaces closer to the sand.

Observing this session brought to life some of the outcomes I’d been hearing about, like positive emotions. Marty’s reaction, while less elated than some reports, appeared to reflect a quiet satisfaction of doing something he loved. Marty was also gaining skills and capacity to pursue a new activity outside the program. Body problems were skilfully managed during the activity, and Marty was also keen to inspire and educate peers about the colostomy that had impacted his well-being by making bowel management much easier. While there were no other guests that day, there was a sense of community amongst the group.

The session also illustrated all three program elements and underscored how they are related. Marty used the short-term accommodation as a means for accessing the recreation program and the world class snorkelling spot nearby: an aspect of the program’s physical context. The outing served as a means for capacity-building as staff imparted skills and tips to continue

with snorkelling longer-term. In this chapter, I explore how these program elements function as *mechanisms* through which the outcomes are achieved, and how their integration in a "hub" enables symbiotic outcomes.

Underlying *operational factors* were also evident during the outing; these are the focus of Chapter 8. The attitude and approach of the staff strongly influenced the session, and I observed a calm, casual yet vigilant approach. I could concur with an online testimonial that described a staff member as "a bright, young guy with a gentle energy that immediately instilled a sense of confidence that everything was going to be great". The rapport among the group also made it feel like a shared activity between friends.

The session also highlighted the staff's determination to expand activity options. Although Marty had been interested in snorkelling for some time, it had been overlooked by other programs despite being relatively simple to adapt. Even with the casual vibe, SCI expertise and risk management were evident throughout the session, as staff both promoted and managed a risky activity.

Finally, the session offered insights – and raised questions – about how the program's *context* shapes delivery: factors discussed in Chapter 9. The equipment required funding and research to find suitable adaptations, and physical barriers, such as the lack of wheelchair-accessible parking, impacted the outing. However, staff demonstrated familiarity with the local area and its challenges, finding practical workarounds and advocating for broader changes.

CHAPTER SEVEN:

MECHANISMS USED TO ACHIEVE OUTCOMES

This chapter contributes to the theory of change by exploring *mechanisms* through which the program achieves its outcomes. It addresses research question 3a)

How does the program achieve its well-being outcomes?

a. **What are the key mechanisms that explain how the program's activities lead to well-being outcomes, and what assumptions underlie the design?**

Some of these mechanisms were introduced in the program overview, but this chapter adds depth and shifts to a more analytical lens. Chapter 6 also alluded to mechanisms at times, because when talking about an outcome it was often natural for guests to explain how it was achieved. I try to avoid repeating that information in this chapter, where staff voices take centre stage as they offer a 'behind the scenes' perspective, including the *assumptions* and *principles* that shaped the mechanisms. Since this chapter connects and builds on the previous two, I refer to their section headings at times: when seeking to make these connections more explicit, or for ease of reference.

The other data sources provided validation and detail. The document review shed more light on the design principles, and were a useful source of the perspectives early designers I was not able to interview. Observing the program enriched my understanding of its delivery and enabled me to include vignettes that illustrate how design is enacted on the ground. I also consider what guests found most valuable and impactful and how their views align – or diverge – from designers' assumptions.

The chapter is framed by the program logic. I first explore the socio-historical context, examining historical design principles, and how these informed the intended outcomes. I then explore the three program elements, first separately, then their integration in a 'hub'. Finally, I consider pervasive, underlying mechanisms of change, which the program logic was less suited to visually representing, but are explored in depth in this chapter.

As a side note, the 'refresh, learn, connect' slogan – which was a vision at the program's inception[1] and became a tagline[2] – also neatly encapsulates key mechanisms of change and could have offered an alternative, more conceptual framing for this chapter. I opted for the more concrete and detailed design insights offered by the program logic, but do refer to these concepts at times.

7.1 The driving principle: an explicit focus on well-being

The program intentionally targets well-being, reflected in its overarching aims to help people with SCI live "full and rewarding lives" and become "happier, healthier, and prepared to tackle the next big thing in their life". Various stakeholders said this was important and distinctive.

A program advisor with SCI explained "there is nothing like this in the world … that focuses on your whole well-being." In a newspaper article, a spokesperson for an SCI research institute noted the field's focus on finding a cure, and praised the program's recognition that "people with an injury want to be living their lives now. They want to see improvements in quality of life."[3]

The well-being also featured prominently in staff interviews. They described overarching aims consistent with those set out in documents, including creating "a place – one of a kind – that our guests can come and see there is a life post-injury… that they're not excluded and they can try new things and that life is ongoing." One staff member captured the multidimensional nature of well-being particularly well:

> *"We want to show that there's so much that's possible beyond the injury ... to be given an experience that changes them for the positive ... or get that bit of positivity or that bit of spark. Hopefully you've impacted them in a good way, so they can still 'chase the dream' ...or find something new that makes them gives them purpose ... find their 'why' in life."*

Interviewees with SCI recognised well-being as a central focus, but found this difficult to articulate: "there's probably something huge, deep and meaningful that they're trying to do. Make the life better for people with spinal cord injury – I don't know." When directly asked

about well-being, their responses became more focused and emphatic, illustrated by a range of examples. They appreciated the flexible and tailored way the program addressed this individualised phenomenon, as Lisa shared:

> *"I think their outlook or their context for everything they do is increasing capacity or increasing quality of life. That's just where they operate from. But I get to say what that looks like."*

A blog post expressed similar appreciation for the individualised, "holistic approach" – recognising that tackling the overarching well-being aim could look different for everyone:

> *"It could be returning to school, study or work, continuing hobbies or starting new ones. It could be about maintaining social connections, starting a family or travelling. It's whatever you want it to be. You might want to just chill out and relax. That's OK."*[4]

The program tackles its overarching aim by targeting more specific factors assumed to contribute to it: the immediate and intermediate intended outcomes. The program advisor with SCI explained the intention to "help people be as connected and independent and self-confident and engaged with a community as they can", believing these factors lead to "a better quality of life" where people "live the best life they can post-injury". Staff shared similar assumptions about what influences well-being: "What do I see as a better life? One of independence. One of community access." Program documents made similar connections between well-being and factors such as "confidence and skills," "refreshment," "inspiration" "social integration" and activity".

While it might seem obvious, it is worth pointing out another assumption at play: that people with SCI need support for these things, and that their needs are not met by existing services. I now discuss service gaps and problems program designers sought to address.

7.2 The problem: barriers to ongoing support

Program designers were guided by the assumption that to live a good life, people with SCI need support from peers and specialist clinicians at various points in their journey. The program advisor with SCI observed "a lot of people that experience spinal cord injury do

need a hand to get back to living independently" and "it takes some people a lot longer than others to do that". Designers also recognised it was difficult to access this support after the early rehabilitation phase.

The program advisor with SCI went on to explain rehabilitation settings are focused on the immediate aftermath of the injury, and are a whirlwind of medicinal, physical and occupational adjustment. But it is not until a person leaves rehab and returns home that they really face the reality of how life has changed. Adjustment can take several years but, many people are isolated from professionals and peers with SCI after leaving the rehab facility, without access to these supports for adjustment, acceptance, and flourishing. As time passes, they may also be unaware of developments that can be life changing. These observations are mirrored in the 'refresh, learn and connect' vision, which seeks to address these very challenges.

The then general manager explained a key design principle in a newspaper article[2]: "there was a very high importance to appeal to different stages in the journey." While at first "it was looking to be a rehab centre" they soon recognised this would not be an appealing environment. Focus groups of people with SCI told them, "We're not coming to anything that looks or feels or smells like a rehab centre … while that's an important stage, we don't want to go back to that."

The program advisor with SCI also felt "nobody wants to go back to rehab" – a shared assumption that fundamentally shaped the design. As well as representing to him "a pretty awful time kind of dealing with a lot of trauma after an injury", he felt it was "just not an appealing destination to keep in touch with and check in with at any point after you've exited".

Guest interviewees supported this assumption. As Ryan put it, "you need to have that separation." Inpatient rehabilitation represented bad memories for him, too:

> *"It's such a high stakes highly emotional place, of good emotions or bad emotions. It's the onset of injury: your whole life is laid out in front of you. Your whole dignity is gone, but that's what spinal cord injury does. And it's a great place to be out of. I don't want to go back."*

The accuracy of the program designers' assumptions likely reflects the contribution of people with lived expertise. This alignment is reassuring, since those assumptions went on to fundamentally shape the program.

7.3 The solution: refreshment and capacity-building in an appealing environment

The former general manager continued explaining the design process in that newspaper article. The recognition that "you are not going to get someone at the end of their journey that is thriving and earning money, coming back into a rehab centre" led to the defining insight " … but you would get them coming to a resort environment". This 'lightbulb moment' shaped a key design principle: creating a genuinely appealing program.

They realised a "resort-like" clinical service still wouldn't be appealing: "it had to be a resort". The donated waterfront site enabled this, and SCI focus groups confirmed the need for accessible accommodation. Together, these led to the creation of what the program advisor with SCI described as an "appealing kind of luxury destination". The addition of a recreation program was in keeping with this vision, making it "kind of like Club Med", as a staff member described it.

People with SCI recognised and appreciated this resort-like environment. The formal general manager would have been gratified to hear her thoughts echoed in an on-line testimonial:

> *"I imagined Sargood would be a bit like 'rehab by the sea' but it's nothing like a prettied-up version of rehab, I love how normal it is."*[5]

The assumptions about a clinical environment being a barrier proved correct. Being non-clinical was crucial to Ryan, as well as his friends, whom he keeps encouraging to give the program a chance:

> *"'You should go down and stay at Sargood.' 'Was it rehab? I'm not going down there.' 'It's not like rehab.'*

While they undoubtedly knew it wasn't literally "rehab", they had preconceived ideas about what the experience would be like – presumably based on what is usually offered to people with SCI. Carrie shared:

> *"It took me a couple of years to get the courage to come stay ... for fear that it was a bit more hospital-based than it turned out to be. I didn't want to go and stay somewhere clinical."*

This concern was especially acute when she booked her first stay with her kids, who wanted a regular holiday. She was therefore "really worried that I'd get there and go, 'it's just a really nice nursing home environment.'" Her fear was also for herself, and well-founded. For someone with long term disability like Carrie, the intersection of 'a break' and 'disability services' still produces a negative: 'respite'. She explained respite is often associated with memories of institutional spaces and anxieties about the future, which means a break in an environment like that is not a holiday, rather:

> *"That's reminding you that you've got a high-level disability that makes you different to everyone. And it's also very challenging for someone like me because the chances are I'll end up in a nursing home earlier than my peers because of my disability. So the last thing I want to do while I'm still able is to go into that environment ... We've all spent very unpleasant time in, in hospital settings. So respite in a hospital: that's not respite. That's reminding you of either your past or your future."*

The program being promoted as a resort was enough to overcome this reluctance, at least for the interviewees. Sian noted: "I think the hotel aspect of it is a bit that cracks people like me. And it would crack my peers that I'm thinking about – long-term wheelies." They were therefore willing to take a chance. Lisa shared how she "was very doubtful, but I thought, 'go for a weekend. If it's anything like a hospital, I won't go there again.'"

Their willingness was well rewarded: Lisa went on to say, "I couldn't believe it when I saw it." Her surprised awe was echoed by many others and captures how strongly the program challenges expectations of what is offered to people with SCI. I return to Lisa's anecdote, and this theme, in the next chapter.

I now return to the design narrative, in which the program was taking shape. The accommodation and recreation program could add a new layer to the 'refresh' part of the slogan, but designers needed to more fully address the 'learn and connect' components.

While peers with SCI could support learning and be a source of connection, designers integrated this throughout the program rather than as a discreet, formal service – discussed later in the chapter. Clinicians, too, could support learning, while also addressing the other well-being factors like skills, confidence, independence, and participation. Capacity-building services therefore became the third program element.

The integration of the three program elements in an appealing, resort-style environment, became the solution to the problems and aims discussed above, and represent the overall mechanism for achieving the outcomes. I now discuss each of the elements in turn, identifying how they contributed to the outcomes, and exploring their design in more detail. I then explore their integration as a 'hub'.

7.3.1 Short-term accommodation: offering a break and unlocking travel

Short-term accommodation is the main avenue for offering a refreshing break. Guest perspectives about the break aligned with the intentions of staff, who said they aim to help guests "really relax and know they are in good hands", and "know that everything will be taken care of for them and they will just have a really stress-free holiday." The program seeks to support "family members too," giving them a reprieve from informal caregiving as staff "take on that role, take that pressure off them". Staff appear to have a progressive understanding of the purpose of respite, which is not about giving the carer a break from the person, rather "true respite is where we take on the logistical load, so a family can enjoy time together".

Guests recognised this was about addressing barriers to promote an equitable opportunity. The former general manager identified this as an intention from the beginning: to enable "a break like all of us would have" including making this possible for people who have never attempted staying away from home, and making it easier for people with lower-level injury and "very brave and talented" people with higher-level injury who already do.[2] Staff explained the broad aim is to reduce barriers to having a break, as well as being a break from those everyday barriers:

> *"… for things to just flow freely in your time here, to just be easy and stress free. For it to be an oasis from all these barriers that they face out in the real world."*

It's worth noting this break is offered away from home. The location of the facility plays an important role: it provides a change of scene, a pleasant environment, and convenient access to enjoyable activities and natural environments. But the aim isn't just to help people stay in that specific location: travelling away from home is itself valued as a worthy pursuit.

The program advisor with SCI reflected that "a lot of people are socially isolated and don't travel and don't get out because it's so intimidating" – an assumption supported by other data. 40% of guests had not stayed overnight away from home since their injury[6] and interviewees with SCI described many barriers that make it difficult to travel, or defeat the purpose of doing so.

The program advisor went on to explain how this assumption guided the design of a service that "is quite extreme, in that there's nowhere else that's quite as bespoke for spinal cord injury." The highly supportive setup is designed to eliminate "that initial barrier of trying to get out for the first time".

Similarly, Tom highlighted how the barrier-free environment made it easier for participants to attend the camp-style course he facilitates at the program: "people like to stay somewhere like Sargood, because it's very sorted. Everything you need … it's absolutely awesome". But he mused that there are advantages to the "more rough and ready" venues he's used, "because if you can stay somewhere like that, then you have more confidence in just staying a variety of places." He described the tension between "being slightly more challenging for people to get out of their comfort zone," and accommodating the "vast number of people who are institutionalised – for lack of a better way of putting it. For them going to Sargood would be a massive challenge. Going somewhere else is probably too big a step."

While the supportive setup may be an important first step, Tom emphasised the importance of continuing to "encourage people" out of their comfort zones. After the initial step where "they have now stayed away from home, because they've stayed at Sargood," people may still need "that bit of extra push, be somewhere different, try something different".

The examples of guests who have gone on to explore new destinations reflect the program's success in this regard. Staff said the experience "often unlocks travel again," and "leads to people being a lot more confident to try traveling to places that aren't specifically for spinal cord injury". By combining hospitality with capacity-building services, the program offers a supported introduction to travel, as well as the skills and confidence needed to travel to other

destinations. This may contribute to the broader well-being outcomes, because travelling represents broadened possibilities and horizons.

7.3.2 'Rehab by stealth'

The capacity-building element contributes to the longer-term program outcomes as it promotes independence and engagement in meaningful activities outside the program, and participation more broadly. As the program advisor with SCI explained,

> *"I think that having the centre there as it is just helps people see what's possible, fast track their journey back to independence get back to living a good life as a person with a spinal cord injury."*

This sounds a lot like the aims of rehabilitation but, as we've seen, people with SCI were clear about not wanting anything like a traditional rehabilitation experience. This created an interesting tension, which the program addressed through an approach the program advisor with SCI called "rehab by stealth". By bundling capacity-building services into the accommodation and recreation offering, the program offers an appealing drawcard, then exposes guests to additional services they may come to find appealing too:

> *"It's funny how once people do come, they realise that the benefit they get is more than what they anticipated."*

Guests appreciated this approach. People doing more than anticipated was a broader theme, and engagement in the capacity-building services was one of these unexpected add-ons for many guests. This may be based on convenience, like for Adam: "I'm not particularly going for the opportunity to learn skills, but whenever I do, I try to make most of it." Guests may also seek advice after being exposed to a new possibility, or following a conversation with a staff member or peer. For example, a guest attendant shared, "if we're ever talking to a guest - like in care or just out in the common area – and if they're like, 'I'm really interested in learning about drones' or something, we can refer them on to [the OT]."

Accessing the capacity-building service is not always unexpected or spontaneous, though. One quarter of guests ask to see a clinician when booking their stay.[7] Common goals for these consultations were listed Chapter 5, which the occupational therapist summarised as "core daily living skills training," mostly involving "wheelchair skills and transfer skills".

While these interventions would be common to most SCI rehabilitation services, it is surprising people seek them in a holiday setting, and some had not received these basic services elsewhere. Staff said they offer these services partly because of limited availability, particularly in remote areas where,

> *... people don't have access to a skilled therapist. You might have one OT covering hundreds of square kilometres, and if they know how to teach you to get yourself on and off the floor, great. But if they don't, what do you do? There's no one else."*

Even people with SCI in Sydney, the program filled a service gap. Alan explained how he "was desperate for more rehab, because they kick you out of [the inpatient facility] based on what the computer says, and you still need a lot more rehab." He appreciated the accessible facility, specialised equipment, and support and guidance of staff, explaining, "I'm at the stage where I do need that help and guidance. Also, it's pretty punishing sometimes, so you really need someone there to check that you're not giving up."

7.3.3 Recreation program: Promoting fun, challenging activities with flow-on effects

While the recreation activities are a drawcard for some people, not everyone plans to engage in them. Some may simply be uninterested, but many are initially hesitant, fearful, or unaware of what is possible. This is one reason the recreation program is primarily delivered through scheduled, group activities, hoping to inspire and encourage guests to try something they wouldn't have otherwise considered. While ideas about new activities are sought from guests– via a suggestion board, for example – staff mostly take the initiative to think of and plan the activities.

Guests are then exposed to the options in several ways. Like at other resorts, a schedule is "offered up on a board at the front desk, so they can look at the activity, read about the activity, and then question us, and then join in under no pressure at all." There is some pressure though, albeit friendly, as staff offer gentle encouragement and cajoling to try something new. Staff shared examples of guests who initially just wanted a passive holiday, but "we persuade them to try out the hand cycle or something similar," and then they're "hooked," eager for more opportunities.

For John, it was the scheduled program, coupled with the enthusiasm of staff, that promoted his engagement: “They were like, ‘let's do this, this and this.’ And the next minute we’re in a bus all loaded up and we’re off down to the beach to go snorkelling.”

Peers also inspire and encourage one another to try new things and challenge themselves. Staff relayed examples of people inspiring fellow guests, who “might have just thought ‘that sounds too difficult’ or ‘I don't think I'm into that particular activity’ until someone else mentions they had a great time.” Interviewees with SCI also appreciated how peers “support each other to give new things a go”. Rob shared an example of encouraging a fellow guest with tetraplegia to try water skiing, where:

> *“He went water skiing and there’s photos of him looking shitscared. But he said he was really glad he did it.”*

Other guests were similarly “glad they did it” – perhaps unsurprising since these experiences were key to many reported outcomes. An appreciation for these broader impacts may be the reason staff encourage participation, even for reluctant guests.

7.3.4 A hub: integrated services with a symbiotic relationship

> *“We’re providing short term accommodation and assistance to people with SCI. But its more than that … we are providing that service with specialty clinicians, which is very unusual.”* (Staff member)

Having the three program elements under one roof provides convenient access to a range of services that might otherwise be difficult to obtain. Staff members noted its “hard to get so much experience in a wide variety of roles under one roof”, and highlighted the benefits of what they referred to as a “hub”:

> *“To come here and to be able to see a very experienced nurse, and fix continence issues, and also sort out some equipment issues with the OT, and also to start an exercise program and also to take up some rec hobbies again … Long term, it's really hard for them to get all of those different things in one place. I think that’s why its unique.”*

It’s not just about convenient access to multiple, separate services, though. Key to the well-being impacts is their integration: program elements often overlap, and they contribute in different ways to the full range of outcomes. I deliberately oversimplified the relationships in

the program logic, prioritising simplicity when introducing the program in that early chapter. But the symbiotic relationship between the various program elements, activities and outcomes is much more complex.

A good example of this symbiotic relationship is the recreation program, which draws on the contributions of the other two elements and, in turn, enhances their impact. These relationships are discussed below and represented in Figure 7.1, which builds on the program logic. It shows again the program elements (green boxes), intended outcomes (orange boxes) and intended relationships (faded grey arrows). The new relationships and components are highlighted in bolder grey.

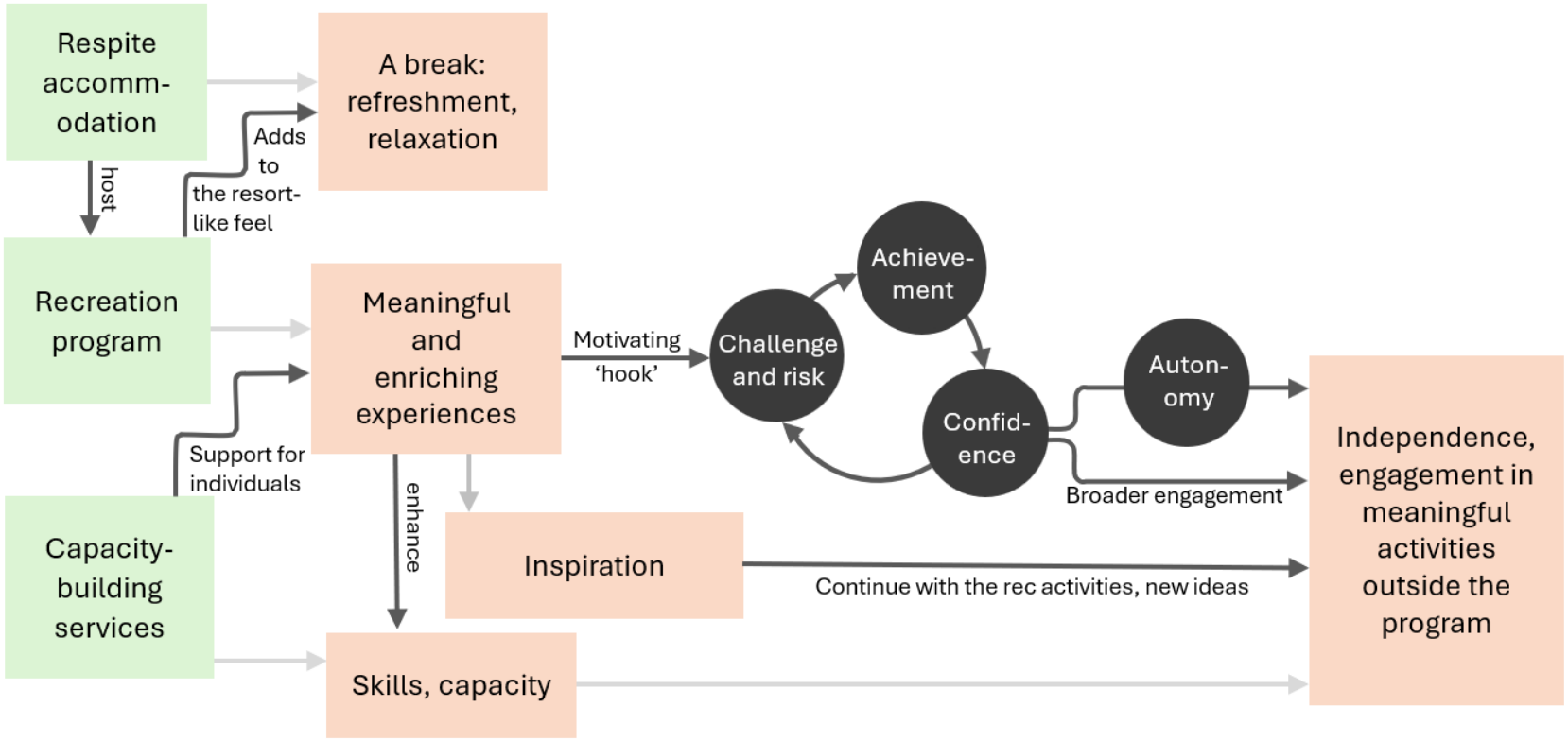

Figure 7.1

Relationship between the recreation program and other program elements and outcomes

First, the other two elements support the recreation program. The respite accommodation hosts the recreation program, in a location rich with opportunities such as beaches and mountain bike trails. The capacity-building services also often facilitate individuals' participation in the activities by modifying them or working on skills. A rec staff member shared an anecdote that illustrates the contributions of various team members:

> *"We constantly will be speaking with [the EP] in the gym ... I might want to do hand cycling in the afternoon or maybe surfing. And we need to know, what's their core strength like, how many strapping aids we're going to need to keep them in the cycle, can they lie prone, how tight are their hips ... With [the OT] and the 3D printer, printing up adaptable things for fishing rods where we can strap a high-level quad hand into a wrist strap."*

The recreation program, in turn, adds to the program's appeal and makes a break more enjoyable and holiday-like.

Importantly, recreation sessions can also build capacity for participating in activities outside the program, like the snorkelling outing in the earlier vignette. They can also build skills transferrable to other areas, like for Lisa, for whom an all-terrain wheelchair outing had unexpected benefits. While she joined the outing for enjoyment, it also ended up providing incidental opportunities to practise wheelchair skills like "assessing terrain… going up and down curbs" and navigating "soft or hard surfaces". In navigating a new and challenging environment, her "capacity and confidence increased a lot".

The recreation program also inspires people more generally, offering "ideas of some other things I could or should do". As well as new recreation pursuits, the program advisor with SCI observed recreation activities can be a "gate opener to pursuing other life goals". Staff explained how "increasing confidence leads them to try [more challenging activities]," which may then lead to goals in other areas, like "my personal care routine: maybe I can actually do more things for myself.' Which may then mean, 'actually I might look at studying… doing some work … volunteering.'" A person with SCI noted similar dynamics and impacts in a newspaper article:

> *"It really lifts your spirits, having the confidence to be able to think 'well if I can overcome this or do this then maybe I can do something else'"*[5]

Increased confidence is a crucial factor in this process, and is what shifts the effects from temporary emotions to longer-term impacts. The process involves a positive cycle: taking on a challenge and risk, achievement, greater confidence, embracing a new challenge (and so on). Because recreation activities are motivating and challenging, they act as both a 'hook' and catalyst for this cycle.

Beyond recreation activities, confidence-building pervades the program more broadly. It supports a broader approach that respects and builds autonomy: another mechanism for achieving program outcomes I explore next.

7.4 Pervasive, underlying mechanisms of change

The chapter now moves away from the tangible program elements to consider pervasive, underlying mechanisms through which outcomes are achieved.

7.4.1 Fostering the autonomy to take control of a good life

Staff explicitly identified autonomy-building as a key mechanism of change. The desire to foster autonomy pervades all program elements, and is rooted in an underlying assumption about what enhances well-being. A manager explained these principles when discussing how the program impacts well-being:

> *"I think increasing people's confidence to then tackle new things is a faster approach to improve mental health than just sort of doing little 'Band-Aid fixes.' If you can give that confidence and allow them to take control and make decisions or be willing to make decisions or test boundaries that they haven't tested before. If we can go that angle, I think it opens a lot of doors rather than just saying 'here's some fancy bit of kit: that'll fix it.'"*

The approach is driven by the belief that increasing confidence and capacity to take control, make decisions and test limits is a sustainable way to impact well-being in the long run – as opposed to staff providing solutions to each problem that arises.

The example the manager used was interesting, because guests really did value the "fancy bits of kit" available through the AT demonstration pool. While the manager did recognise the importance of AT elsewhere in the interview, here it represented top down "Band-aid fixes" that don't produce longer term impacts unless accompanied by broader efforts to promote autonomy.

The 3D printing course is a good example of this mechanism in action. A staff member explained the guiding principle is empowering guests to be "more independent in solving their own problems in their life". He elaborated on this in a newspaper article, explaining people are often best placed to recognise and solve their own challenges. The course recognises and promotes this autonomy because "they are in complete control of creating the designs." He shared an example to illustrate this principle and its impacts:

> *"... someone was frustrated they couldn't trim their own nails, and had to wait for a carer to come. They 3D printed a bracket for a nail clipper, and now they can do it themselves. It's those little frustrations no one would understand until it's taken away from you. They have the idea in their head of how to fix it, and we give them the tools."*[8]

People with SCI shared their own experiences of this course. Adam gained the skills to participate in a collaborative design process, where he "helped make a new hand drive for me to practice [wheelchair driving] on," with clinical input from the OT, who "off-centred it slightly so I can externally rotate my arm easier". The course encouraged Lisa to take a more proactive approach to problem-solving. Reflecting on her experience, she said, "I'm thinking about what adaptive things, what would make a difference? What gives me the shits that I can fix?" Another participant shared on-line how "learning how to approach a problem with critical thinking and creativity" is a "great skill set to have" more generally.[9]

I now explore a related mechanism though which autonomy is realised: the opportunity to experiment with possibilities.

7.4.2 Exposure: A chance to find, and experiment with, possibilities

> *"The first time that I went it really helped me feel confident being independent ... just having a bit more personal space but also testing, doing things for myself for the first*

time post injury. So it definitely helped a lot in that confidence in being able to have hours where I'm just on my own doing my own thing." (Marcus)

Staff said an aim of the program is "to show that there's so much that's possible beyond the injury." Crucial to this aim is "an opportunity to explore the options", which is what "empowers them to embrace" these possibilities. Guests appreciated this approach, which they described as "exposure", "finding out what is possible" and "showcasing what can be done". They appreciated the program "showing you new things, new tricks, different attitudes, different things in life" and the availability of a "whole library of resources there to try, trial, motivate, encourage".

I now explore the assumptions and principles underpinning the approach. It is another way the program respects and fosters autonomy, based on a belief that people are ultimately in control of determining the direction they will take, and the supports they need, for a good life. At the same time, people 'don't know that they don't know' and without being exposed to possibilities – especially in a context of low expectations and many barriers – people may not know what the options are. Rather than being limited to addressing the goals identified by guests, the program showcases "more options than what you could think about", as one guest put it.

Staff felt this approach was especially important for people who have "just got on with life and haven't wanted to hear anything about it", or who may be "isolated in a little bubble". They recognised people can "get lost in society", which they saw as a healthy sign of autonomy: "you should get lost: you shouldn't have to stay linked to your injury." But staff observed they do end up appreciating the opportunity to "refresh and look at what's new and what they can build on". This offers additional layer to the 'refresh' part of the slogan, and may be a more appealing framing for services offered at this stage.

It is worth tempering this theme by briefly sharing the perspective of one staff member, who has a leadership role and helped design the program. While "showing what's possible" is often emphasised, this doesn't fully "capture the idea" of the program. Less obvious program outcomes shouldn't be overlooked, which could be "the smallest thing" like being able to recover from surgery in a comfortable setting rather than a hospital. The success of the program lies not only in dramatic life changes but also in smaller, meaningful contributions to well-being. As they put it, "if it maintains their mental health and those sorts of things then I feel like, job done."

That idea connects to another important finding: people with SCI value low-key opportunities to explore options. “Showing what’s possible” need not result in inevitable or life-changing impacts. Instead, people appreciated the freedom to dabble or experiment outside a formal pathway, and without commitment.

People often sought updates without a specific question or topic in mind. Booking forms sometimes contained broad, exploratory goals like seeking “an update on assistive technology”.[7] Staff said guests often ask similar questions, like “I actually don’t have any problems that I know. But is there anything new?” Their advice may provide affirmation (“I wouldn’t change anything”) or a helpful new direction (“Oh thank God, I’ve just been struggling for so long”).

The chance to experiment without commitment can be especially useful before pursuing funding or investing in expensive equipment. Helping people become aware of, trial and acquire AT is valuable, but guests identified a valuable step between awareness and formal trials: the opportunity to test the idea. Ben explained outside of the program, trials are mostly available through suppliers, if at all, and require a level of certainty and commitment to initiate. For this reason:

> *“Just to try something and figure out whether you like it is impossible unless you have somewhere like Sargood. I’m not going to go and put in an assistive technology request to buy a jet-powered surfboard so I can try surfing … But I can go to Sargood and … work out if that's going to be the kind of passion thing that I'm going to pursue. And that can be life-changing.”*

Interviewees with SCI also appreciated the opportunity to explore – and then reject – options. Sometimes they realised the benefits weren’t worth the costs, where they decided “no bugger that, I'm not going to bother with that. I'll get someone else to do that.” Or they may have discovered a possibility keep it in mind for later: “I think that will be something that I will pursue later on but not immediately.”

They didn’t view this as a dead end, but part of continual process of exploring “what else is out there?” with the encouragement of staff and peers to consider “well, what do you want to go and do? Let's go and do it.” Most people would recognise failures are inevitable when experimenting, but interviewees took it further than that. For some, the process of trying and failing was itself a valued experience. Ryan highlighted how it helps people better understand their potential, celebrate their efforts, and move forward:

"All your theories and dreams can come true, or your doubts can be confirmed or not confirmed. You have an outcome. Doesn't always have to be positive, but an outcome really is positive ... you're solving problems."

7.4.3 A base to return to

"I think the rapid growth and social network you can see ... [is] because you've got a base here in a desirable location that they want to keep returning to." (Staff member)

Staff said program offers a "base" – a place people with SCI can return whenever they need services or want to work on their goals over time (with a reported return rate between 70-87% [10,11,12]). Staff saw this as central to the success.

Returning enables people to gain confidence and skills gradually, building autonomy over time. For example, Angela shared how the program has "given me more confidence, because I've had some long stays there". Staff relayed similar examples related to challenging activities such as swimming, which might "take a couple stays after and then they'll do it". Repeat stays provide more time and opportunities for the positive cycle, where "the more they come the more they change and the more they want to be here and the more they want to do."

The community program provides locals with any disability the opportunity to gradually work towards their goals at the gym. One guest shared in a media article she was "thankful that I have a facility like Sargood on Collaroy [gym] in close reach" because "it took a lot of effort for me to regain my confidence and independence."[13]

The "base" also creates an environment of familiarity and comfort that supports the gradual, ongoing process. As Rob said, "it also helps that you go back to this familiar place," and the fact that "they know you" is motivation to do so. This is another benefit of the sense of community built up around the program.

Repeat stays are also an opportunity to 'top up' the valuable but temporary program outcomes, like positive emotions, to maintain well-being. People can also keep experiencing the reprieve from everyday challenges and barriers.

7.4.4 Involving families

> *"A guiding principle from the start was that you should be able to experience this with and alongside your family, and your support mechanisms that come with you are a part of the journey. That was pretty crucial to the design and the thinking around how we create the most impact for people with spinal cord injuries … having formal supports provide your care so that your wife or partner or loved one isn't having to do that, is allowing you as the person with spinal cord injury to be a husband and a dad and all of those other things … You can actually be there and enjoy being a family and focus on that element rather than the caring side."*
> (Program advisor with SCI)

This lengthy quote, which I will unpack, identifies the involvement of families as another key, intentional mechanism through which the program impacts well-being. Another staff member emphasised this as a core purpose of the program: "Family: big. Giving people the opportunity to spend time with their families in a carefree, supported environment: massive."

The guiding principle was to facilitate shared experiences without the usual constraints and challenges of SCI that interfere with roles, relationships, and inclusion. This principle shaped design choices, such as allowing significant others to stay and providing personal care services, which gives family carers a reprieve and shifts relationship dynamics.

"Enjoy being a family" presumably includes the recreation activities, which families are encouraged to do together. The "full participation" part of the intended outcome may refer to meaningful inclusion in family activities, at least in part. As a staff member explained, they seek to make people with SCI,

> *"… a central part of the experience—to have a shared holiday where you're not just a spectator but you're actually participating in doing something together as a family."*

Yet while the program seeks to impact well-being of family members, the quote above is mostly framed in terms of the benefits for the person with SCI. Even taking on the care duties of family carers was seen through the lens of how this might benefit the person with SCI, as they can enjoy different roles and dynamics. The program considers the needs of family members while recognising that supporting them can also positively shape the experience and outcomes of people with SCI.

7.4.5 Gathering a learning community of peers

> *"An intentional community for people with spinal cord injuries to learn from each other and keep in touch with the latest advancements in how to lead an independent life as a person with a spinal cord injury."* (Program advisor with SCI)

Another 'intentional side benefit' of the program's appealing design was bringing peers with SCI together. This is another mechanism the program actively fosters, and is reflected in the 'connect' part of the tagline. This recognises the contribution of peer interaction and support to all the aims, and ultimately to well-being. Guests, again, deeply valued the resulting sense of community.

The program advisor (quoted above) elaborated on the assumptions underpinning this mechanism. He appreciated the "intentional community that I got through sport" but recognised not everyone has an avenue for these connections. The program was therefore intended to be a place to "come back, keep in touch, connect with other people in a similar situation". Focus groups also shaped the peer support focus, but did so in an unexpected way: the General Manager who facilitated the groups observed that "when you put them together, they all try to solve each other's problems."[2]

Peer support is sometimes facilitated intentionally, when staff strategically connect two guests:

> *"Sometimes you might have a whisper in an ear like 'hey can you go and talk to so-and-so and see if you can just share your experience a bit and get them keen. Because I think they'd want to go cycling but they need to hear it from someone who has had that been in that position before.'"*

But peer support mostly happens incidentally and informally, and one way the program differs from other peer support services is the casual and low-key environment in which it takes place. Sian recognised this as distinctive and complementary: "I guess it's an informal version of that really, which is a good extension of what peer support guys do." Staff reflected on how the environment promotes interactions that might not have happened in a more formal context, because,

> *"… that pressure is taken off and everyone's on the same level I think there's a lot of conversations that happen in these walls that probably wouldn't happen outside."*

This intention strongly influenced program design, including the design brief for the building. Guests talked about the social interaction in communal spaces; staff explained this was deliberate. For example, instead of having more substantial cooking and dining facilities in each bedroom, the communal kitchen and dining area were "designed around getting people out of their rooms to come and cook a meal and have a wine together". Program designers assumed doing enjoyable things near others would promote engagement because,

> *"... they are very natural scenarios, so it's not forced: 'Okay. Now is the chatting time'. They're times you'd naturally be talking and relaxed."*

The shared spaces are also a place to observe peers as they go about their day, "seeing them just live a normal life". The opportunity to witness – not just talk about – a good life with SCI is another unique aspect of the peer support. Seeing what peers are doing can prompt conversations about "the reality … the real-world experiences," which Sian identified as a key benefit of peer support. Ryan noted that staying together was an opportunity for this practical learning, where he could "just show people what you do", like "come on, let's push down here" and "let's push to the pub".

Witnessing the life of peers can also powerfully shape expectations about what is possible. This opportunity is particularly helpful for people who might not have otherwise initiated conversations. For example, staff explained that people visiting "early in the piece" for weekend leave are usually "very focused on just spending time with their family" and getting a "mental health break from the hospital" – yet these are the families who might most benefit from peer support. In this context, the chance to quietly observe people with SCI going about their lives is "very powerful", enabling people to "see that maybe there's more. Maybe there's going to be more for them than what they're thinking."

In addition to the communal spaces, the program schedules regular opportunities to interact during group recreation activities and social events. A staff member reflected on the interactions at Friday sunset drinks, where informal social encounters are facilitated naturally, and can turn into something more substantial:

> *"[Guests] just get talking to people. And it was nice for them to see ... these kinds of things can happen. You can still have children, have a family, get married, have a successful life, have a successful job. And life goes on. See that they're not the only ones. And there's a lot of people with a lot of different injuries that come here, and their lives are all very different but they're still getting on with their life."*

Facilitating this process is the somewhat unique gathering of people at different stages in their journey, which may not occur outside formal peer support, and not often in large, diverse groups. A staff member observed:

> *"You've got people who've got 20, 30 years of experience, and then you've got people coming along for their first time to a facility like this. And there's some classic characters that come here, and that's the best: watching them communicate and socialise with someone who's very new, who's just had their whole world flipped upside down and they can communicate and socialise together and learn things like 'this is how I did this' or 'what's your process of doing this?'*

Sian, who has lived with SCI for many years, noted people like her who "have been in chairs for years" are well placed to "tell you about how normal things can be". Interviewees with established SCI also valued the peer interaction: as well as experiencing a sense of meaning when contributing to peers they appreciated learning themselves, explaining "in some ways your learning never stops." The opportunity to access peer support at any point in the journey means people can seek information when it becomes relevant, like "all the more informal stuff that you don't get taught in rehab".

The relaxed, low-pressure environment also helped those who were reluctant to interact with other people with SCI, especially when the connection felt forced or unnatural based on a shared injury. By allowing genuine connections to develop naturally over time, and gathering a large, diverse group of people, the program created an environment where the benefits of peer support could be more easily accessed by people who may have otherwise missed out.

For some people, their reluctance was simply because they wanted a quieter or more private experience. While some interviewees valued the deep connections they made, others were happy to keep things casual, engaging only in "pleasantries and interacting with the activities, but no real follow-up from that". They, too, appreciated the unpressured and flexible environment, which offered optional opportunities for light, casual connections "where you naturally will say 'hi' and get to know [the person] a bit." The common areas also helped strike the right balance, with opportunities for "just chatting … casual conversation," while also being "big enough that if you want your own time … a quiet drink on the veranda, we could do that."

Document sources of specific information and extended quotations

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CHAPTER EIGHT:

OPERATIONAL FACTORS INFLUENCING DELIVERY

The mechanisms in the previous chapter do not solely account for the outcomes. Their effectiveness depends on underlying *operational factors* that influence and support their delivery, and which are the focus of research question **3b): what operational factors enable or influence the program's ability to achieve its well-being outcomes?** The chapter primarily draws on interview data, considering how staff describe their approaches, their intention, and how guests with SCI experience them. The findings fall under two broad categories: the staff attitude and approach, and a culture of pushing boundaries.

A note about terminology: in program theory, these factors are sometimes referred to as 'contextual factors', representing the internal and external influences that shape program delivery. However, I instead use the term 'operational factors' to avoid confusion with the different meaning of 'context' in case study research, which refers to the bounded system surrounding the case.

There is overlap, however. For example, funding could be considered either an operational factor or an aspect of the institutional context, which is also influenced by the policy context. The overlap between program theory and case study research is arguably a strength of the study, so I won't attempt to force a distinction between the two approaches, apart from avoiding confusing terminology.

8.1 Staff attitude and approach

> *"The facilities are amazing and the rec activities are amazing. But it's the staff that make the whole experience what it is."* (Sian)

Staff said their approach is a key influence on the experience and outcomes, reflecting that "a huge part of what Sargood is, is the people that are here. And any service, I've realised, especially by working here, is shaped by the personalities of the people that run it." This was strongly affirmed by other perspectives and data sources.

The attitude and approach of staff was one of the strongest themes in guest interviews. They repeatedly highlighted their interactions with staff as crucial to their experience, using superlatives like "just awesome: everyone", and "phenomenal" to describe the team. Adam, like Sian above, made this point by downplaying the seemingly more impressive aspects of the program in comparison: "it's the people there that keep me going. Location would be, like, third on the list ... Personability, activities, location." This was also common emphasis in in on-line testimonials, including one that made the same comparison: "The place is just fabulous, but what really makes it special is the amazing staff."

The exemplary team was also recognised by external stakeholders, including by insurance funder icare with *Outstanding Team* award in 2019.[1] A board member with SCI highlighted the staff approach as critical to the program "from a governance point of view", identifying it as what the program "hangs its hat on" and "what makes the place special". Like the guests, he emphasised his point by downplaying the relative importance of the building, which in comparison is "really nothing special. The secret sauce or the magic in the place is the attitude of the staff… and the culture and the attitudes they exhibit."

To cultivate this culture, management staff said they went to great lengths to establish what they described as "an incredible team". Guests recognised this, and one attributed it to the training: "How they've trained the staff, I do not know, but they've done a very good job." I observed the training and support provided to staff and concur with this sentiment. Managers appeared well-versed in managing SCI-related needs, and provided modelling and training in the service approach – illustrated in a vignette.

I sat in on a weekly planning meeting, where the clinical manager, spinal CNC, and a receptionist gathered around a table to finalise the upcoming bookings. The complexity of the task struck me, especially compared to (what I imagine) the planning required for a regular hotel. Ensuring every guest's needs were met required detailed SCI-related expertise, and their care and equipment needs affected room allocations and staff rosters.

The atmosphere was busy but informal. Guests with SCI wandered in and out, stopping for a chat, and no one discouraged them. Midway through the meeting, the receptionist-in-training answered a call from someone hoping to join the upcoming fishing charter, and explained there were no spaces left. After she hung up, the manager gently suggested she call back, offer to put the person on a cancellation list, and suggest a similar outing scheduled soon after.

What stood out was the balance staff managed between complex clinical planning and a relaxed, welcoming atmosphere. Even as they worked through detailed decisions about equipment and care rosters, they made space for casual chats with guests and used everyday moments like a phone call to reinforce a service culture built on flexibility, friendliness, and customer service.

While training clearly plays an important role, the managers themselves emphasised recruiting the right people in the first place. "You've got to pick. I don't think it's luck." They described a deliberate and intentional approach to recruitment, where "we've always employed here on fit for Sargood." It helped that they were in a position to establish the team from the start, where they "handpicked" staff based on a clear vision of the culture they wanted to cultivate.

Fitting into the culture has remained a recruitment priority, and candidates are considered "based on attitude rather than experience". A "positive, flexible personality" is highly valued, especially for guest attendants, who have the most day-to-day interaction with guests. When crafting this role, program designers sought "people with enthusiasm and a willingness to learn and deliver high quality care, with a sense of fun."[2] Staff explained their assumption that "you can learn the clinical skills, but you can't learn the customer service as quickly."

While clinical experience was a key consideration when recruiting allied health staff, their attitude and interpersonal approach were also important.

In this section, I describe aspects of the staff attitude and approach that appear to be the most impactful.

8.1.1 Customer-service approach

> *"It's the ethos of the place. It's about the client, and not about the routine. They're very flexible. Maybe that's what the hospital could learn. Even a little bit of flexibility goes a long way. You're a human being."* (Angela)

Guests highlighted the "personal, client-centred" approach as crucial to their experience. They described "accommodating and welcoming" staff, who "know about you enough to think of what your needs might be and respectfully accommodate those". Staff agreed: they intentionally adopt an approach where "nothing's too much trouble, and we try and cater to everyone". Several staff took this one step further than "client-centred" though, calling it a "customer serviced-focused" approach.

The phrase "customer service" is particularly striking, and the word "customers" arose several times. While more common in the business sector, it represents a shift for rehabilitation and disability services. A foundational, and distinctive, driver is that "first and foremost, it's a hospitality service."

This was a guiding approach from the beginning, and informed the role creation and recruitment of the resort manager, who has a background in business and hospitality. A colleague observed this means he "understands what it is to have customer service… that people are going to complain and that they're right to complain when something's not right and not up to standard." The resort manager himself explained a key driver of his decisions is enhancing the experience of guests, identifying "enjoyment of their stay" and repeat visits as key indicators of success from his perspective.

Staff recognised and embraced his approach, explaining, "I just know every time he's going to say, 'If the guest gets a better experience, then we have to do that thing.'" They are supported to go "above and beyond" to ensure guests were "having a good time". This

philosophy extends into resource allocation, which supports service development as well as delivery. Staff reported a "can-do feel about the place", where managers tend to respond to requests with "if you think it's going to be something that would help somebody, get it in." Feedback is also sought from guests, who appreciated that "they constantly make changes. If you provide feedback, by the time you come next, then they're going to have made changes."

The customer service approach is a key way the program enacts its 'non-clinical' ethos, a theme that appears several more times in the chapter. Leadership staff explained this intention has "been really powerful" in shaping the customer-focused design and delivery, where they "don't want to make decisions that are just like a hospital". Instead, they are "constantly coming back to the question of 'what's best for the guest? How do we want them to feel when they're here?'"

As well as being an intentional reframing, the customer-service approach is a natural outflow of the program's distinctive scope and model. The program advisor with SCI identified the key point of difference: people with SCI are in the unusual position of being "the one that asks for the service when they want it rather than being treated like a patient." As a result, they engage with the program as consumers, arriving with specific expectations and greater awareness of the funding required for their stay. This changes the power dynamic and creates "a huge responsibility and obligation to provide a service that's focused on them and gives them what they're looking for." Staff also noted the approach is also self-reinforcing: "now that [guests have] a certain expectation of Sargood, it's like their expectations just keep getting higher." This "is good because it pushes you" – and also stands in stark contrast to the low expectations people with SCI usually encounter.

The context also affects the way staff perceive service users, because "you just see people differently when they're patients than when they're customers who need to be given the best possible service." Language is carefully chosen to communicate this reframing, as a manager explained in a magazine article: "Our concept was to provide this service where people aren't 'patients', they are 'guests.'"[3] But staff said implementing this approach requires more than new terminology; it involves "a different mindset", which "has upended the hospital culture in a lot of ways".

Shifting mindsets is challenging, though. A staff member reflected on their own limitations compared to the resort manager, stating, "Coming from a [health] background… I could

never have done as well as he's done." Nevertheless, it is viewed as an essential condition for the program. Staff are protective of this ethos, to the point where they felt,

> *"... there's some people that could actually never work here. Some people who are from a hospital culture would still see themselves in the power position, and a complaining person is a problem who just needs to be brushed under the carpet rather than a worthy voice that needs to be listened to."*

The program advisor and board member with SCI expressed a similarly high value for the customer service approach, suggesting it was a key factor in choosing the program's operator. He shared the initial scepticism about partnering with a "traditional hospital and rehab provider", noting that such institutions often "don't really inspire much confidence when it comes to innovation and customer service in a hospitality-type environment". It was therefore crucial that their pitch "didn't position it as a medical facility" and instead demonstrated an attitude where "the person with the spinal cord injury is the customer, is the client, is the one that's always right." He commended the program for delivering on this vision, praising "the culture they've been able to implement" – which he added "has been fantastic to the point where it's probably had a positive influence back on the mothership" of the broader rehab organisation.

8.1.2 Warm, genuine and intentional connection

> *"The staff were just awesome. Everyone. Very open, very approachable, very down to earth. They were great."* (Carrie)

Guests emphasised the importance of having genuine and warm rapport with staff, who communicated care, interest, and respect and knowledge of them as individuals. For Adam, "the personability of it" was a key takeaway for other programs, recommending they "just keep it person-centred and try to remember people's names and faces and a little bit about them." They described the staff as "really friendly", "nice", "very pleasant", and "very open, very approachable, very down to earth". This translated to being "treated as a person" – a seemingly basic expectation yet one that contrasted with their other encounters.

Staff described similar level of rapport, where "most people develop friendships with returning guests" and where "we know everyone by name, we know their families, we know

their kids." This suggests the care and interest guests felt is mutual and genuine. Staff explained the rapport is a distinctive and intentional aspect of the program's culture, which is "a lot more casual than a more traditional working environment in that respect: the comfort level between staff and guests." Staff are encouraged to help guests feel included and comfortable, and prioritise small but meaningful interactions, like "having a chat in the common areas" or sharing lunch tables on the balcony.

Both staff and guests identified rapport as crucial to the outcomes. It contributed to the sense of value, belonging and community. The comfortable, friendly atmosphere would also support guests to step outside their comfort zones and embrace new challenges, thereby indirectly influencing the longer-term outcomes.

8.1.3 Empathy, understanding and encouragement

> *"They're accommodating in your emotional side of things as well … Like if you're doing an activity for the first time, that might have caused you injury, they can help you. Be that shoulder to talk to or help you or guide you through that activity to achieve it."* (John)

Interviewees appreciated that staff are "sympathetic" and "showed empathy". On-line testimonials expressed appreciation for their "empathy and understanding, which doesn't come naturally to everyone", whereas at the program "it's almost as though the staff can read my face and support me on my journey to acceptance."

This is another supportive factor for guests challenging themselves: "It was a big step otherwise, whereas here it's not a big step. They're right there." In the following vignette (occasionally paraphrased for brevity), a staff member explained how empathy and understanding enable challenging activities.

> There are so many memorable guests, especially those who conquer their fear of water. I remember one guest who was petrified of the water. We started by just sitting by the water, talking for half an hour. Gradually, we took small steps: getting her feet wet, then going up to her knees, half way down the ramp. And eventually – I don't know how long we were down there for but it was a fair while – we got all the way in still sitting on the wheelchair. And then – it took time again

– and then eventually got to just floating around with her partner helping her in the water. And that was huge.

And other examples of watching someone progress – who might be fine in a swimming pool – we'll progress from the swimming pool onto surfing with us on the board. We start by tandem surfing, so we'd go double on the board, to watching them progress to using a big board where we're doubling and then we'll maybe drop off the back and they can surf the last bit of the waves by themselves. To the point where they're now surfing consistently when they come with us pretty much independently like catching waves by themselves on their own surfboard.

If someone mentions they used to kayak, we show them videos of others kayaking and discuss their history, pain levels, and grip strength. We have three Hobie Kayaks. They're amazing vessels – super stable, top of the line kayaks – which we've adapted with hand controls, allowing even high-level quads to kayak. So Hobie kayaks usually have a foot pedal system: you use your feet and you push it forward, kind of like on a bike. We've had them transferred into the same mechanism but push and pull with a hand. So we can take guests down to our storage shed, show them all those adaptions. Show them videos of past guests and how we would set them up. We can do a dry set up if they want: we can get the kayak off the rack into a set up downstairs before we're even close to the daunting part of the water.

The process is very individualised. Some guests are ready to jump in, while others have many questions. We use our experience to ensure their safety and enjoyment, never pushing them too far. It's about building confidence step by step, knowing when to encourage and when to hold back.

The vignette outlined a gradual approach to engaging in a confronting or risky activity, as staff started with a more comfortable setup then incrementally increased the level of challenge. They initially provided supports for safety and a sense of security, then faded these supports as the person gained capacity and confidence. Staff also provided information to help alleviate concerns, and shared examples of peers who have engaged in similar activities. They adopted an intuitive and sensitive approach to tailor their support. Evident throughout the vignette is a continual process of assessing and managing risk, discussed more below.

Empathy and understanding combine here, as staff demonstrate an understanding of both the emotions of guests and how to facilitate the activity safely. However, staff also understand the importance of guests challenging themselves, so their role extends beyond empathising with

fears to actively encouraging people to push past them. They described a range of strategies they use "to sneakily push them in the right direction", knowing they are usually grateful for the encouragement in the end: "Then they are so thankful that you just put in that little joke to get them across the line, and they've done an activity that they didn't think that they would do while they were here, or ever." This light-hearted approach might include gentle teasing, where staff "laugh with anyone who's a bit hesitant … and not force them to choose things, but in a nice way encourage them."

Rapport helps again with this approach, enabling staff to communicate a positive message of, "I want to go kayaking with you because we have developed a friendship. You're staying here, let's go and hang out." Staff also tailor their approach, which requires perceptiveness: "you can push it a bit with the right people. You've just got to make sure you read that personality right first, and you get a good sense of that after a while." Peers also encourage and challenge each other, and don't need to be as sensitive as staff when doing so. The shared experience gives them a deeper understanding of both the fears and benefits, and licence to use "that sort of peer pressure, and that banter that goes with it".

8.1.4 Communicating respect and value

> *"The staff are amazing. They're amazing. They are super passionate. They get spinal cord injury. Obviously they've been doing it for years. They're not in your face. They are just there if you need them. I just don't know how to explain it – they just get it. They don't push, but they're just there. They're support. If they didn't have good staff, if they had staff that were looking down on people with spinal cord injury or pitying people with spinal cord injury, then the whole experience would be totally ruined."*
> (Sian)

Sian's quote, which I've provided in full to retain her strong emphasis, highlights another crucial aspect of the staff approach: their respect for people with SCI. She valued their positive, unpatronising manner, and was relieved not to encounter pity or condescension. Ryan made similar comparisons to patronising encounters with other people, where "you are the most amazing, inspiring person I've ever seen in my life!'" whereas at the program "you are just Ryan, and that's it". He appreciated staff being unfazed by his SCI and treating him in

the same way as others, rather than as delicate or fragile: “They don't put up with your shit. They're quite assertive. They know the ropes. You can't trick them.”

Guests also experienced this sense of respect when staff valued their input and ideas. Adam shared how the interactions felt like “a two-way street” because they sought his input and advice on new ideas and projects. This made the program feel “inclusive”, a place where he felt “welcomed and wanted”. Ryan also appreciated the opportunity to exchange ideas with staff, sharing an example of “testing one piece of equipment there, and I'm arguing with the main recreational fellow about whether it's good or not.” This exchange facilitated mutual learning: “So I know that this piece of equipment in some areas is good … my piece of equipment is better in other areas.” He also appreciated the laid-back, mutual banter: “I think there might be a little bit of bullshitting there, you know … but you give that garbage.”

The sense of reciprocity was enhanced when guests noticed staff benefitting from the program themselves. While interviewees with SCI appreciated the dedication of staff, some also recognised that the program isn’t solely about helping others: it’s a rewarding and enjoyable place to work. Ryan didn’t view the work as a selfless duty, but rather a shared, meaningful experience:

> *“You hear of these special places, and sometimes they can feel a bit patronising, like ‘we’re just here to help you, and that’s our sole purpose.’ But, you know, they were there not only for us but also for themselves. It seemed like a pretty good job, and the attitude was great.”*

This environment challenges the traditional, paternalistic approach of disability services, which often casts people with disabilities as passive recipients of care. Instead, it fosters a more equal and mutual dynamic, where neither party feels like the sole beneficiary nor burdened by a sense of obligation.

8.1.5 Dignified support

> *“When you go surfing at Sargood, you're with one other person and you're actually catching waves … it’s a completely different way of approaching life as a person with disability.”* (Sian)

Here, Sian illustrated how the thoughtful, balanced approach she described above plays out in the way staff support guests during activities.

Once again, interviewees made comparisons to “other well-meaning services in the past” whose approach was described as “patronising and are not very pleasant”, and derisively as “a happy clappy environment”. This patronising approach can result in an excessive level of support: “they have like a billion volunteers … And you go down this corridor of people going, "Yeah! Yeah! You're so great! Oh my God! That's amazing!" This made for a “ridiculous” and “weird” experience, where “you're expected to be like, "Yay! That was so fun.’ And it's not fun. It's like … it's not made for ordinary people.”

In contrast, guests appreciated the program’s low key and unobtrusive approach to support. What they seemed to value relates to earlier themes – a sense of ‘normality’ and respect – as opposed to experiences that felt undignified and emphasised their difference. Tom described this experience as “really good for my wellbeing”, which suggests the experience itself fosters well-being, independently of activity-specific outcomes.

8.1.6 Non-clinical clinicians

> *“[In other places] you go and see a physio for 50 minutes and then they do a report: It's not like that: it's a more accessible, less formalised, way of engaging in a natural setting … It's not clinical, it's living skills or how to go about those things. That removes that initial speed hump or barrier … you can explore rather than have prescribed.”* (Rob)

The desire to be distinct from a rehabilitation service poses a challenge to the allied health staff: providing clinical services without being too ‘clinical.’

They once again achieve this through a deliberate shift: “we pride ourselves on getting [guests] to step away from that clinical health side of things that they're so used to.” The approach they rejected was described as “all very strict and very bland”, with a “clinical push” that can feel “regimented” and “pressured” and offers little choice or control: “You have a session today and you need to do this.” They aimed for the opposite by adopting an informal “casual” approach, where “there's a bit more flexibility, it’s a bit more relaxed than a clinical setting.”

This includes allowing people to opt in to clinical services, because staff recognise they "can't go in and fix somebody's routine or fix something with somebody if they don't want it to be fixed", and that people will seek advice when they are "ready to take on board that information". This approach may end up being effective because, "they actually request it. And we're actually giving them something that they really want."

For guests who do seek their support, clinicians use the 'exposure' approach: "My role is to provide them – if they want to – with the new evidence-based practices, provide support, have a look at their routine, see if we can make any positive changes." This interaction goes both ways: staff also value learning from guests, who can "bring some different perspectives on things and teach us things that we don't know".

The perspectives of guest interviewees aligned closely here: they rejected the same traditional aspects, valued the alternative approach, and used similar terminology. This alignment is evident in Rob's opening quote: consultations felt like a mutual exploration of options, as opposed to a more top down, passive approach of having solutions "prescribed". Other guests agreed the program strikes the right balance: "I learned a lot, but I didn't have the experience of being taught or lectured to."

Carrie's helpful but unplanned consultation with the spinal clinical nurse consultant was the result of this informal approach. It occurred in a relaxed, comfortable environment, where "we sat outside – see that was lovely – we sat outside in the courtyard … so I wasn't in a clinic room." In addition, the conversation was only initiated because she had an existing personal connection with the CNC, "and so I said, oh, I'd love to see [nickname] to catch up about kids and family and all the rest of it." The casual conversation transitioned naturally to SCI-related topics and resulted in the impactful advice she ended up receiving. Several other guests were pleased to encounter clinicians they'd known at other points in their rehab journey, which presumably made them more likely to converse with them – at least socially.

These findings underscore the importance of rapport and the sense of community, which would contribute to this comfortable, informal atmosphere and foster social conversations that can lead to mutually beneficial discussions about living with SCI. These findings also reinforce peer learning and support – as another 'non-clinical' way of learning and contributing to others.

8.1.7 High, positive expectations

> *"Setting out on a new adventure is no big deal for the staff – their attitude is just; 'ok guys – we can do this', with no hype and no bother, they just make things so easy and normal for us. But don't forget that they're making it possible for us to do some really extraordinary activities – things that we'd never have imagined it would be possible to do – it's just a genius place."* (Person with SCI, on-line testimonial[4])

Interviewees with SCI appreciated the positive, high expectations of the staff: an attitude of "come and do it – we'll make it happen", which offered a "different perspective on what's possible". Staff were able to manage their concerns or perceived barriers, meaning "everything I asked, it was like, 'that's fine, no problems at all.' It's like nothing was an issue." Some guests expressed pleasant surprise at encountering higher expectations at the program than they held themselves, like Sian:

> *"I feel like at Sargood, it's the opposite way [to other SCI services]. They do push you to do things that you don't think you can do or that you're technically not able to do at your level. They do push you. They're just like, "Why don't we try it?" Or "Why don't we try doing this instead?'"*

Staff similarly described their colleagues as capable and experienced: "just very unfazed by anything … And they've got so much experience." They, too, talked about guests having their concerns addressed and expectations raised even higher. A receptionist, usually the first point of contact with prospective guests, shared some examples:

> *"Sometimes I'll say over the phone, 'do you want to book in for some recreation?' and they'll be like 'but I'm in a wheelchair.' I'm like 'yeah!". And then, 'I'm a quadriplegic.' I'm like 'yes!' I think maybe after a while some people get used to being told 'no you can't do that.' So they're kind of pre-empting that by saying 'I probably can't do it and I don't want to get disappointed'… And the mentality here is very much if you want to do it, we'll make it happen, within reason. So I think that's surprising to people."*

The impacts of high, positive expectations on program delivery and outcomes are broad, powerful and probably self-evident. Staff are willing and able to address the goals and hopes

guests bring to the program, and also push these further. This has a direct influence on skills and independence. The high, positive expectations would influence the ways staff support and challenge guests, and would reinforce the positive cycle of risk, achievement and further challenge. As well as raising awareness of possibilities, high expectations drive staff to open new ones – explored below. These combined outcomes contribute to a more positive outlook and life satisfaction, thereby enhancing well-being.

From individual to group approaches

The themes so far relate to the approach of individual staff. Two additional themes emerged related to the staff approach as a group: a diverse, collaborative team, and a positive, supportive workplace culture. These 'behind the scenes' operational factors were less evident to guest interviewees but were evidently crucial to staff: they impact job satisfaction and, indirectly, guest experience and outcomes.

8.1.8 A diverse, collaborative team

> *"It's kind of like a big family. Everyone's different, but when we're here we all work as a team and everyone helps out ... And we're all here for the same reason: to make the stay really good for the clients. And I feel like that common goal keeps us really focused and driven."* (Staff member)

Staff described a diverse, "beautifully balanced" team where "everyone brings their bit". Rather than viewing differences as "weaknesses or hindrances", they are valued as "complementing strengths". The team is characterised by this embrace of diversity: "It's what the team's about."

The diversity within the team reflects a mix of personal styles, and recruiting for personality has not produced a homogenous group. Staff spoke equally fondly of their "showman", "guru" and "quiet, calculated and resourceful" colleagues. These personalities would contribute in diverse and complementary ways to the staff approaches and mechanisms that support the program's success. For example, showmanship can communicate high, positive expectations, cajole people to try things and inspire them about possibilities. A quieter and more thoughtful approach might be just what is required when providing expert, dignified

support or communicating understanding and empathy. High expectations need to be backed up by a solutions mindset and resourcefulness.

The team also includes a diverse range of skills and professional backgrounds. Guests noticed this: “Their work ethic’s good, their knowledge is good, and they’ve all got different abilities and strengths. I don’t see any weaknesses.” A manager stressed the importance of the “truly hybrid team”, which “separates us from anywhere else and makes a difference … having those unique specialised staff.”

This diversity is found amongst the leadership team, supporting the distinctive combination of hospitality and clinical services: “When working in a business like this, it’s always going to have an element of hospitality, clinical setting, and also just the general business that needs to function and be financially viable.” While the clinical staff appreciated the hospitality background of the resort manager, he, in turn, identified their rehab, SCI and adapted recreation expertise as being crucial program resources. This provides “things at our fingertips that we can draw on to make wise decisions”.

The allied health team is also multidisciplinary, and staff described a culture of “collaborative teamwork”. This enables the collaboration to support individual guests – the nature of which would be familiar to most multidisciplinary teams even if the activities and contributions are somewhat unique. Clinicians also appreciated being able to seek advice and share ideas amongst a supportive team of experts as they tackle complex and novel problems. Guest attendants can also draw on their expertise to better support guests, as Lisa noted: “If there’s an OT question, they’ll contact [the OT], or the nurse, and just check in that they’re not putting me at risk.”

The appreciation for diverse perspectives extends into program decisions. Managers explained that staff can meaningfully influence on delivery and direction: “We’re not a dictatorship. We value expertise and input and often weigh up different perspectives.” A staff member concurred, explaining they were able to shape the original design as well as ongoing development: “The management gave those of us on the ground a long leash or a lot of trust to experiment. We were allowed to imagine and implement ideas.” This approach meaningfully harnesses the team’s diversity and contribution – and causes me discomfort when I refer to “program designers” in the thesis. While this remains the most practical term

to describe the leadership team who initially crafted the program, in reality a range of staff have had, and continue to have, a significant influence on its design and evolution.

8.1.9 A positive, supportive workplace culture

> *"There's just a sense of care that everyone here that works here is really passionate about … it's a really good positive workplace culture. I think if we didn't have that, it wouldn't be as positive a stay for the clients because that's reflected in the way that we do our job."* (Staff member)

Staff described a uniquely positive, supportive workplace culture, which they viewed as vital to the program's success. A shared sense of purpose channels this passion: "We all push each other to be the best we can be … we want the guest to have a great experience, and we want to enjoy being part of that."

The workplace culture is characterised by a sense of community, which doesn't just exist between the guests. Staff spoke of "a very close-knit working friendship" amongst the team, which felt like "a bigger community, like an extended family". Lisa also observed amongst the staff "there's already a kind of community or safety net", which influenced her own sense of comfort and community because "I feel comfortable coming out and having a cup of tea and talking with people."

The small size may help: "Because it's smaller and more intimate, everyone knows everyone … it just helps with positivity." Staff contrasted this with the challenges in larger organisations, especially in healthcare, where "you can just be like a number".

The leadership team plays a key role in promoting the workplace culture, with staff recognising "it's got to come from the top down." Managers were described as caring, supportive, and modelling a 'servant leadership' approach: "They set the tone … you'll see them doing things other managers wouldn't, like plunging a toilet if needed. When you see that, you think 'that's the person I want to work for.'" Staff said this sense of support flows through to program delivery, because "if you feel valued and supported, you're going to do a really good job."

Staff strongly emphasised the influence this culture has on job satisfaction: “I’ve never worked anywhere like this … I feel blessed.” One staff member called it “a once-in-a-lifetime job: the culture is so positive. I drive a long way, but it’s worth it.” Guests notice this too, with one observing “everyone just seems so happy … people are happy to work here.”

This environment presumably creates a positive cycle, where a happy workplace attracts and retains good staff who further enhance the culture. A guest made this link in a social media post, noting how the positive culture and resulting staff retention adds to her own sense of belonging and community, because long-term staff know her well. Posting during one of her stays, she wrote:

> “*I AM HOME … It is such a fabulous place to work that staff rarely leave. Which means when I arrive I'm greeted by name & everyone is aware of my insane Jason Momoa crush ... Being here is life changing*[5]*.”*

Staff retention is also crucial to sustaining the dynamics described in this chapter. This is crucial given the somewhat rare combination of distinctive personalities and niche technical skills: staff noted that losing a colleague would create a significant gap that would be difficult to fill.

From staff approaches to a broader culture

The discussion has gradually shifted away from individual staff approaches towards team dynamics and the workplace culture. The second part of the chapter considers another distinctive and influential aspect of the culture: a boundary-pushing approach that challenges the limits of what is available to people with SCI.

8.2 A culture of pushing boundaries

The program outcomes are supported by a culture of questioning the status quo, going beyond the minimum requirements and forging new possibilities. This section explores how this boundary-pushing culture is enacted.

8.2.1 User-centred building design, offering a new standard of accessibility

> *"The amount of consideration that I wouldn't have thought of. It's like they went above and beyond. Whereas other places do just the basic or not even quite there."* (Lisa)

The building plays an important role as it hosts the program elements, and its design influences the experience and outcomes. Accessibility to people with SCI was therefore crucial.

The program advisor with SCI explained the building was "designed purposefully" for wheelchair users "to the point where we put the window heights at the right height for people in wheelchairs, so that it's a bit awkward for someone standing up." The aim was to ensure "every corner of Sargood on Collaroy is accessible" – not just the bedrooms – and make it "practical and useful for a broad range of people with spinal cord injuries". He added in a newspaper article the result: "able-bodied people fit into our world for a change instead of the other way round", which added to the sense of 'normality' valued by guests.

Specific features of the accessible design were listed in Chapter 5, and here I discuss the design principles and process. The program advisor with SCI – who is quoted throughout this section unless otherwise indicated – explained the aims required "taking accessibility to another level": a key aspect of the boundary-pushing approach.

This involved designers going "above and beyond and mak[ing] it more accessible than what the building code says", because those codes are often "not actually good enough" to meet real needs. The architect echoed this approach in a newspaper article: "even when there was an Australian Standard we challenged it."[6] The aim also meant "everything had to be customisable… because a high-level quadriplegic and a low-level paraplegic or an incomplete para have such different needs from every aspect." The boundary-pushing design approach was important not just for the target beneficiaries, but in service of the broader aim to set an example and precedent as a "showcase". The architect was on board with this aim, too, explaining "this facility would set the tone for lifestyle care in all genres."[6]

A co-design approach was crucial to meeting the needs of service users. The facility was designed based on extensive consultation with people with SCI, which happened "from the

very beginning, before there was even a building design put on paper". The architect's website described the approach: "we followed no rule book, gaining much of our inspiration from listening to, and interacting with, end-users."[7] As Angela observed, "it's actually thinking what would a person in a wheelchair like."

Consultation involved focus groups with "probably close to hundreds of people with SCI" sharing "what they think the need is, and what the gap is." Discussions were "around access", including fundamental design features, and eventually minutiae, like "what side do you want the toilet hose on?"

Consultation needed to extend beyond wheelchair access, however. The then general manager relayed in a newspaper article a key request from the focus groups: "We just want to be able to go somewhere where we can forget we have a spinal injury."[8] Meeting this "big ask" – and the aim to offer guests a hassle-free, enjoyable and relaxing experience – required designers understand less obvious considerations. The focus groups were therefore consulted about "what people would like to do, what they can't, where are the gaps, what can't they do, and the frustrations", as a staff member explained.

The resulting design was appreciated by guest interviewees. They agreed the facility stood in contrast to other accommodation, where "people do the minimum" and "accessible means you can get the wheelchair in the front door" (if that); whereas "going to Sargood, I've really seen the difference." Angela attributed this to design that "has at its heart, people in a wheelchair, their interests: that's what makes it unique. You don't have to fit in."

Angela and others relayed how seemingly "small things" that go beyond basic needs, like the accessible benchtops, large beds, and easy-to-use dishwashers, are actually "a big thing" because they reduce hassles and enhance the experience. The generous circulation spaces particularly stood out to several guests, especially in comparison to typical hotels or their own homes. They shared how "I love that the fact that I wasn't going '[squashed sounds]' to try to get around the bed", and "I went to Collaroy with bruises, and they're all cleared up." For Lisa, this reshaped her perspective on her "crowded" home: "I now know the difference that creating space makes … how I don't need to have as much attention on getting around."

People with SCI expressed appreciation in newspaper articles for the space designed to meet their needs, which meant they "don't have to look down" all the time, and felt like "when I

wheeled in, my wheelchair disappeared." These experiences closely mirror the requests made by the early focus groups, suggesting the designers met the brief. External recognition through the 2017 Good Design Award, which described the design as a "game changer" and "a new benchmark", [9] underscores its success and bolsters the program's aim of being an example to others.

8.2.2 Raising the standards of aesthetics

> *"... rocking up and being like, 'holy crap, this is like a 5 star facility' ... from when you first walked in it was like 'wow': the wow factor- "this is awesome!" ... I'm still impressed by it now."* (John)

In addition to accessibility, the design brief was for a high quality, luxurious environment. The intention was to provide a pleasant atmosphere that enhanced guests' mood and served as a physical representation of the new, positive stage in their journey. This was another aspect of program design that sought to move away from being 'clinical', as staff explained:

> *"It's not meant to look like it's disability friendly. It's not meant to look like it's particularly accessible. And it's not meant to look like a hospital."*

While a brief of 'not being like a hospital' was probably new to the architects, they praised this principle in a design magazine article, recognising that "the built environment has a profound psychological impact on quality of life. If it looked like a hospital, felt like a hospital or smelt like a hospital we would have failed in our job."[10]

This posed a challenge: how be "disability-friendly" without being visibly so? Program designers described a "universal design approach", where accessibility and convenience are built into the design instead of a visible afterthought. Disability-related features, while essential, were designed to be as subtle as possible. Adjustable beds and benchtops were partly chosen based on their aesthetic and similarity to regular fixtures and furniture. Ceiling hoists are hidden in cupboards.

Accessibility and aesthetics aren't completely in tension: accessible design often enhances the appeal. The level and spacious access create a generous, open aesthetic within the building, which connects seamlessly with the surrounding beachside environment. The manager

explained another benefit from his perspective: the wide spaces and lack of steps means "looking after this place is a dream."

Guests appreciated the aesthetics, which resembled mainstream environments and stood in contrast to their preconceptions about SCI services. This was partly based on the finishes:

> *"I'd been in a lot of Western hotels when I travel, and that's what it looked like. Lots of wood, and just the design, how lovely it was."*

The subtle integration of disability equipment also drew praise. Interviewees often used the hidden hoist as an example of the appealing design, which represented to Stewart "the beauty of the place. Someone could walk in and not know that it was even there." They made favourable comparisons to hospital rooms "where you have big equipment sitting there" and accessible hotel rooms, which are often "just so hospitalised". Carrie was relieved her fears about a nursing home environment were unfounded, which was key to the positive experience and outcomes she reported. Although she noticed "tiny aspects" that revealed the disability-related nature of the facility, these were subtle and overshadowed by the overall design: "It was modern enough and clean enough, and I think the natural light and the open courtyard and all that sort of stuff managed to just diffuse that clinical aspect of it."

8.2.3 Novel service design and development

> *"… a world first, world class resort…"* (Staff member)

The program itself is a testament to the power of pushing boundaries and challenging the status quo. Many of the succinct stakeholder descriptions highlighted it as unique and groundbreaking, and its establishment represented a significant, and deliberate, departure from traditional approaches. A local parliamentarian described it in a speech to parliament as an "outstanding example of what happens when specialists are allowed to innovate and start their own businesses to provide medical support."[11]

Staff continue to push boundaries as they expand and improve what is offered. They said their aim of "creating a bigger, better service constantly" requires a continual process of asking, "how do we push it a bit further? How do we make it a bit better?" This is another area in

which the program challenges the status quo, as staff are "often questioning 'are we just doing that because that's what you imagine you would do?'"

Staff don't appear to push boundaries just for the sake of being novel, however. They explained they keep coming back to reflect on "what's the reason we're doing a particular activity?" instead of "putting something on for the sake of putting it on". Service development is shaped by the needs of users, with an emphasis on, "who we're doing it for, and is it going to benefit them?" and "how can we make sure the guests are having a better experience?" The consumer advisory group continue to provide helpful advice in this regard.

Creative ideas are also grounded by practical considerations, like making sure activities "work for different levels of injuries" and "weighing up what's desirable for the guests and what's manageable to do". The following vignette draws on a program manager's description of how this approach works in practice.

> We usually start by whiteboarding everything. We go into a room, put up a big board, and jot down all the questions: What are we doing? Who are we serving? What services are we using? How are people paying? How many people are we serving? What software and equipment do we need? It's like creating a mini business plan each time. Then I research by talking to others who offer similar services to see how they do it and what limitations they face.
>
> For example, when planning the SCUBA course, we asked: 'Who are we serving? How many people? What's the cost? Who's providing it? Where's the equipment coming from?' We put all these questions on the board and slowly answer them. Then work out the finances: we break down the costs and see if we have enough to cover everything.
>
> We let our brains go wild, thinking about every scenario from every angle. We throw all our ideas on the board and compile them into a business plan. After running the plan, we reflect and improve it. It gets better each time we do it. For instance, the first SCUBA course was expensive and lacked support. The second time, we cut costs in half and had more support, making it run more smoothly. Everyone who took the course qualified and can now SCUBA dive anywhere.
>
> That's how [co-worker] and I do all our planning – just us and a big whiteboard.

The process combines creativity and imagination with detailed logistical and business planning, requiring staff to think both creatively and pragmatically throughout. It requires skill to switch between these two mindsets. It is also noteworthy they start with service user needs and benefits rather than potential constraints.

Developing the service also involves "being in a headspace where you can dream of different ideas all the time". This can be challenging to sustain – "It's hard being creative all the time … trying to always be the person that's thinking of how to build something" – but "it's also really fun." Managers reflected these mixed feelings were particularly intense during the early stages of planning: "Starting this job was really challenging but very stimulating. It's the most almost excited and longest hours I've ever worked in my life, but it was a total adrenaline rush for a long time." Mirroring earlier themes, having team members to "bounce ideas off" and offer different perspectives was key to navigating this process.

The program also seeks external support at times. Staff make connections with existing services to learn from their experience and, when appropriate, partner with them to deliver activities and courses. The SCUBA course is a good example of this learning and partnership. Staff "did as much research as we possibly could" about the concept, including what others had done. This research confirmed their own assessment that "people theoretically could SCUBA dive with spinal cord injury". The next step was finding a training and certification body to partner with, who wouldn't give the usual black-and-white answer: "If you can't do some skills, traditionally they would say you can't be certified to dive." Staff research led them to RAIDAptive, who adopt a more supportive, nuanced approach: "if you can't do some skills, but someone else can do those skills for you underwater, we'll give you a certification so long as you have a support person to be able to dive with you." The next hurdle was daunting, though: "We still had to get dive medicals. And it was a scary thought." I pick up the story in the next section.

8.2.4 Embracing and managing risk

The program pushes the boundaries of activities offered to people with SCI, as they seek to provide enriching, challenging experiences, which are key to the positive cycle and longer-term outcomes. These aims particularly relate to the recreation program, and developing this offering requires both embracing and managing the inherent risks of these activities.

Opportunities for the benefits of risk

Staff understand and value the 'dignity of risk', recognising people with SCI often encounter over-protectiveness, where they are told, "it's too risky now". They observed in the context of an already-constrained life, people with SCI "don't want more restrictions. They're sick of rules and doctor's orders and prescriptions. They just want a more ad-hoc life." This may be especially valued when risk-taking is part of someone's identity – "once a risk-taker, always a risk-taker" – for whom an overly cautious approach would be "like wrapping someone up in cotton wool and trying to suppress who they really are."

The program therefore offers risky activities, recognising people "don't want to be bubble-wrapped, they still want to take part in things that are genuinely fun."[12] Staff explained the "genuinely fun" aim means pushing these activities beyond a protected, introductory level: "what use is building someone's skill set up to go and do something, for them to just can consistently participate in that activity at a very entry-level mediocre way?" The desire to avoid over-protectiveness and promote real enjoyment presumably also underpins the low-key, dignified support, and is a reason staff encourage hesitant guests to challenge themselves.

A balanced, pioneering and meticulous approach to risk management

While staff encourage risky activities, they emphasised their role is "to do it in the safest manner possible" with the right equipment and trained staff. This does not involve eliminating all risk; instead, the team focuses on minimising unnecessary harm. A recreation team leader explained, "all our activities have a risk assessment"; this is a formal part of planning, and staff are also "consistently running through a risk assessment" while facilitating the activities. Because the program offers experiences often overlooked by others, they cannot rely on established risk frameworks. Instead, they experiment and gather evidence to develop their own guidelines:

> *"On the leading edge you need to be evidence-gathering, not just evidence-based… use existing evidence to make wise decisions, try something new, do it safely, then push things further."*

The program's risk assessment documents initially resemble standard formats – hazard lists, color-coded matrices, and control measures – but their distinctive content reflects the unusual activities and SCI-related risks that need to be considered. Expanding opportunities for people with SCI requires significant research and expertise. The snorkelling risk assessment is an illustrative example, and offers a behind the scenes perspective on the outing described earlier. It addresses general risks of an outdoor activity like weather, water-related risks like drowning, activity-specific hazards like faulty snorkelling equipment, and SCI-related considerations such as autonomic dysreflexia. Eash risk has detailed mitigation strategies, many of which were observable during the outing, such as supporting the person into the water, and wearing wetsuits and bootees. Even seemingly minor details, like sun protection, reveal practical planning and an understanding of their heightened importance for people with SCI.

This approach was also evident in a comprehensive database used for training and operational procedures, where safety is embedded throughout. The tension between embracing and managing risk is evident there too: procedures enable flexible opportunities (such as lending equipment for independent use) while setting clear boundaries (like requiring managerial approval to borrow some items).

Working with, and challenging, gatekeepers

Engaging in activities often requires approval from various gatekeepers to obtain medical and funding approval. Staff often need to confront these gatekeepers' "preconceived ideas" about what is safe or permissible, and unconsidered reactions: "It's too risky because this person has a disability, and I don't know what to do." Through education and persistent questioning, staff work to expose misconceptions and guide gatekeepers toward more informed decisions. As one explained, "We need to be prepared to keep asking those questions because their response is often, 'Oh, I don't know,' or 'I haven't actually thought about it.'"

Returning to the SCUBA story, obtaining medical clearance was the final hurdle, but staff were met with blanket refusals: "No, someone with a spinal injury can't dive, it's too dangerous, we won't sign a medical." Staff persisted past what other might see as an insurmountable hurdle. They challenged the reasoning behind the refusal, shifting the conversation from assumptions to evidence. This process narrowed their concerns to a few

specific medical conditions rather than an overarching restriction, opening up the activity to many people with SCI.

Funding bodies can also act as gatekeepers, and staff explained how “we might have the best laid plans and then we put them forward and we might get the advice that ‘the [guest’s] insurer is nervous about this’, or ‘how are you going to mitigate that particular risk?” The program’s indemnity insurer has an (arguably more legitimate) interest in the way risk is managed, and influences what the program can offer overall.

The risk assessment process helps address concerns and gain a “real-world tick of approval”. Staff highlighted a tension in documenting risks, where gatekeepers’ unexamined assumptions and default reluctance might incline them to downplay the risks. But other program staff also read these documents, and a risk matrix where “everything is green” may falsely imply the activity is no longer risky and be “filed away”. Conversely, presenting insurers with overly catastrophic assessments would mean “they're going to laugh at you and send you out the door.”

To manage this tension, risks assessments are deliberately upfront about hazards and potential consequences, while including a second risk rating based on the planned management strategies, where “it might become a moderate risk as opposed to a catastrophic risk”. The program can also demonstrate their experience and good track record after several years of implementing the activities, where “all those ones that have been moderate risk, if we reassess them, they could very well be low to minor.”

As well as reassuring insurers, staff sometimes challenge them too. One key argument they make is “there's actually a lower risk profile because we put so much more planning in place than you would do with someone off the street.” In making this argument, staff acknowledged the higher level of scrutiny faced by people with SCI compared to non-disabled people, for whom “you don't get someone's whole medical history and everything about them”, and who aren’t getting the “one-to-one … or two-to-one level of support” the program offers.

Staff also noted the trust they’ve built over time, where they “probably don't get the scrutiny we used to get when we first opened”. They again demonstrated their balanced approach by adding, “there's always room for scrutiny so it shouldn't go completely, and we need to be disciplined here.”

Reassuring family members and guests

Staff also face the challenge of managing "both the fear of the client and the fear of the family, when you're addressing a risky activity", requiring them to communicate risk management approach to this audience as well. Their approach was described in an earlier vignette and involves helping people "see the way you work and that you've considered a lot" rather than a formal process: "It's not like you're running through a risk assessment with the family." Staff also point to peers as examples: "If all these people can do it, for sure you can do it and you're safe."

The visible actions of staff are also reassuring, as I observed during the snorkelling outing. The wife of a person with SCI apparently noticed the same kind of attention to detail during her husband's surfing session, which gave her confidence he was in safe hands. A staff member relayed the conversation with her, explaining she was most reassured by his attending to the "small things with spinal cord injury" like protecting her husband's legs from cold and injury. He reflected these seemingly "little actions" help reassure people "oh, these guys know what they're doing, they're in safe hands" which is "very key in building that trust". The framing of this anecdote implies that these 'minor' details are often overlooked, yet are of crucial importance to those who understand SCI, and are relatively easy to address.

Recognising who 'owns' the risk

Staff explained they ultimately respect the right of guests to make informed decisions about the risks they want to take:

> *"We can provide the information that's there and we can say what we can safely support someone to do. But with said information available, if the client participant decides that they still want to go ahead with it, that's a decision that they've made."*

This demonstrates an understanding of who 'owns' the risk and has authority to make decisions. In most cases, the person with SCI is the one in control – at the program, at least. This is based on the respect for their autonomy, as well as a practical outworking of the capacity and independence enabled by the program. For example, when using an adapted mountain bike, "the person's propelling themselves forward, and they're essentially

controlling their own destiny." The program creates opportunities like these for people with SCI to exercise control, while also supporting them as they weigh and manage risks.

While guests reported positive outcomes from taking risks, staff explained that injuries occasionally occur, like one person who "rolled off their mountain bike and ended up with a dislocated shoulder". This account provided valuable insights. While staff actively challenge the notion that people with disabilities should be sheltered, they also recognise SCI raises the stakes of such incidents: shoulder injuries are more impactful, and the person being unable to "be walked out" meant they "had to have a whole lot of emergency services come in". This "makes a big incident out of something that's quite a small injury".

The staff member did not catastrophise the incident though, describing it as "nothing overly serious", and framing it as a successful example of their planning for such emergencies, meaning "everyone knew exactly what to do when it happened."

This incident reportedly stemmed from a decision made by the guest: he chose to attempt an obstacle staff had cautioned against, and "short of standing in front of the obstacle and putting a barricade up, this person has their own free ability to ride their cycle and do what they want." The guest apparently didn't express regret over taking part in the activity, only frustration at himself because "he then couldn't continue to ride for the rest of the week". The staff member also recognised the potential benefits of the risky decision to attempt the obstacle – especially if he had been successful – and the learning that could come from the experience. Summing up the situation, he returned to the theme of this section: "And it's that dignity of risk as well. That's what it comes down to."

Who 'owns' the risk is not always straightforward, however: relying on the support of others can mean people with disabilities are not always in control. A staff member reflected on how he becomes responsible for managing risks in certain situations, like when controlling a surfboard for someone and "I become the driving force in deciding whether we take on a certain wave or not."

Another staff member explained how facilitating activities also gives the program both responsibility and authority to set boundaries, such as assessing rough surf as "too dangerous". This is where the risk-taking approach would reach its limit: he explained that if someone insisted on going out, staff would intervene ("no, you're not") because it could

endanger both the person and the team. However, he went on to add “That's never happened: people listen to us.” The program’s generally positive approach to risk helps people accept limits without feeling constrained. The shared enthusiasm for fun activities also helps, as people recognise staff “want to be in the water as much as they do”. This is reinforced by trust, where “they know that if we say it's not safe to go out, they're like, ‘yeah, I think it's not safe to go out.’”

While recognising they often hold the power, staff generally wield this power to support the interests of guests rather than the program. Enabling people to take positive risks inherently means the program takes on risks of its own – whether in terms of liability, resources, or managing uncertainty – but this is embraced as part of delivering meaningful outcomes. Resisting the temptation to take the safer, more conventional route is another way the program pushes boundaries.

8.2.5 “There's a way, and let's make it happen”

> *“I think a big part of what's on offer here, and why we have a positive impact on well-being, is because there's an atmosphere that there's a way, and let's make it happen. The answer should be ‘yes. And how are we going to make it a yes?’ And I think people catch that when they come here.”* (Staff member)

Underlying the above findings is a capable, determined approach to developing the program offerings. This approach happens at a micro level too, when staff doggedly support the pursuits of individual guests.

Staff explained they are “super determined” to find solutions, “making sure they can do the activity, and we’ve exhausted every possibility with what we have”. Underlying this determination is a positive mindset, with “the mentality that there's always a way to do something. So let's figure out how to make it happen.” This optimism is somewhat tempered by realism, and staff acknowledged that “sometimes the answer is ‘no’, unfortunately: there are some practical barriers.” But they went on to emphasise, “it's ‘yes’ a lot more than a lot of people think.” This quote nicely captures their reported approach: continuing to push for solutions where others may have given up, meaning “we haven't been stopped by stop by much at all, I don’t think. We will always find a way.”

Guest data supports this perspective. Interviewees appreciated staff were not limited to familiar or readily available solutions, which some said (or implied) was their usual experience of SCI services. They said staff were creative and proactive, describing their approach as "lateral thinking: 'bang – solution, no problem" and "improvise, adapt and overcome… we'll get around it. We'll do whatever we need." As Rob explained,

> *"They'll make an effort to make stuff happen … They tend to have an attitude of 'let's have a solution' rather than 'no, that's a bloody problem.' Normally it would be you either can or you can't. Whereas there it'll be, 'let me see, maybe. We'll have to look into that. We'll see what the issues would be, and what would we need to do to enable that to happen.'"*

The board member with SCI similarly recognised program outcomes are often due to staff "helping clients pursue whatever it is their ambition is and being quite relentless in that pursuit of trying new things and helping people be as independent as they can".

But staff felt the impact of their approach went beyond the more obvious benefits of achieving a specific goal, and observed that the experience of having boundaries pushed can itself enhance well-being. Being immersed in an "atmosphere that there's a way" can result in the more positive outlook and mindset, helping them "see things anew, a fresh perspective based on some assumption being completely put aside". A staff member captured this dynamic well in a key quote:

> *"So to come, to be exposed to a piece of equipment, a recreation activity, a new skill that completely eliminates some barrier that you've just accepted as being an immovable object in your life: I suspect that that's probably a big part of what impacts people's well-being here. To have their eyes lifted and for to the horizon to be further away than they thought."*

8.2.6 Innovation: creating new solutions

> *"There's also an innovation bent that others could benefit from in terms of seeing how Sargood approaches things – seeing how [the OT], for example, is helping people 3D print custom things, and to control remote control boats or cars."* (Board member with SCI)

Sometimes there are no readily available solutions, especially for the less-commonly addressed goals and activities tackled by the program, and the complex needs of people with SCI. This is where determination turns into innovation, as staff customise or create a new solutions. As a staff member explained, “there might not be an [existing] answer but how do we make it happen?”

An important program resource is its “really nimble staff” who have the willingness and skills to create custom solutions like “building a bespoke piece of accessible equipment”. A staff member went on to say, “We love doing things like that”, presumably because it supports their role and produces satisfying outcomes.

Staff explained guests with “the highest level of disability” are especially underserved by existing solutions. Even at a facility striving to provide a ‘gold standard’ of accessibility, at first “there was really not that much on offer for them.” The occupational therapist explained how “a big chunk of my role has been chipping away at all of the things that originally were barriers here and trying to make them more accessible and accommodating to that group of people”, seeking to “cater to them, give them things which expand their horizons, give them independence while they're here”. This has required innovative solutions, including the sensor-controlled lift, and expansion of the home automation system to include voice control of disability-related devices like adjustable beds. These were complex and bespoke projects, involving pushing the limits of mainstream systems designed for people with good hand function.

These examples highlight both the program’s dedication to pushing the boundaries, and the challenges inherent in doing so. Despite the complexity, innovation is valued by staff and managers – as well as the governing body, according to the board member with SCI. He praised the “innovation bent” of the staff in the opening quote, and later elaborated on this approach:

> *“It's just a bit of a can-do attitude to overcoming minor hurdles when it comes to people's disability and how they can contribute to society and fit in with everybody else. That problem-solving attitude and that sort of approach to service provision is a little bit unique. And it would be awesome if other services came and saw it and said, ‘Hey, we can adopt some of that in our own service.’”*

This quote offers useful insights about why innovation is valued. It contributes to people being able to "contribute to society and fit in with everyone else" which echoes the intended outcomes. The innovative approach is also perceived as unique, and an important – but achievable – lesson for other services.

The examples in that quote also offer some noteworthy insights about innovation. First, 3D printing. It is not uncommon for OTs to create custom solutions, and the board member's earlier reference to "overcoming minor hurdles" is a good way to describe the small but significant impact of these creative tweaks. But guest data and news and social media reports[13,14] suggest using 3D printing for this purpose is still rare and noteworthy. The occupational therapist talked about the "ancillary skills" he brought to the role, which includes 3D design. The lack of these skills and equipment may be a barrier to other OTs using the technology in their own settings. However, I'll echo the board member's sentiment by suggesting these barriers could be seen as "minor hurdles" that could be fairly easy to address.

Second, the system that enables guests to "control remote control boats or cars". This system came up in several other data sources: it was noted by interviewees like Adam and on-line,[15,16,17] and I observed it in action. It is a complex new AT system that enables guests to operate remote-controlled cars and boats using an adapted joystick or their chin. It is unsurprising that several people noted it as an example of innovation, which went beyond simple customisation to creating something new.

This example also stood out to me as an occupational therapist because, in my experience, not many of us are supported by their employer to invent AT solutions. The support demonstrated by the board member is therefore striking. This project, and the other innovations described earlier, required a significant investment of resources.

In the next chapter I explore how the program context influences the availability and allocation of resources, as well as the program's approach more broadly.

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CHAPTER NINE:

SUPPORTS AND CONSTRAINTS IN THE PROGRAM CONTEXT

9.1 Contextual supports

This chapter addresses the final research question: **3c) What are the program's limitations, and contextual supports and constraints?** It builds on the program logic, and draws on all three sources of data. The perspectives of interviewees, all of whom were asked about program limitations or suggested improvements, are drawn from. The interviews with managers and the board member then become prominent. Documents were a particularly useful source of data about the perspectives of external stakeholders in this chapter.

The chapter begins with supports in the program context that enable its well-being outcomes. I begin with the temporal context: the point at which the program engages people in their SCI journey. I then consider the institutional and socio-historical context, discussing how a vision shared by key stakeholders continues to support the program's well-being outcomes. The social context is then magnified as I consider the embrace and support of the local community. Finally, I explore funding supports in more detail – an important task considering the significant resources required to support the approaches discussed so far.

I turn to funding challenges in the subsequent section, which considers a range of contextual constraints that limit the program and its reach.

9.1.1 A different stage in the journey

> *"In their world there's a massive focus on their health, medical issues, and a lot of the interactions they have with people are based on something medically that's gone*

wrong and they have to fix it. So for people to come to a place where they can focus on whatever they want to focus on, positive staff, rediscover hobbies and do things that they really love, you see an immediate benefit to their well-being." (Staff member)

One contextual factor that enables the program's success is the point at which they can reach people in their journey, meaning they can offer services that represent a new stage. Ryan recognised the distinction between the scope of this program and others: "they're not going to fix all your medical problems. They're going to fix your physical lifestyle things." A staff member described the program as complementing other services by offering a new phase of support:

"This is just another journey for people with spinal cord injury. You've got acute, rehab, transition to community, and then we're that transition to living a life that you never thought you could. Being able to do things that you never thought you could."

This quote mirrors the early intentions of program designers. On the surface it appears to describe a later chronological stage in the journey, and the later timing certainly is an enabling factor. The program is not bound by the usual demands and priorities that shape inpatient services, where discharge planning predominates, and where medical issues are more common and pressing. These needs have usually been already dealt with by the time guests come to the program, and any ongoing issues are the purview of other services. Freed of these constraints, the program can focus on things like "people's passions and interests rather than 'fix them up and get them out of here as soon as possible.'" Staff can also adopt a different approach to hospitals, where people are "still in quite a lot of trauma." While "in an inpatient setting you've got a social worker" or psychologist supporting people with SCI, the new stage makes possible an informal, peer-based approach to emotional support, where "people can have a meal and a beer together."

The difference in scope is more nuanced, though. While Ryan (above) recognised the focus was on lifestyle rather than medical issues, he also "loved the health aspects to it … you could go down there with a skin problem, and they could help you out with it …they'd show you how to prevent it." Staff do consider ongoing health problems and secondary complications, especially when guests may have limited contact with health services otherwise. The clinical nurse consultant explained she is sometimes the first clinician on hand

who can identify and respond to issues such as untreated pressure injuries, where "I see it as an absolute immediate: they need to go into a spinal plastics team. I've then referred them." But medical issues are not the main focus, and are contextualised within the broader well-being aims. As a staff member explained,

> *"While we cater to people's personal care and medical needs if they arise, we're not here because people are sick, and we're not here because people are broken and need repairing. We're here to provide people with a positive experience, a holiday, a time with their family."*

This quote also suggests a more fundamental difference: in the way staff perceive people with SCI. Although the statement "we're not here because people are sick" could simply refer to the literal reality of working with people when they are medically stable, it also reflects a different mindset, where people are not viewed as unwell, or "broken" and in need of services to "repair" them. Evident throughout the findings is the opposite mindset: respect for the value, dignity, potential, expertise, responsibility and autonomy of people with SCI. This mindset underpins the distinctive scope and approach – one that focuses on strengths, passions and possibilities, rather than viewing people with SCI through the lens of problems that need fixing by experts. It also reflects a holistic understanding of well-being that does not overlook the impacts of bodily problems, but frames these within a broader context.

9.1.2 A shared vision and mandate to improve well-being

The aim to improve the lives of people with SCI provided a clear, shared vision, which shaped program design and continues to guide delivery. Management staff enact this vision through their personal approaches, priorities and allocation of resources, which are directed toward improving guest experience and outcomes. A staff member reflected on the importance of having people in leadership roles that "get it": they have "good instincts around what can lead to wellbeing. Or that peoples' well-being is the point." Front line staff are also "of the same mind", which guides their enabling approaches and service development initiatives.

Program managers are not the top of the hierarchy, however; they report to their superiors and governing bodies. The extent to which these stakeholders support the vision is therefore a crucial contextual factor I now explore, starting with the program's early establishment.

A common vision to improve the well-being of people with SCI was evident from the program's early inception. The community group that sparked this vision also provided most of the establishment funding. This meant program designers had a mandate, financial backing and freedom to pursue creative, ambitious ideas and craft a program that would best fulfil the vision. A staff member reflected on this freedom, which meant they could "do what you want, within reason." They acknowledged the "luxury" of working in a context where financial profit was not the primary driver of decisions, meaning "we don't have to make money. That's not the aim of the game." While donors undoubtedly would have expected their contributions to be managed responsibly, the priorities were guided by the shared vision rather than profit-making.

Another manager reflected on that early stage, noting contextual factors like the donated facility, which meant up-front costs could be directed to setting up the service, and the backing of senior leaders in the "rehab" organisation that administers the program:

> *"We were in a position here where we were given a building – so we weren't paying rent, for example, to start with. So you had time and money to play with. We had the luxury of playing a bit, thinking outside of the square. And you've got to have that behind you to have that luxury. And in NSW Health you don't have that luxury. You don't have spare cash to just be like 'well I'm going to spend four hours a day just like dreaming about these ideas.' That's pretty amazing. It's a fortunate position to be in where you can. And hats off to rehab for letting us do that."*

The impact of being "given a building" can't be overstated, and this is a crucial contextual enabler. And the funding was not endless or ongoing, as a manager explained: "We have lots of ideas: we're not constrained with what we can come up with, but the resources to get there can be constrained … the time and money to make it happen."

Resources are not the starting point for decision-making, however, as illustrated in an earlier vignette. Instead of beginning with limitations, staff adopt an open, positive stance to explore what could be possible, then seek ways to make it happen. This approach mirrors the colleagues I admired in the past, and was captured neatly in an earlier staff quote: "The answer should be 'yes, and how are we going to make it a yes?'" While that quote referred to pursuing solutions for guests, it represents the approach more generally. A determined, solutions-focused mindset drives staff to find creative ways to fund service development. For

example, they source donated and loan equipment, and apply for charitable funding for new initiatives, and adapt the fee structures to new offerings and changing policies.

This highlights a complementary dynamic between the staff approach and the program context, as their determination mobilises additional support and resources. The program context, in turn, enables the staff approach, which is supported by governing bodies. Underlying this is a shared vision and common aims, which I now explore.

The program's scope and focus aligns well within the stated aims of Royal Rehab Group, as the broader administering body is now named. The vision is "providing client-centred care and empowering people to live their best lives", while striving more broadly for "a world without limits".[1] They tendered to operate the new program in the context of a broader expansion and rebranding,[2] and a key priority in the current strategic plan is "expanding well-being and disability services in areas of need". Royal Rehab Group now deliver a range of community-based, specialised services that target, amongst other aims, well-being.[3,4] The recent incorporation of the national peak body for people with SCI, with hopes this will support collaboration, innovation, advocacy and connection[5,6] is likely to have at least some influence Sargood on Collaroy's operations, and may underly the partnership to deliver the new peer support BBQ lunch.

The well-being aims are also shared with The Sargood Centre, which is the entity that owns the building, and whose board provides program oversight. Their aims are to ensure "the continued operation" of the facility and "continually improve the quality of the services provided." [7] Their investment in quality improvement, not just sustainability, presumably underpins the board member's support for the staff approach, determined pursuit of solutions, and innovation. It's also worth noting the likely influence of the board member's lived experience of SCI, and having several people with SCI in similar positions of oversight is another contextual factor that shapes and supports the program's approach.

The Sargood Foundation (the current iteration of the community organisation that initiated the program) also provides some ongoing oversight and support. Their ongoing commitment to well-being is evident in their stated aim, which closely aligns with the program's goals and is built on shared assumptions about what promotes well-being:

> *"To support people with a spinal injury in their endeavor to play an equal role in society by promoting social integration and activity, by increasing workforce*

participation, and by promoting innovations that enhance the lives of people living with a spinal injury."[8]

9.1.3 The embrace and support of a community

"They just love that the community is so welcoming … we're very open towards making this place 100% accessible. And everyone's really gotten on board with having Sargood being built here. I definitely think the community plays a big role in how the guests enjoy their stays." (Staff member and Collaroy local)

The local community is another key influence in the program's design and outcomes. A board member with SCI said what makes "the place special is the community that surrounds it". He went so far as to identify the local community as a stakeholder:

"The attitude towards people with disabilities is so positive because this community has decided to get behind creating Sargood on Collaroy in the first place and is a stakeholder. A shareholder is invested in its success."

According to media and other documents, locals do appear to feel a sense of ownership and pride about the program. As a Vice Patron of the Sargood Foundation put it in a newspaper article, the program is "a brilliant story of what a determined community can achieve."[4] A local parliamentarian also highlighted the role of the community in establishing the program, identifying a range of community stakeholders. He described the program in a speech as,

"… a true reflection of an entire community's passion and dedication. From local residents, health-care providers, clubs and businesses to all three tiers of government, everyone has got involved."[9]

The sense of community ownership and support now influences the experience of guests when they visit the area. Carrie identified two factors influencing the community's unusually welcoming and friendly stance:

"I think one, the fact that the community invited it there. Two, they're used to it … they see the X8 every day. So to see me in it, no one needs to ask me what it is or make a smart comment."

The inclusive stance also enhances physical accessibility of the area, as a person with SCI noted in a website testimonial:

> *"What is truly lovely is that the broader community of Collaroy is committed to accessibility and inclusion as well, which means that most places you go nearby – including cafes and restaurants – are easy to access and the people are very accommodating."*[10]

The Vice Patron of the Sargood Foundation explained this was part of their intention for the program, which was, "specifically designed to be a wellness place for people with spinal cord injuries that can work in a community that is totally receptive of them."[11]

The board member with SCI highlighted in his interview the contribution of local businesses, who "want to be a part of the community and make their shopfronts accessible and welcome people in chairs, that's all part of the experience." Staff shared examples of local businesses seeking their advice on how to better accommodate guests with disabilities, such as how to make making dining more accessible at a local club. They supported the tennis club in planning and securing funding for accessibility upgrades,[12] enabling them to better accommodate guests and other people with disabilities.[13] However, staff noted advocacy is still required because not everyone is as willing to make such changes.

The local council also supported the vision to make the community welcoming and inclusive, in their designation of the surrounding area as an accessibility precinct. The related accessibility projects opened up new locations and activities to guests with SCI, but its convenient location is not a coincidence: the mayor at the time explained in a media article the vision to establish "a tourism precinct for people with disabilities" and the planned accommodation facility was one reason Collaroy was chosen for this precinct.[14] The then Sargood on Collaroy CEO provided an additional insight in that article: the precinct would not just improve the experience of visiting guests, but be another example of pushing boundaries and showcasing possibilities to others – in this case an example of a truly accessible, inclusive, welcoming community:

> *"This whole precinct will be a basis for understanding what's possible …There is a strong desire - and the council bought into this - to make it a showcase of what inclusion can be about. Lots of councils … put in ramps and they remove barriers but*

an inclusive community is one which provides a point of welcome that is emotionally accessible as well as physically."[14]

It is therefore noteworthy the precinct has won federal and state government awards as an exemplar of accessible communities[15] and playgrounds.[16] The vision in that quote also aligns with the vision the Sargood Foundation has for a welcoming community: presumably the reason they contributed funds toward upgrading the accessibility precinct.[17]

These combined insights suggest a reciprocal, reinforcing relationship between the program and its immediate context, which is – once again – enhanced by shared purposes. The community's welcoming and inclusive stance initiated and supported the program's establishment and contributes to its positive experience and outcomes. The program provided impetus for further improvement of the surrounding area, its staff provide support to local organisations, and exposure to its guests makes the community even more welcoming of people with disability. The Sargood Foundation, itself an organisation made up of locals, provided resources for both initiatives. The impacts are also broader: the increasingly inclusive community would benefit other people with disability who visit the area, while contributing to the program's broader aims of being an example to others.

The local community is therefore viewed as a critical factor influencing the program's success. As a board member with SCI explained, "you need a community that's going to wrap their arms around the concept and actually drive it so that it fits and it's welcomed." Yet reproducing the program elsewhere is not a matter of finding or cultivating a welcoming community; he stressed that such a program would ideally need to be initiated and led by the community itself. However, he also recognised the contextual factors described here would be "hard to replicate", involving the "unique situation of having a community and pretty influential figures in a community that are actually supportive and driving the whole thing".

9.1.4 Funding support

The program is primarily funded through service fees, and while a minority of people self-fund their stay or gym membership, the costs would be prohibitive for most without additional financial support. Consequently, external funding plays a crucial role in supporting individual guests and sustaining the program.

Guests recognised insurance funding often makes their stays possible: “The NDIS have changed the game too … and now that this place has been facilitated, funded for that.” A website testimonial put it bluntly: “I would not have been able to book a respite accommodation holiday package without the NDIS.”[10]

Staff help people access insurance funding by ensuring they can meet relevant policy and administrative requirements, and by providing information to prospective guests about the logistics of accessing funding. The fees are below benchmarks, as a manager reported in a media article: “We’re only charging half what the NDIS allows for, because we don’t want to be abusing that.”[18] Managers explained to me the nuances of this comparison (which is complicated by the various funding and fee levels) but said the fee always falls below the gazetted NDIS respite fees, and those charged by residential aged care facilities. This would be one less barrier to obtaining approval, since an important factor weighed up by insurers is the comparative cost of alternatives.[19]

Even for guests who could stay in less specialised accommodation, the program may end up being comparable to other accommodation options when tallying the total costs. Some guests said accessible rooms in mainstream accommodation may meet their basic needs – though they described common issues in these – but when factoring in equipment rental and support workers, the total cost is similar. Lisa shared her experience:

> *“When I looked at having a facility that was suitable for me … I either had to get a hotel room and bring in my carers every day and hire all the equipment … or go to a caravan holiday park that has the accessible cabins. By the time I hired everything it wasn't going to be expensive to stay at Sargood.”*

Rob also found the cost to be comparable – for an inferior experience. He gave an example of “if I just pop up to the Blue Mountains to visit friends”. While non-disabled people may opt to stay with friends, this is not an option for Rob: “my friend’s got this beautiful huge house, and I can't stay with them” because it is not wheelchair accessible. He said his accessibility needs are usually only met in relatively high-end accommodation that costs “a minimum of $500” per night. It’s not just about the extra expense though: he would prefer to be with his friends. The program offers a refreshing contrast, where “I can stay somewhere with family for example: I can't go and stay with family anywhere [else].”

These factors mean the program is more likely to comply with insurance funding requirements. However, insurance funding doesn't cover some costs, such as travelling to the program, and a staff member noted additional barriers in the program context that make this difficult and costly: "Australia is a huge country. Travel is very expensive. And I think that's probably the biggest barrier." While anyone travelling within Australia faces these barriers, they can be more burdensome to people with SCI.

A program manager explained barriers like these are made more consequential by the program's integrated model, which means "if people can't afford to come here, then they miss out on everything." This is a reason the Sargood Foundation "raise funds to put towards people's travel as well as many other things". However, at times "that may not be enough" to cover costs, and the gaps this charitable funding seeks to fill are widening due to insurance policy changes (discussed next). Further, Tom shared a concern that the cost of the program may put people off before they investigate funding support:

> *"It's not cheap, is the other thing. And if people don't have the funding, I know there's the Sargood Foundation and we would never want to turn anyway because they couldn't afford it, but it would put people off."*

9.2 Contextual constraints

All interviewees were asked about limitations of the program or improvements they would suggest. Some responses related to refinements within the program's purview, like providing a bath or a clothes airer for beach towels. There were a few maintenance issues, like the gym machine settings sometimes not working as programmed or the carpet needing an update. Improving accessibility and activity options for people with high-level SCI is an ongoing challenge staff are working on. One guest also identified the need for equipment for people with higher levels of function and are able to walk or transfer, such as seat raisers for the toilets, which are intentionally low to accommodate commode chairs.

The suggested improvements were few and arguably minor, which may reflect the customer service approach and openness to guest feedback. Most limitations related to contextual constraints that limit the program's operations and reach, which I now discuss.

9.2.1 Challenges in the funding policy context

An important factor influencing the sustainability of the program is the reliance on insurance funding, the availability of which is dictated by the policies of the insurers. Rob highlighted a risk arising from this context: “That’s what I'd worry about, that they might withdraw it one day. Because there's no way on earth I can afford to stay.” The program is currently in a context of significant policy change that limits availability of funding for people with SCI, affecting their access to supports generally, as well as for the program.

Tightened scope of NDIS respite funding

Of particular relevance to the program are recent changes related to short-term accommodation and respite funding, which is the funding category NDIS participants have generally used to fund their stays. The category was renamed “short term respite” and is now framed solely as a break for carers. This means the funding is now only available to participants receiving at least 6 hours per day of unpaid family care, and people who live alone or in supported accommodation are no longer eligible. For those eligible, the funding can only be used to facilitate time away from informal carers.[20]

These changes were only recently formalised into operational guidelines, but staff said about 18 months of vague policy[21] and rumoured changes had affected guests already, especially those wishing to stay with their families or those without family carers. The changes were implemented after I interviewed guests, so I lack first-hand accounts of their experiences. But staff reported a trend of declined or cancelled bookings, and their discussions with guests and funding organizations suggest that uncertainty surrounding the new policies has left many hesitant to proceed, fearing they might misuse funds. One person with SCI recounted their own experience on social media: “The NDIS planner said that I was miss using [sic] NDIS funding by attending Sargood with my family or with anybody else for that matter.” Even though it costs the insurer no more, having family members stay with the person now defeats the stated purpose of respite.

Holiday accommodation is viewed by the NDIS as a day-to-day living cost,[20] and instances of short-term accommodation funding being used for non-disability related travels costs appears to underly the tightened (or some might argue, clarified) policy.[22] To adapt to these changes, the program has added a cost category for people who attend for a holiday, which

separates the cost of accommodation for self-funding. In theory, NDIS participants could still use their package to pay for equipment rental and care during their stay[20] and separately fund therapy consultations and adapted recreation.

Challenges and unmet needs arising from policy changes

While this arrangement appears reasonable on the surface, and may be reasonable in many instances, the case study findings also reveal challenges and complexity. Staff reported the administrative burden of separating funding in this way has been challenging for the program and prospective guests. People with SCI do not always have the required line items in their plan, and need to adjust to a new way of planning and managing their funds. Developing and administering new billing structures has also required significant, ongoing program resources. The administrative burden may be the reason respite funding has traditionally bundled accommodation, care and equipment costs into a single category: an approach that has continued in the new NDIS policy.[20]

Further, not everyone can afford the separate cost of accommodation due to socioeconomic disadvantage. Although this is not the responsibility of the NDIS, it nonetheless limits access to a much-needed break, as well as all of the integrated program's benefits. The resulting increase in demand for charitable funding, together with decreased occupancy, has meant program managers have needed to explore alternative models and funding sources.

The findings also suggest at least part of the accommodation cost could be disability-related: for people whose SCI-related needs were only met in higher-end accommodation, and for people whose only suitable accommodation option was the program, at least initially. In such situations, the cost above budget accommodation, which non-disabled people with limited funds can choose, should arguably be met by insurers. However, NDIS policy is unlikely to recognise this holiday-related cost any time soon – and even the respite policy explicitly states it will only fund basic accommodation.[20] These insights underscore the importance of the program's capacity-building services, which can enable some people to stay in less specialised, expensive accommodation.

It's worth highlighting the program does not cater to people who simply need short-term accommodation (e.g. for an event in Sydney) and do not have complex disability-related needs to access it. Staff explained the basic accessibility standards of most mainstream accommodation would be suitable in this scenario, which they encourage and support people

to find instead. The program does not offer an accommodation-only rate for this reason, which, apart from being outside the scope of insurance funding, would also be outside the program's scope. The intended beneficiaries have complex travel needs that are functionally inseparable, and/or are likely to benefit from the broader offerings. This intention is reflected in the program's complex, integrated design. The case study findings highlight the immense value of this integrated model – yet it can pose a problem in the program context, which I discuss next.

A novel integrated, model meets rigid policies and processes

The program's integrated model means services are not easy to separate into funding categories or align with standard procedures, and the model would be unfamiliar to many. This can pose a barrier for funders. A staff member described instances of insurance delegates challenging invoices because respite stays funded under the 'core' category also included capacity-building services, a different funding category. That the program's respite fees were below the scheduled cost, and that no additional charges were applied for the capacity-building services, did not matter; delegates focused on the rule that core funding cannot be used for capacity building. Lengthy explanation was required to resolve these issues; this remained inadequate in one instance, where the delegate insisted the program invoice separately for the capacity-building services, in addition to the respite stay. This example illustrates how the program's flexibility and attempt to offer value for money (one of the insurer's funding criteria) can clash with rigid procedural adherence – resulting, paradoxically, in higher costs to the insurer.

The staff member explained these clashes are unusual, and that "people on the ground in this [SCI] space see the value of what we do" – another example of the importance of stakeholders that "get it". Like with their risk management approach, the program has built "high credibility in this space", which means "no-one sees us as rorting the system", at least those in the SCI field. He said clashes are more common with larger, generic fund management providers, which are more likely to employ staff unfamiliar with the complexities of SCI, and to rely on automated processes. This insight is particularly salient given the proposed new NDIS planning framework which, based on information provided by those developing it,[23] will involve more impersonal methods of budget allocation alongside more flexible spending arrangements. How this will impact programs like these remains to be seen.

Another complication of the model is the spontaneous way in which people engage with the capacity-building services. This makes it hard to plan and allocate funding in advance, and means the 'goal' of a stay may only become clear in hindsight – often more than a holiday. Further, the need for some people to travel to a metropolitan area to access specialised capacity-building services is not formally acknowledged by NDIS policies. In fact, in one of the above examples the delegate's concern was based on a suspicion the person had accessed respite specifically to engage in capacity-building. The potential skill-building benefits of short-term accommodation were recognised by the previous respite policy,[24] which was more accommodating of these unplanned or integrated outcomes. However, this purpose has been explicitly excluded from the new policy: "Short term respite is not for building new skills".[20]

In addition to the constraints and challenges posed by its context, the program is also expensive to operate, especially relative to comparable programs. The combination of hospitality and clinical services costs more than either of these services alone: mainstream accommodation providers do not incur the additional costs of meeting SCI-related needs and, unlike other clinical services, the program funds an expensive model to reach people with SCI. Managers also explained the resources are a mixed blessing: the oceanfront building is subject to the weather and costly to maintain, and experienced staff attract higher salaries.

More expansive, but still vulnerable, policy

Funding policies of icare, the other major insurer of people with SCI, appear to recognise the challenges described so far: they bundle a range of costs into a single funding category for short-term accommodation, while allowing – even encouraging – this funding to be used to support regular holidays. They also recognise the broader benefits of time away from home for peer support, skill-building, well-being and families. [25,26,27] These more expansive policies facilitate smooth access to the program for icare participants and may underlie the significant financial investment icare has in the facility.

Any policy is subject to change, however. The program advisor with SCI noted that icare's involvement was driven by "one or two key people at icare that understood the value proposition" and influential members of the Sargood Foundation. These influences are tenuous and he, along with other staff, noted some individuals within the organisation are not supportive of funding holidays, as a general principle or for individual participants. That said,

he noted the risk of icare withdrawing support “is less of a concern though because they're so committed to it by virtue of what they've put in already”.

9.2.2 Limited eligibility

Another key limitation affecting the program’s reach is the policy of only hosting people with non-progressive SCI (and their loved ones, if the insurer allows). The barriers to staying away from home are not exclusive to SCI and relate to impairments that are shared by many other conditions. The challenges to well-being are not limited to SCI either. Therefore, there would be many people with disability who would benefit from staying at the program yet are ineligible. Carrie highlighted one example:

> *“And that's what breaks my heart. My best girlfriend has got Charcot-Marie-Tooth ... For all intents and purposes she's a C7 quad in every way, shape or form. But she can't go to Sargood. ... she would really value it with that opportunity to have that stay. She won't get it.”*

The eligibility criteria relate to the mandate of the charitable funding that seeded the program, which was driven by a desire to support people with SCI. The program also aims to specialise in meeting the specific needs of people with SCI, and program resources are directed to this end. As a staff member explained,

> *“We're all specifically trained for spinal cord injuries. And we have such a select knowledge that I think if we learn [to support] other disabilities, it just it defeats the purpose a little bit because you want you want them to be 100% confident and efficient in that one specific injury. Rather than being able to cater for three different disabilities and having not as much knowledge.”*

Being exclusive to people with SCI is also thought to facilitate the peer support and sense of community. A staff member explained, “I think that is always an argument for why we’re spinal cord injury only. Because there's something very unique about going through a spinal cord injury that other people will never be able to relate to.” The board member with SCI agreed, and explained that extending the program to people with,

> *“ ... other disabilities that were different complexities that were unrelated to spinal cord injury, I think you would lose some of that special kind of community,*

intentional community that we've created. So I'd be nervous to change the essence of what it is thinking that that might actually break the effectiveness of that intentional community."

He elaborated on the "different complexities" that characterise the SCI journey, where people typically share a traumatic, life-changing event in their history, as well as potential to rebuild a good life. The assumption is this will enable people with SCI and their families to offer each other empathy and support, as well as inspiration. On the other hand, this stance also overlooks the commonalities these conditions share with SCI, as well as the useful perspective they might offer from their diversity. It also means many people with disability miss out altogether.

The community-based gym and recreation services seek to support people with disability who are ineligible to stay – at least those who can travel there regularly – and the roadshow program reaches out to people in regional areas. Still, staff expressed disappointment about not being able to meet the needs of a wider range of people. They were unanimous about the benefits of remaining exclusive to SCI, but wished there were alternatives available for people with other conditions:

"It's still hard for the person on the phone who feels that their life looks very similar to someone with a spinal cord injury .. then it's hard to say, 'actually I don't know somewhere [else] you can go that's purpose-built for you and your disability.'"

9.3.3 Reaching reluctant people with SCI

The program has succeeded in its aim to provide services to people who are otherwise poorly connected – but this is limited to the people who do come. While several guests overcame their initial aversion to SCI services, it appears this is a barrier limiting the program's reach.

It would be difficult to obtain data about people who do not come to the program, and the interview recruitment methods only reached current and former guests. But some interviewees talked about peers who were reluctant to engage, despite their urging. For example, Carrie was concerned others were missing out due to similar misapprehensions to hers:

"I think the biggest challenge for Sargood is finding people like me and getting them to engage … I've got another friend that I'm going to see tomorrow, and I can't wait to say, 'you need to trust me. You need to go to Sargood.'"

The program is – of course – optional, and it would not be realistic or appropriate to expect every person with SCI to engage. But inherent in Carrie's quote, as well as other interviews, is an appreciation for the benefits of the program and a desire for others to experience these. Sian highlighted a key challenge:

"… how to change the perspective of those people who have been injured for a very long time and have had a lot of those negative experiences with well-meaning organisations, I don't know. But you need to do it … I've been trying to convince my colleague to go and stay at Sargood four years and he won't go. He just won't go. And I'm like, "It's not like the other things that you have experienced."

9.3.4 Wanting more of them

"Any chance of a Sargood Centre in western Sydney????? Time for growth and change and inclusion everywhere in Australia !! Not much out this way at all – nothing like Sargood that's for sure. Everything should be modelled on Sargood, as the industry standard for all holiday destinations in this country!!!"[28]

When interviewees were asked for suggestions to improve the program, the most frequent response was the need for more programs like it, and in other areas. This is a commendation rather than a complaint, however the program's being limited to one location is an important factor restricting its reach and impact.

Interviewees with SCI shared the desire of the person quoted above: "It would be great if funding bodies would be able to establish things like in other cities … trying to set up more satellite places around other areas." Ryan expressed a similar wish after experiencing the program's benefits: "and now I imagine in a hundred years that there'll be hundred or 200 of those places around Australia. How good would that be?"

Staff, too, wanted more facilities like it to be opened in other areas: "long-term I'd love to see other Sargood-style properties scattered around the country. … the capitals or the main tourist hubs." This may stem from a desire to reach people in more locations, but may also reflect

the program's appreciation for broadened travel horizons. This was particularly evident in the vision one staff member shared:

> *"I will say only that I think we are fantastic. And if this can be modelled – if we can do this in other pockets of Australia – it would just be fantastic. And I know it means that people don't come to Sargood, but it actually just means that people have options of going to other places in Australia they would love to see … And possibly international … these centres everywhere. That's what I would love."*

The quote also expresses a perspective shared by other staff and stakeholders, who view the program as an example to others – mirroring the broader aim of program designers. The boundary-pushing approach is not just to benefit the program, but to expand its impacts by raising the expectations of others and being a role model.

Guest interviewees talked about the lessons they would want other programs to learn from this example. People with SCI also identified the program as an exemplar on-line, calling it "groundbreaking, a total game changer and a role model for what is possible". The quote that opened this section was particularly emphatic, and noted lessons for the travel industry. They went on to talk about lessons for healthcare, as "a role model for not only spinal units in Australia and around the world, but for other contexts and people with other injuries."[28] Another online testimonial highlighted the program's potentially broad impact:

> *"Sargood on Collaroy's vision to set a new standard in accessible travel really means the world to our family. They are leading the way with inclusiveness and are changing people's lives for the better ... I would love to see councils and businesses follow Sargood on Collaroy's lead and actually do so much more to accommodate people with disabilities, so that they can properly participate in life and be part of the community."*[29]

This view is not just held by insiders. The local representative spoke again in parliament about the program being a role model for innovative, person-centred support in healthcare,

> *"... harnessing the innovative drive of the private sector, coupled with government support for individual choice. This is the trifecta of modern health care. This is how we will create affordable quality care into the future … These are the kinds of businesses that we need to be incentivising to grow and develop."*[30]

This commendation from someone with influence over policy development suggests, at least from his point of view, the program offers valuable lessons for policymakers and broader healthcare practices.

The case study findings can support the expressed desire for others to model themselves on the program; the thesis now moves on to these transferrable insights in the discussion chapter.

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CHAPTER TEN:

DISCUSSION

10.1 Introduction and overview

The thesis set out to identify how rehabilitation can move towards an explicit and intentional focus on well-being. The systematic and scoping reviews (Chapters 2 and 3) contribute to this aim by strengthening the conceptual foundations of well-being in the field, mapping how it is currently addressed in practice, and identifying how influencing factors can be addressed. Their findings and contributions are discussed in detail in the preceding chapters; taken together, they highlight the potential for services to shape well-being through engagement with these factors.

At the same time, the systematic and scoping reviews revealed important gaps in how well-being is defined, intentionally targeted, and translated into program design and delivery, and point to the need for in-depth exploration of an intentionally designed program. his led to the design of an in-depth case study of a deliberately constructed program, exploring its design and components, intended and reported outcomes, and the mechanisms and contextual factors that influence how well-being outcomes are achieved.

To support the translation of these findings into practical guidance for program design and delivery, the discussion now returns to the gaps and challenges identified in earlier phases of the thesis, which the case study had potential to illuminate. These are addressed through a set of *issue questions* that structure the analysis, focusing on how the case study findings can provide insight into these previously unresolved areas. In case study research, issue questions are broad, conceptually driven questions that guide the interpretation of findings, enabling them to be understood in relation to real-world challenges and translated into practice-relevant insights [1].

The background literature identified the need for practical, transferrable insights for program design and delivery. The systematic and scoping reviews reinforced this need, highlighting a lack of detail about program design in the existing literature. This gap informed the first issue question: **How can the theory of change support adaptation of the case study findings to other contexts?** Drawing on the case study findings, the discussion considers how its underlying logic and design can inform adaptation in different rehabilitation settings.

Responding to the call for an unambiguous focus on well-being requires clearly defined aims, a challenge explored in Chapter 1. The systematic and scoping reviews showed how this challenge persists in the literature, where even ostensibly well-being-focused programs often lack clear definitions. This informed the second issue question: **How can explicit well-being aims be formulated and communicated to stakeholders?** Having established that the case study program explicitly targets well-being, the discussion examines how these aims were formulated and communicated to a range of stakeholders.

The systematic review examined how programs address well-being through its determinants, reinforcing their relevance, their interrelationships, and the potential for services to influence them through diverse means. The scoping review further explored the extent to which these determinants are intentionally targeted, highlighting both the promise of multidisciplinary, holistic approaches and the tendency for well-being impacts to be identified retrospectively. Together, these findings pointed to the need to examine programs that target well-being determinants deliberately and comprehensively. This informed the third issue question: **What is the value of well-being theory in informing the intentional and holistic design of programs that aim to impact well-being?** The discussion draws on the case study to consider how theoretical frameworks, including SCI-specific determinants, may support program design and evaluation.

Occupations were highlighted by the systematic review as a key influence on well-being, with particular characteristics associated with stronger impacts. This, together with the areas of need and interest identified in Chapter 1, informed the fourth issue question: **What guidance can be offered for goal setting and program design, considering the characteristics of occupations that appear to have the greatest impact on well-being?** The discussion explores how the case study findings can inform more effective use of occupations in rehabilitation practice.

Finally, the discussion turns to specific insights for rehabilitation service delivery. While the reviews highlighted the broad potential for rehabilitation services to influence well-being - through their approach, the opportunities they create, and the relationships they facilitate - they also pointed to significant gaps in how these supports are designed, delivered, and made accessible, particularly in community contexts and at later stages of life after injury. These gaps informed the fourth issue question: **What clinical support do people with SCI want and need as they build a good life, especially later in their journey?** This section examines how these supports can be more effectively delivered in practice, offering insights for both service models and the day-to-day practice of clinicians.

Together, these issue questions provide a structured way of engaging with the key challenges identified across the thesis, using the case study findings to explore how they can be addressed in practice. In doing so, the chapter brings together the conceptual, empirical, and applied strands of the research to offer clear guidance for rehabilitation, highlighting how well-being can be more explicitly defined, intentionally supported, and meaningfully integrated into service delivery.

For those ready to centre well-being in their practice and research, this chapter provides encouragement and actionable insights. Yet the ideas may not always meet a sympathetic audience. The discussion also serves as a challenge to the status quo: drawing attention to service gaps, non-enabling approaches, and persistent barriers that constrain services, and underscoring the need for continued research, theory development, and systemic change. I conclude the chapter by exploring contextual constraints that limit opportunities for change yet make a clear and explicit focus on well-being even more critical.

10.2 How can the theory of change support adaptation of the case study findings to other contexts?

The case study research confirmed that the program is indeed a practice example of the explicit, intentional design called for in the literature. Well-being is clearly identified as the program's ultimate intended outcome. Specific factors understood to support well-being are embedded in the program's design and reflected in its intended outcomes and three core elements. The program logic illustrates the strong alignment between these elements, the

activities, the intended outcomes, and the overarching focus on well-being. Reported outcomes aligned with the intended outcomes, and the program produced significant, broad well-being impacts. Capacity-building was central to the program's outcomes, and the novel approach to offering ongoing rehabilitation to people with SCI was meaningful and appealing.

Stakeholders, including guests, staff, a board member and local parliamentarians, also viewed the program as exemplary in a number of ways. Various awards have recognised the staff, building and local area as outstanding. It was also always intended to be an exemplar, as a "showcase for innovation and connection".

Having established the case as an exemplar, the discussion begins by considering transferrable insights for program design and refinement, addressing the issue question **how can the theory of change support adaptation of the case study findings to other contexts?**

Adopting a more explicit focus on well-being could 'simply' involve replicating the program as it is, and stakeholders expressed a strong desire to see it reproduced in other areas. As a manager put it, "I still live with the hope that we would duplicate Sargood." The case study contributes to this possibility by providing a detailed account of the program's *elements* and underlying *logic*, offering guidance for those interested in replicating its key components.

However, an exact replication of the program in other contexts is unlikely to be feasible. Nor may replication be desirable: the program exemplified a spirit of innovation, and it is unlikely that stakeholders, or the sector, would want progress to stop there.

Responding to the call also looks different for existing services. In a sector that is already well established, change may need to involve incremental refinements within current structures rather than wholesale redesign. At the individual level, rehabilitation professionals may also seek to adapt their own practice to better support well-being, even when they have limited influence over broader program design.

For these reasons, the primary aim of the case study was outward: to explore the transferable insights the program could offer to other contexts, using 'exemplar' in the sense of an illustrative case rather than an evaluation or endorsement. To support this, the case study was designed to generate rich, contextual detail, and the theory of change generated deeper insights about what enabled the program's success.

The *mechanisms* illuminate the dynamics that produced the outcomes, considering the *assumptions* and *principles* underpinning their historical design and current delivery. This enables program designers to see what worked and why and consider how similar processes might operate in their own contexts. An understanding of *contextual* supports and barriers that influenced this program would further support this process.

While an examination of how all these concepts could be applied in any context is not possible or appropriate, I offer one example to illustrate how they could inform program design. The example considers two aspects of the program – short-term accommodation and the charitable donations that enabled it – that may seem the least transferable to other contexts. Program designers might look at the program's donated accommodation facility and wonder whether, and how, it could be replicated. This would be extremely difficult without comparable funding or historical circumstances: precisely the kinds of *contextual* factors that should shape design choices. The importance of the charitable donations that enabled this program element can't be overstated, and this may be an understandable sticking point.

But to those tempted to think "I can't do anything because I don't have that resource" or "well anyone could do that if they had those resources", our findings show the charitably funded accommodation facility is neither necessary, nor sufficient, for impacting well-being. Examining their role using concepts from the theory of change reveals how similar well-being outcomes could be achieved in different ways.

10.2.1 Mechanisms: Moving beyond visible program elements to consider their purpose

The accommodation facility is, of course, necessary for the holiday-related aims, but the theory of change findings show these aren't the program's ultimate – or even original – aims. Beyond providing a break and contributing to well-being directly, the accommodation attracts guests, hosts other program offerings, and creates opportunities for peers to connect (which are themselves mechanisms for achieving outcomes). The specific form this program element ended up taking was shaped by the available resources and consultation with people with SCI, but addressing barriers to travel and accommodation was not the initial impetus.

Programs with different resources could identify alternative offerings that serve the same purpose: attracting and gathering people, while also being well-being enhancing. Similar

consultation with service users can help determine what would be appealing and impactful. Because well-being is broad, programs may pursue it through various avenues – though adapted recreation stands out for its clear need, strong impact, and similarity to accommodation as a mechanism.

10.2.2 Considering the mechanisms of existing models

Applying these insights doesn't require designing an entirely new program from scratch, and existing models may in fact be more adaptable than the program we studied. The theory of change could guide the consideration or evaluation of existing models, based on whether they deliver similar mechanisms.

For example, camp-style recreation programs, especially those that integrate other offerings like skill-building and peer support [2, 3] deliver most of the same mechanisms and may serve as useful models to adapt. They, too, involve a prolonged stay, offer appealing and impactful recreation activities, and bring peers together. The key difference lies in accommodation: rented camp facilities may incur less costs but could be less appealing, meaning other offerings must take on more of the role of attracting participants. Accessibility would also likely be less ideal for people with significant disability, which may be a barrier and/or enriching challenge.

Community-based group recreation programs also share several of the program's mechanisms (appealing activities with well-being impacts, peer interaction) and could play a comparable role with fewer resources. They would need scaled-back objectives since they lack an extended stay. On the flip side, this might make frequent participation more feasible.

Either of these existing models could be enhanced by incorporating capacity-building services, which they don't generally offer, but were key to the case study's broader and longer-term benefits. While short consultations or exposure to new options may be all that is feasible in these models, the findings highlight the appeal and value of these approaches, nonetheless. Conversely, capacity-building programs might consider adding aspects of these models, such as recreation or social activities, as a way of attracting service users, and for their own impact on capacity.

While outside the scope of the thesis, it is also worth briefly considering lessons for accommodation and respite services, since they already offer the accommodation element

being discussed here. Concepts from the theory of change could guide the expansion of such services to impact well-being more broadly, by adding additional elements, and by ensuring the accommodation itself is appealing and impactful. The theory of change also highlights less obvious considerations, such as the need to consider the target market and eligibility if peer support is an intended mechanism.

10.2.3 Why resources alone aren't enough

This brings us to my next idea: as well as being unnecessary to impact well-being, the donated accommodation facility is also *insufficient* to do so. Even if accommodation is a viable offering, programs need additional mechanisms to offer a similarly appealing and impactful service. Charitable donations alone were also insufficient to deliver the program or its outcomes, and the theory of change highlights additional considerations for services seeking similar funding.

Private benefactors are no less stringent than government funders; they may just have different aims. To win and retain the contract, program designers had to pitch and deliver a compelling program. An appealing, high-quality service is also crucial to attract service users, the main source of ongoing revenue, and impact their well-being. This alignment of purposes – between benefactor aims, program goals, and the desires of service users – was fortuitous for the program, though not always easy to obtain.

The findings also revealed a paradox: this kind of 'premium' service is more expensive to deliver, yet problematic for the insurers who became the main source of ongoing funding after most charitable funding ended. Insurers can't be expected to pay for more than a basic service and may in fact be suspicious of programs that offer 'luxuries', a topic I return to later in the chapter. This creates a tension: the very features that made the program appealing to benefactors and service users also poses challenges for sustainability.

This discussion illustrates how resources alone are not sufficient for program delivery and outcomes, and how applying theory of change concepts, particularly mechanisms and context, can inform program design beyond the surface level of resources.

10.2.4 Operational factors: Essential in any program configuration

The above discussion also foreshadowed the importance of *operational factors,* such as staff approach and service culture, that shape how the mechanisms work in practice and were equally crucial for program outcomes. Their influence suggests program designers should look beyond the headline features and consider the underlying conditions that enable delivery.

These more detailed operational insights are also relevant for existing services and individual practitioners who have limited scope for structural change, offering practical entry points for improvement without requiring a complete overhaul. Later in chapter, I discuss how rehabilitation services may adopt these insights.

From direct adaption to broader insights

The discussion now moves away from direct adaption to consider broader insights about intentional design for well-being. I explore two central aspects of such an approach: formulating and communicating clear well-being aims, and holistically and intentionally addressing well-being determinants.

10.3 How can explicit well-being aims be formulated and communicated to stakeholders?

The call to focus more explicitly on well-being included being clear and unambiguous about these aims [4], which would provide clarity to stakeholders and guidance for program design and evaluation [5, 6, 7]. Insights from the case study may inform that process, and the discussion now considers the second issue question: **What can be learnt about formulating and communicating well-being-related aims?**

10.3.1 Simple, accessible language

The program's overarching well-being aims were evident in documents and discussed in interviews. This section explores the program's approach to communicating them, returning to the website description introduced earlier:

> *"We aim to provide an environment of refreshment and inspiration for guests and their families, while promoting social integration, activity and support. It is a combination of our equipment, our expert clinical knowledge and the overall environment of facilitating change at Sargood on Collaroy that helps us in our ultimate goal — to provide improvement to the lives of those with a spinal cord injury."*

This description offers a number of insights. First, it is an example of how lay language can be used to succinctly communicate complex ideas. Notably, the jargon-free language still effectively captured key aspects of well-being's theoretical underpinnings, encompassing both hedonic (e.g., happiness, pleasure, life satisfaction) and eudaimonic (e.g., meaning, growth, character) dimensions [8, 9].

Interestingly, while 'well-being' has been suggested as a less medicalised term than 'quality of life', [7, 10] the term may itself be the kind of jargon the field has been encouraged to move away from [11, 12]. The term 'well-being' was not well-understood or used in the case study: it wasn't often volunteered and sometimes required clarification when I used it. There was also a sense that framing a program explicitly around well-being might be misleading or even off-putting, as one interviewee explained: "it's not plastered on the walls or advertised as a well-being centre." The term 'well-being' also appeared to carry new age connotations for some interviewees, suggesting its meaning and cultural associations may have evolved beyond those typically assumed in the rehabilitation literature

These insights underscore the need to move away from 'top-down' terms that are recommended or defined by theorists, and highlight the potential of flexible, accessible language that is relevant to the context.

Second, elaboration and tangible examples may help explain the meaning of broad, multidimensional concepts like well-being. The program description is somewhat lengthy and supplemented by specific examples and program offerings. It zooms in and out between a broad and specific focus. The examples appear thoughtfully chosen to cover a wide range of pursuits, which may resonate with different people. The range of examples also highlight the

program's breadth. While broad aims might be confusing, here they are framed as a strength of the holistic program.

Finally, the program's cohesive, intentional design is evident in the description, which would have provided clarity to whoever crafted it. Communicating explicit well-being aims is presumably made easier when they genuinely informed the design, especially for broad, complex programs.

10.3.2 Communicating well-being aims – or not – to service users

Understanding the program's overarching aim did not appear important to guests, who found it hard to identify or articulate. Apart from one interviewee who had briefly looked for a mission statement, none of the interviewees expressed curiosity about the overarching aim, which is prominently displayed on the website should they have sought it.

The program appeared restrained in how it presented its overarching aim to the public. Not wanting to promote the program "as a well-being centre" might be about more than just a problematic term, but more fundamentally about the idea itself. Perhaps service users could view this as vague, judgemental or patronising; this warrants further investigation, but it's clear, at least, the overarching aims were not what drew people. Their reasons for participating were more specific and tangible, such as engaging in a particular activity or working on a skill.

This begs the question: are explicit well-being aims important when it comes to promoting programs to service users? The thesis opened with a critique of the way services take well-being aims for granted, but this is one context where it may be appropriate they fade into the background or hindsight. When promoting programs to service users, it may be more helpful to be clear and explicit about program offerings than well-being aims.

10.3.3 Accommodating diverse needs and understandings

Although well-being was not front of mind for guest interviewees, the concept did resonate when they were asked about it. They agreed this was a broader and important contribution of the program, and shared a range of examples of well-being impacts they'd seen or experienced.

The examples revealed how interviewees understood well-being: unsurprisingly, as a broad and individualised concept. The impacts varied in scope and focus, suggesting programs should be holistic, flexible, and individualised to accommodate a diversity of needs.

The findings also challenge the tendency to rank or compare well-being impacts – an inclination I had to consciously resist when crafting the paragraph above. Interviewees didn't usually frame them as big or small: what mattered was whether they met their needs at the time. Seemingly small experiences can also carry broader significance. A shared cup of coffee was an example mentioned by several participants, and the value appeared to lie in connection and community, especially for one interviewee, a regular gym-goer, who referred to it several times. There may be some merit in evaluating the significance of outcomes, especially at a programmatic level. But at an individual level, the apparent magnitude of impact may be less relevant than its personal significance, and the person themselves is surely best placed to make that evaluation.

This mirrors the caution expressed by a staff member about overemphasising obvious or dramatic outcomes over seemingly minor ones, and aligns with research about the power of small, daily events to influence meaning-making and growth [12, 13]; these are important well-being influences after SCI [14, 15]. In a similar vein, guests shared how seemingly small aspects of service delivery significantly impacted their experience and outcomes. Several interviewees deliberately contrasted less tangible factors, such as staff approach, with more visible or 'impressive' features like the building.

Planning, resourcing, and evaluation frameworks should not disproportionately favour large-scale changes while neglecting less obvious supports and outcomes. Caution should also be taken when choosing, reporting and interpreting outcome measures in program evaluation and research, because scores may fail to capture the personal significance of what they measure, or overlook entirely. Development of broad outcome measures that adequately capture the complexity of the construct is required. More specific outcome measures could be chosen in collaboration with service users to capture what is meaningful to them, and reporting of any outcome data should be supplemented by the qualitative insights of service users.

10.4 What is the value of well-being theory in informing the intentional and holistic design of programs that aim to impact well-being?

The background literature highlighted the potential of well-being frameworks to guide a more explicit focus, as they identify specific factors programs could target. Reflecting on the systematic and scoping review findings, I argued that because well-being is broad, most programs could influence it to some extent, and proposed that a more effective approach might be to holistically and intentionally address well-being determinants. This informed the third issue question: **What is the value of well-being theory in informing the intentional and holistic design of programs that aim to impact well-being?**

To frame this discussion, I explore the alignment between the well-being determinants addressed by the program and those identified by theory. This serves two purposes: first, to consider whether intentionally and comprehensively addressing theoretical well-being determinants underpins the program's significant impacts; and second, to explore the practical utility of these theories. I conclude this section by reflecting on the role of theory in program design, since the program intentionally and holistically targeted well-being determinants without reference to it.

There are a range of well-being theories that could have been explored here, and I did not identify them based on a comprehensive survey and critical evaluation of the options. I chose theories that could offer a breadth of insights: SCI-specific factors, general dimensions of well-being, and the characteristics of occupations most strongly linked to well-being.

10.4.1 Factors that influence the well-being of people with SCI

The systematic review examined the factors people with SCI identify as influencing their well-being, and highlighted their utility as a guiding theory. The factors addressed by the program align closely with these SCI-specific determinants of well-being.

The program specifically targets *occupations*. As well as addressing occupation-related goals identified by guests, it opened up new possibilities and encouraged people to aim even higher. Participation in valued occupations, even when highly modified, helped restore *self-continuity* as people relived familiar experiences, participated in their communities, and did

something central to their identity. These experiences and possibilities also helped reduce a *sense of loss*. Participants alluded to various negative psychological consequences of SCI, and the program offered a reprieve from these challenges or helped restore a better balance.

The program went beyond reducing losses to facilitating an improved outlook, and this key outcome reflects a broader shift in *values and perspectives*. Linked to this was an expanded sense of possibilities, fostered by enhanced confidence, awareness and inspiration. These factors are linked to the *self-worth* determinant, which goes beyond self-esteem (not a prominent theme in the findings) to include a sense of competence, satisfaction, self-awareness, dignity and value [16]. The program also recognised the crucial importance of the person's own *responsibility and control* in living and building a good life.

Relationships are another central focus of the program, which facilitates shared, positive experiences and strengthens bonds with loved ones. Our findings also highlight peers as a valued source of interaction and support for many people with SCI [17, 18], while also challenging the assumption that shared disability alone is a sufficient basis for grouping people together [19]. While hesitation around socialising with disabled peers may reflect internalised ableism or legitimate resistance to disability identification [20, 21, 22], our findings suggest these perspectives were not fixed; consistent with evidence that they can vary across the life course and in relation to social exposure and meaning-making [19, 23]. For some guests, encountering peers within the program led to a re-evaluation of earlier perspectives, which became grounded tangible, positive interactions rather than abstract ideas about disability.

The program also addresses both *body problems* and, to a limited but unusual extent, *environmental* barriers, recognising that well-being is both embodied and shaped by external conditions [24, 25].

As shown here, the program fostered all the SCI-specific determinants. The case study and systematic review also showed the factors are inter-related, and changes to one can have flow-on effects to others. The program appeared most intentional in targeting occupations, body problems, relationships, and values and perspectives; this indirectly impacted other determinants, such as sense of loss and self-continuity.

These insights underscore the value of holistically and intentionally targeting well-being determinants, which can result in ripple effects and disproportionate impacts. Programs could strategically target some determinants while impacting others indirectly. Outcome measures

and evaluation frameworks should capture this complexity and the broader impacts. Theory could support both endeavours, and the case study again supports the utility of these SCI-specific determinants, while offering insights to develop them from a list into a more actionable framework that considers how they relate and can be addressed.

10.4.2 Subjective, psychological aspects of everyone's well-being

Another framework for understanding influencing factors is the PERMA model [26] from positive psychology. This model considers what all people need to live a good life, and proposes that human flourishing is influenced by five core elements, which I now discuss in relation to the case study findings.

Positive emotions are central to the PERMA model. Their balance with negative emotions and cumulative effect can shape overall life satisfaction, and they are components of well-being in their own right [26, 27]. The model informed my use of the term to capture the range of emotions guests reported, which they also described as rare, deeply missed, and in contrast to the negative emotions in their daily lives. Positive emotions – vital for everyone and especially vulnerable post-SCI – should therefore be considered essential outcomes for well-being programs.

While happiness is well recognised in disability and rehabilitation literature, positive psychology literature and the case study point to a broader spectrum of positive emotions that merit attention [28, 29]. The case study also highlights the particular emotional impacts of holidays, recreation activities and being in nature. These experiences are known to influence positive emotions and well-being in the general population [30, 31, 32, 33, 34, 35, 36] but the reviews showed they are not often accessible to people with SCI or addressed by services.

Positive psychology literature also highlights the enduring impacts of positive emotions, explaining how they enhance well-being in the long term and not just as transitory experiences or an aggregation of these. Fredrickson's *Broaden and Build Theory of Positive Emotions* posits positive emotions broaden our "thought-action repertoires" – the range of thoughts and actions we consider in response to emotions – and build enduring personal and social resources over time [37, 38]. For example, joy encourages playful exploration and pushing boundaries, contentment fosters savouring the present moment and positively influences life evaluations, inspiration motivates growth, pride motivates sharing

achievements and envisioning future accomplishments, and love drives the pursuit of deeper, meaningful connections [37]. These ideas relate closely to the case study themes.

The *Broaden and Build* theory also links positive emotions to the improved outlook, because they widen perspectives and undo the narrowing cognitive effects of negative emotions. This expansive mindset fosters optimism, cognitive flexibility and problem-solving, ability to see the bigger picture, meaning-making, variety-seeking, and a sense of possibility – while building resilience through compounding effects [27, 37, 38, 39].

Hope theory is another contribution from positive psychology that explains the well-being outcomes, and broadens my lay understanding of hope in Chapter 6. Hope theory validates improved outlook as a contributor to well-being, and explains its origins: the motivation and ability to identify pathways towards goals, and a sense self-efficacy and capability [40, 41]. Hope is also itself a positive emotion, and it elicits other positive emotions, such as joy.

Engagement is another PERMA element that aligns closely with the findings. Engagement in "meaningful and enriching experiences" elicited positive emotions and had longer-term impacts on confidence and participation. Fredrickson posits positive emotions can motivate engagement in meaningful activities and novel experiences [27], which would add fuel to the positive cycle of challenge, achievement and confidence, and explain the program's broader, enduring outcomes. Exhilaration, pride and accomplishment were also central to the positive cycle, which often followed risk-taking and personal challenges: important aspects of engagement programs should intentionally foster. The findings also highlighted subtle improvements in engagement valued by people with high levels of disability.

These experiences also provided a sense of ***meaning*** and ***accomplishment***, which are also PERMA elements. These ideas also expand on the meaning of *occupations*, which are a SCI-specific determinant, and explored further below.

Relationships are identified by both PERMA and the SCI-specific determinants. This shared focus underscores the universal importance of relationships to well-being, and the need to consider relationships from the perspective of people with SCI's loved ones too. Mutually beneficial relationships can restore balance and promote well-being for both parties, even – or especially – for people who need a lot of assistance. This highlights the importance of *interdependence,* the understanding that we are all vulnerable and depend on one another, which has gained traction in disability studies. It offers an alternative value to 'independence', which is not always feasible for people with disability and does not reflect

the realities of most relationships anyway [42, 43]. Interdependence also recognises the value of caregiving and mutual contributions, offering an alternative to the negative perceptions critiqued by disability scholars [43, 44, 45, 46, 47].

These theoretical perspectives align closely with the findings in affirming the importance of relationships and interdependence – yet the findings also resist a romanticised view that such relationships can absorb unlimited care demands. Family carers did want a break; relational and interdependence theories help explain why this was not sought away from the person they care for, and why shared positive experiences and enhanced relationship dynamics were so valuable.

Although the theory arose from the psychology discipline, the program influenced all the elements even in the absence of psychological services. This does not imply these services wouldn't be a useful addition, but highlights the potential of this theory for other disciplines. While the PERMA elements might be difficult for other disciplines to target directly, they are influenced by other outcomes that within their purview, like engaging in meaningful activities. This indirect pathway may be particularly valuable considering psychological support is recommended post-SCI [6] yet some people are ambivalent about seeking psychological services [6] or face other barriers to accessing them [48].

Other disability scholars have begun to recognise the potential value of the PERMA model for exploring a good life after SCI [49, 50]. It warrants further exploration as a complement to disability-related well-being models: it foregrounds subjective experiences, and extends the focus beyond the impacts of disability toward what all people need to flourish – a broader orientation explored next.

10.4.3 Beyond basic functioning: the broader orientation of positive psychology

The PERMA model originated from positive psychology, and its alignment with the case study findings invites a brief step back to consider this field's broader principles. A core premise is that people aspire to flourish, not merely function, and psychology should move beyond restoring a baseline state toward promoting growth and a good life. This mirrors the calls to rehabilitation outlined in Chapter 1, and could help shift the field away from a deficit focus and toward supporting people to thrive, not just survive.

The case study illustrates how this approach could be applied in the rehabilitation sector. While not explicitly grounded in positive psychology, a similar commitment to pushing beyond a minimum, basic level was central to its design, delivery, and well-being impacts.

Like any rehabilitation service, the program solves problems and addresses identified goals – though guests noted their relative competence in these basics. But it also extends beyond this by encouraging and enabling people to push further and keep striving for an even better life. The program modelled higher expectations than guests held for themselves, offered more than anticipated, introduced new pursuits people hadn't thought of, and found or created new solutions.

The program also set a new benchmark for accessibility, quality, and experience, consciously pushing past what is typically available to people with SCI. A staff member explained they had stopped marketing the program as a luxury not only because of the impression this might give funders, but because they believe the 'premium' service should be the expectation for all disability services. They argued a high-quality service that meets people's needs and respects their dignity should be the benchmark; programs adopting a similar perspective would push beyond minimum requirements. I return to the idea of 'luxury' vs 'basics' later in the chapter.

10.4.4 Characteristics of occupations that most impact well-being

Here the discussion narrows to explore the *occupations* determinant in more depth: a worthwhile undertaking given the important contribution to well-being found by all three studies. This extends on the current exploration of well-being theories, while also addressing the fourth issue question: **What guidance can be offered for goal-setting and program design, considering the characteristics of occupations that appear to have the greatest impact on well-being?** I explore the coherence and utility of a theory of *occupational well-being.*

First, a note about terminology, since *occupations* are notoriously difficult to define. I adopt the same term as the SCI-specific determinant above, while noting it was rarely used in the case study and may be another example of jargon that does not resonate on the ground. Nevertheless, its technical definition within occupational science is useful for this discussion, as it captures dimensions of meaning and identity that extend beyond the lay term *activities* [51]. I offer again the simple definition from the systematic review – "the things people do in their daily lives" [49] – but later explore how the findings complicate the 'daily' part.

The three studies reinforced the contribution of occupations to well-being and added detail about how they shape it. Engaging in occupations enhances well-being and affects the other well-being determinants. Even small gains profoundly impact daily life, enabling choice, engagement, participation and autonomy even if people still need help from others. These changes also enhance confidence, self-worth, freedom, mood and relationships. Having a greater scope of activities available is key to a broader and more positive outlook.

These insights are probably affirming – but not especially new – to OTs. The issue question goes further to ask which occupations are likely to have the greatest impact: an important question for program design and goal setting. While occupations are known to provide a sense of meaning [12, 52] and it is widely acknowledged that programs should promote 'meaningful' occupations, there is little practical guidance about how to identify and prioritise what would be meaningful – especially in relation to well-being.

Traditional categories are too simplistic for this purpose, which would be better served by considering the characteristics and impacts of occupations [52, 53, 54]. The three studies found occupations were most meaningful when they related to the person's roles and identity, which can be disrupted by SCI but can endure even when occupations are done in a modified way. Pre-injury occupations were valued for this reason, although people with SCI appreciated the opportunity to discover alternatives and keep trying new things. Occupations that promoted community and social participation were also impactful, as were opportunities for challenge and risk. Occupations could be identified and prioritised based on the extent to which they exhibit these characteristics. It is worth noting they were most prominent in the 'leisure' category – recreation activities, holidays and travel – which was valued by people with SCI yet often neglected.

Offering language to these ideas – and linking them to well-being – is the theory of *occupational well-being* [54]. The theory explores the subjective experiences of occupations, and proposes they most enhance well-being when they meet our 'occupational well-being needs' for accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal.

Most of the above findings could align with these ideas, suggesting the theory could be useful for exploring occupation-related outcomes. Recreation activities offered a sense of *accomplishment* because of their risk and challenge, in context that is often paternalistic and risk-averse [55]. *Coherence* appears to capture the themes of identity, roles, familiar

experience and participation. *Pleasure* and *renewal* are especially pertinent to the case study outcomes – as well as describing the unique starting points that guided program design. The design also seemed to be driven by a particularly strong appreciation of *accomplishment*, *companionship* and *agency*.

A comprehensive discussion of the alignment warrants a separate publication, but this cursory exploration suggests the theory holds promise for well-being focused programs. When exploring, prioritising and evaluating occupations, the extent to which they meet these 'occupational well-being needs' could be a consideration. This theory, too, would need further development to turn it into a guiding framework for program design and evaluation.

The theory could also be the basis for tools that explore meaningful occupations with individuals. Such tools could help prioritise what would most impact well-being in constrained settings. They could also guide more appropriate conversations about goals with people with significant and life-changing injuries, for whom "what did you used to do?" and "what is meaningful to you?" may be confusing and confronting questions.

Pre-injury occupations may still be a valid starting point for these discussions, and these were important to participants even many years post-injury. While a simplistic goal to resume them in the same way may be unhelpful or unrealistic, the theory could help explore their deeper meaning. Understanding the subjective experience might help pinpoint what could be restored even when other aspects are modified, or identify alternative occupations that offer the same experience.

The findings also suggest goals should also extend beyond pre-injury occupations, since new and non-routine occupations can provide novelty and support growth. The theory could guide the exploration of new possibilities, beyond the usual "describe a typical day" or "what did you used to do" questions. It could also extend this focus to the broader pattern and balance of occupations, with the theory offering a useful subjective well-being lens for doing so. This is an overlooked but worthwhile undertaking, since the way occupations are organised across everyday life is closely associated with health and well-being [56, 57, 58].

Limitations of the theories and discussion

As I draw this section to a close, two limitations of the discussion need to be acknowledged. First, the chosen theories – and our studies more broadly – reflect a predominantly Western perspective. Future research and theory development should incorporate theories from other

cultural perspectives to enrich understanding and ensure relevance across diverse contexts. Since relationships are an important well-being contributor that vary across contexts, theories that explore less individualistic understandings of well-being, such as the *Social and Emotional Wellbeing Framework* [59] and *relational well-being theory* [60], are particularly worthy of consideration.

Second, the discussion assumes the importance of theory, but our findings highlight the need to critically examine that assumption. I now step back to reflect on the role of theory in program design, since the program comprehensively addressed well-being determinants without it.

10.4.5 Does intentional design require theory?

The program was intentionally designed to target explicit well-being aims and determinants, yet program designers did not apply a formal well-being framework or theory to guide their decisions. Given the coherence and effectiveness of the design, this raises an important question: what role should theory play in intentional program design, and what other perspectives could inform that process?

Abrahm is one of the scholars advocating for an overhaul of rehabilitation services to focus more explicitly on well-being, and he helpfully discusses the perspectives that should inform this process. Abrahm emphasises the value of theory while cautioning against its rigid application, arguing that "to require that anyone participating in a life-affirming rehabilitation practice have a firm grounding in abstract theory" would only replace traditional barriers with a new one. Abrahm acknowledges theory is only "one kind of language", which should be complemented by the language of lived experience. When (re)designing rehabilitation services that better promote well-being, Abrahm argues the critical point "is that we do it together" [5] pviii. The discussion now offers insights for how this may be achieved.

The case study findings concur with Abrahm and many others who point out the important perspective people with disability should contribute, particularly to the design of clinical, well-being and tourism services; as well as buildings [5, 12, 61, 62, 63]. Co-design was crucial to the initial crafting of the program, which was meaningfully informed by a large group of people with SCI who participated in focus groups and advisory roles. This influence diminished somewhat once the program was established, and employing people with SCI in leadership roles in day-to-day operations might enable the program to more fully experience

the ongoing benefits of co-production, or co-delivery [64, 65, 66]. People with SCI do continue to meaningfully shape the program in a range of ways though: through governance roles, a consumer advisory group, occasional employment and the internship program, and through the influence individual guests can have over the services they receive.

"Do[ing] it together" will usually involve professionals to some extent, so the value of professional perspectives also needs to be considered. The program was largely designed based on the intuition, experience, and imagination of its leadership staff, and the findings support the influence professional expertise may have for program design – with some caveats. Clinical expertise was a vital perspective offered by managers and clinicians employed partly for their experience in SCI rehabilitation. This informed their understanding of what contributes to a good life and, crucially, how programs can influence it. It also underpinned their high expectations and ability to find or create solutions.

Yet clinical expertise alone was not enough, and the case study highlights that not all professional perspectives should be treated equally. Factors such as personality, approach, and values of staff play a critical role, and should be considered when assessing the potential contribution of clinicians to program design. Diverse perspectives were also valued and influential, including those of the manager with hospitality experience. Program design should similarly draw on a range of perspectives that can supplement and challenge those of clinicians.

These perspectives effectively took the place of theory in informing the program's overall focus, identifying specific areas to target, and planning how to do so. These findings validate the importance of lived and professional expertise for program design, while also highlighting the contribution these perspectives should make to shaping theory.

The process by which program designers integrated these perspectives into a cohesive design – another potential role of theory – is also worth exploring. They appeared to use a reflective, deliberate design process, driven by a sense of purpose and mandate, and influenced by personal and organisational values [61]. Organisational theory would explain these principles, and insights from this field could further strengthen programs in the disability sector. Future work might explore the intersection of participatory methods and broader organisational processes for program design.

This does not suggest that theory had nothing to offer. Theory would likely have shaped the education and background of program designers and advisors, even if this was not

consciously applied or articulated. Intentional application of theory might still have enhanced the design process; perhaps by increasing efficiency or confidence, or by introducing divergent perspectives. Theory can also serve an important retrospective function in interpreting outcomes and articulating program design: it can provide clarity and coherence, explain the significance of outcomes, strengthen legitimacy, offer a shared language for communicating with stakeholders, and help programs respond to contextual challenges.

These may, in fact, be contributions that the case study can return to the case itself, through the program-specific theoretical framing. While the perspectives and processes above helped program designers identify 'what' to target and 'how', the theory of change could help the program articulate these components, and explain 'why' the design is successful.

10.5 What clinical support do people with SCI want and need as they build a good life, especially later in their journey?

The discussion now turns to the fifth issue question: **What clinical support did people with SCI want and need as they built a good life, especially later in their journey?** I consider the ongoing role of clinical support in facilitating well-being, and how people with SCI wanted these services delivered in the community, particularly people with established SCI.

Program designers saw a tension: rehabilitation-like aims continue to be important to a good life in the long term, but they thought people wouldn't want to return to a rehabilitation centre – even a nicer one. They created a unique service model that supported these aims "by stealth". Yet it would be an oversimplification to interpret this as 'people don't want rehab, so we're going to trick them into it.'

People with SCI did appreciate clinical services that built capacity and independence, even many years after injury, and they impacted well-being. But this wasn't usually what drew people to the program, and they wanted these services to be appropriate and useful. They had varying levels of aversion to rehab: ranging from actively seeking it, to friends of interviewees who wouldn't engage with any SCI-related service. Everyone valued the unique approach to clinical service provision. No-one called it rehabilitation. I now discuss insights arising from these findings.

10.5.1 The ongoing potential of rehabilitation services to support well-being - if clearly conceptualised

Although intensive rehabilitation (appropriately) diminished for participants over time, the case study findings mirror other studies that show people do need and want clinical input at various points in their journey of adjusting to, and recreating, a good life with SCI [67, 68].

The program was both similar to, and distinct from, conventional rehabilitation, and the case study offers new insights about how such services can be offered in the community. Capacity-building services are a key program offering, and the reported outcomes align with the traditional goals of rehabilitation: enhanced body functions, engagement in meaningful activities and participation [69], thereby improving function and reducing the impacts of disability [70, 71]. These improvements were key to the longer-term, well-being related outcomes for many participants. Yet functional gains alone were insufficient to explain the broader outcomes, which related to maintaining long-term adjustment – or improving a good life even further – rather than just ability to perform discrete tasks.

These findings support the conceptualisation of rehabilitation promoted at the start of the thesis: one that re-centres its purpose beyond the restoration of functional capacity, and towards supporting people to adjust to, reimagine, and rebuild life with disability [72, 73, 74]. Clarifying rehabilitation in this way supports a broad scope, aligns its focus with its stated overarching aims, and provides a coherent context for understanding capacity-building not as an end in itself, but as a means to these broader life-oriented purposes. The program's aims and approach align closely with this conception, and if rehabilitation were more widely understood in these terms they might have been less reluctant to position themselves as a rehabilitation service, or would no longer need to offer it "by stealth".

This conceptualisation of rehabilitation need not require a new definition. Established definitions, such as that of the World Health Organization [75], are broad enough to accommodate these purposes. However, this very breadth is partly what has left the sector vulnerable to the narrowing influences discussed in Chapter 1. The clarified definitions by Hammel [72] and others presented in that chapter could support a more life enhancing interpretation of this definition, while clarifying the role of rehabilitation for people with life-changing conditions.

These ideas resonate with the *recovery-oriented approach* from the mental health sector, which emphasises living a meaningful life rather than focusing solely on symptom or impairment reduction [76, 77] – an orientation that mirrors longstanding calls within physical rehabilitation [5, 72]. Adopting ideas and tools from recovery-oriented practice, such as collaborative goalsetting, strengths-based planning, and long-term peer support, could help rehabilitation move beyond narrow functional targets toward clearer and more appropriately defined well-being aims. This field of literature also reinforces themes discussed earlier: the importance of occupational engagement, and the need to explore the experiential aspects of engagement that matter most for wellbeing [78].

10.5.2 Enhancing capacity and providing clinical support via broad, integrated service models

The program offers capacity-building as an essential part of a broader and integrated "hub". This model is analogous to *schools as community hubs*, which provide low-threshold access to a range of supports in meaningful settings where people already gather [79, 80, 81]. In this analogy, capacity-building is viewed as an important support that requires friction-free access. The program facilitates this by gathering people in an appealing setting: a key purpose of the other two program elements. Other programs could similarly consider how to meaningfully attract service users, or reach them where they already gather.

These two elements themselves build capacity. Interestingly, while the program hesitates to describe its capacity-building services as 'rehabilitation', even its distinctly 'non-rehabilitation' elements produce rehabilitation-like outcomes. The contributions of the recreation program are perhaps unsurprising, given the known impacts of such activities on skill-building and confidence [33, 34, 82, 83].

More unexpected was the way the accommodation element functioned as a vehicle for capacity-building: not only as an attractor to these services, but also in less obvious ways. The accommodation provided a rare means for some people to access specialist clinicians in Sydney, spend extended time with peers and observe them going about daily life, and attend capacity-building courses. Staying away from home also built confidence – key to increased autonomy, which is arguably the end goal of capacity-building. It also sparked goals related to capacity to travel, which should be routinely considered by other rehabilitation services

given the low rates of travel reported in these findings and other research [84], and the known positive impact of travel on participation and well-being [85, 86].

The findings support the effectiveness of this broad, integrated model as a meaningful and appealing way of providing clinical support and building capacity, especially for people many years down the track. Yet the findings also reveal the challenges of such a model, which may not align well with rigid policies. An integrated model also creates an opportunity as well as tension when positioning itself to various stakeholders: which may involve foregrounding some elements while backgrounding others, depending on the audience [79, 80, 81]. Yet such selective framing risks obscuring the complex and integrated nature of these models, and their aims and outcomes. I explored how programs can more effectively articulate well-being aims earlier in the chapter, and consider other audiences later on.

10.5.3 Respecting and promoting the autonomy of people with SCI

Program designers sought to cater to a new stage in the journey, and study participants shed light on what this new phase looks like – characterised by people being firmly 'back in charge' as the primary agents of their own lives and well-being. If building and maintaining a good life is viewed as a project, the person becomes the project manager.

This perspective shaped both the program's approach and what people with SCI valued from it. In this analogy, the program acted as a consultant: offering suggestions and advice that people with SCI could choose to seek, evaluate, and apply according to their own needs. The emphasis shifted from intensive, service-led support, to exposing people to possibilities. Other programs should consider adopting a similar approach, which appears particularly appropriate when supporting people with established SCI.

Self-Determination Theory helps explain why such an approach is effective once people with SCI are positioned as the primary agents in their own wellbeing. Srengthening competence and connectedness alongside the self-directed orientation people with SCI already bring creates conditions that can harness or rekindle intrinsic motivation [87, 88]. Consistent with this theorya mix of peers, new ideas, and clinician partnership may also create a psychologically 'safe' setting for people with SCI to experiment and integrate new strategies, supporting more sustained engagement [89].

10.5.4 Proactively offering opportunities to continue building a good life

While people with SCI directed their own lives, they also appreciated advice and inspiration. Most participants continued striving for a good life and welcomed ideas for improvement when they were offered. But some had not been actively seeking new possibilities before the program and appeared to have reached a plateau or stasis. For these people, the proactive approach that brought new ideas and opportunities to their attention was particularly valuable.

Importantly, people valued having ideas presented to them rather than bearing sole responsibility for identifying what to pursue or ask about. Staff played a key role here by being proactive: actively scanning for opportunities and suggesting options rather than being directed by problems or assuming 'no news is good news'. Since opportunities for flourishing may be influenced by what programs think to offer their service users, who may themselves be constrained by imagination and risk-aversion [61, 90], the culture of pushing boundaries and encouraging risk-taking was crucial. Peers were also influential in this process, offering inspiration, cajoling encouragement, and advice.

This approach contrasts with deficit-focused models that concentrate on fixing problems or restoring function. Instead, it emphasises growth, possibility, and ongoing development – even after initial rehabilitation goals have been met and obvious problems addressed. It acknowledges that life after SCI is not static: people continue to evolve, and programs can support that evolution by fostering curiosity and confidence to explore new directions.

This orientation resonates with the *Capability Approach*, which emphasises expanding people's real freedoms to pursue lives they value [91, 92]. The approach recognises that well-being is not only about meeting basic needs but about sustaining growth, choice, and meaningful participation over time. Its scope is also not limited to deficits or stopped by what is getting in the way. Instead, it proactively seeks opportunities and solutions. The Capability Approach has been widely applied across human and community development, and has been called for in rehabilitation as a way of aligning the field with a more explicit focus on well-being [93].

Autonomy and choice only flourish when broader conditions support them, and the Capability Approach also draws attention to the role of environmental and systemic factors in shaping real freedoms [92]. Even when rehabilitation works to expand opportunities and

strengthen individual capacity, its influence over structural barriers is limited because it generally works at the level of the individual rather than policy or infrastructure. The case study program, unusually, did create new infrastructure, so it was able to address some barriers directly and serves as a positive example of what inclusion can look like. Beyond this bounded context, however, systemic constraints remain. The program mitigates some of these through advocacy, information, and creative workarounds, yet optimal capability ultimately depends on broader systems-level change that lies beyond the reach of most programs.

10.5.5 Describing clinical services

It is worth stepping back to consider the suitability of the term ‘rehabilitation’, which carries strong connotations of recovery and dependency [94, 95] and is often associated with the period directly after the onset of illness or injury. The term itself implies restoration or return to a former state, which makes it problematic for people with life-changing conditions [5], even early after injury. It becomes even less appropriate later in the journey, when the focus shifts from restoring what was lost to building new ways of living [72]. Terminology also becomes ambiguous outside an inpatient context, because ‘community-based rehabilitation’ also refers to a specific strategy within community development [96].

It is highly unlikely this widely used term will change, nor are we close to finding a universal definition. Wade outlines the challenges inherent in doing so, and proposes a solution that mirrors the approach I adopted for other terms: use the term but explain its meaning clearly [97]. The existing connotations of the term make it even more important for programs to clearly and unambiguously communicate this focus, and such definitions would ideally reflect the clarified purposes proposed earlier.

While the term may still be required at a system level, individual services might avoid using it altogether, as the case study program did. Other services (including recovery-oriented services discussed above) have also found ways to avoid the term, as part of a broader move away from any deficit-focused, clinical language [12, 98].

Interestingly, the program’s avoidance of jargon made it challenging for me to succinctly describe the rehabilitation-like service in the program logic. Rehabilitation-like aims were easy to find and recognisable (independence, skills, capacity, participation) but documents were vague about the service itself. They referred to clinical services and clinicians but didn’t

offer an overarching term or definition. Guest interviewees simply talked about “catching up with [CNC nickname] ”.

A staff member suggested ‘capacity-building services’ when I asked for an overarching term. This term seems to capture the approach fairly well, nested within the broader approach – which itself remains unnamed. It is worth noting the program had not felt the absence of these terms until they were sought for the case study, and this appears to be another example of where technical terms are not appropriate or necessary. It is also worth noting that ‘capacity’ in this context referred to ability to engage in meaningful activities outside the program – reflected in the program’s immediate and intermediate intended outcomes. It was not used in the legal sense of decision-making capacity.

10.5.6 Complementing or challenging traditional rehabilitation? Insights for existing services and clinicians

Since a strong theme in our findings was the distinction between the case study program and traditional rehabilitation approaches, I now consider whether the program complements or challenges existing services. In doing so, I discuss the extent to which the findings can be applied to a range of existing rehabilitation and clinical services.

First, inpatient rehabilitation services – which the program appears to complement by offering different services, and in a different phase. While negative comparisons were common, these were framed as appreciation for the alternative approach rather than a criticism of inpatient settings, which participants viewed with a sense of acceptance or inevitability.

It is worth remembering guests weren’t always in this new phase yet, and the findings suggest important benefits to people with recently acquired SCI as they encounter peers living well many years post-injury and try enjoyable and meaningful activities. Rather than challenging inpatient services to change their scope, these findings suggest a complementary approach may be an appropriate model. The benefits are only available to people in Sydney-based hospitals though, strengthening the case for scaling the program to other regions.

The program also complements what, in theory, should be offered by community-based services, which reflects its original intention. In the program context, government funded community-based follow up is limited to the first 1-2 years after discharge, or to occasional

rural clinic visits [99, 100, 101]. The case study identified funding and availability issues consistent with other studies in the same context [48] and more broadly [15, 68].

The program partly addresses this gap, and given the enduring impacts of these services, regular access to a specialised 'hub' with follow-up by generalist services may be a reasonable service delivery model. In addition, promoting the benefits of intermittent rehabilitation to funders might address some of the contextual challenges that limit the program's reach – though this is another complication posed by the integrated model.

Overall, the findings suggest that the program largely complements existing services, and participants' accounts were generally sympathetic to them. Many of the critiques outlined in the thesis introduction were directed at the field more broadly, and this chapter has focused on lessons for researchers and program designers to address system-level issues. Nevertheless, the thesis suggests there is scope for change at the level of everyday practice too.

The scoping review and case study explored valued aspects and limitations of services; the combined findings suggest programs should offer opportunities for peer interaction and support; prioritise activities that better promote well-being (especially neglected but impactful recreation activities); provide opportunities to experience positive emotions; and recognise and foster the dignity and autonomy of people with SCI. The scoping review also highlighted the negative impacts of unpleasant environments and inflexible, impersonal approaches, while the case study modelled an alternative approach.

These experiences were influential early after injury, making the insights directly relevant to inpatient services. Even within constrained settings, there may be scope to prioritise a recreation activity over something more 'basic' but less impactful, or to organise enjoyable social activities that bring together peers and loved ones. Greater flexibility was explicitly identified as a key lesson for inpatient services. It is also worth questioning the assumed inevitability of unpleasant hospital environments, given participants' strong negative memories and the positive outcomes of a contrasting atmosphere. While the negative associations probably relate to the traumatic time, a more well-being-promoting environment may be especially important at this stage. The case study suggests that even modest improvements to physical environments – making them more pleasant, dignified, and human – could be meaningful. Similarly, small opportunities to experience positive emotions may have disproportionate importance during a period when distress often predominates.

These insights are also relevant, and arguably more actionable, for community-based services, which should continue to build skills and address secondary complications while also broadening their focus. Earlier discussion highlighted approaches that service managers and practitioners could adopt, particularly fostering autonomy and proactively offering opportunities to explore new possibilities. This would require a shift in mindset, and would challenge systems that rely heavily on clear goals or problems for service planning and funding [102, 103]. Practical applications might include routinely setting goals related to discovering new activities, and supporting all clients to become aware of new solutions e.g. at assistive technology expos.

Finally, the interpersonal approaches of staff are perhaps the most important and transferable lesson for existing services. Chapter 1 identified this as a priority for recruitment and service delivery, participants described it as a key take-home message for other programs, and it was valuable across all three studies. The case study offered particularly rich insights into the staff qualities valued by people with SCI, how these were enacted in everyday practice, and their influence on both program outcomes and well-being.

These detailed, practice-level insights may both affirm and challenge existing staff approaches. Fostering well-being depends heavily on staff who build authentic, warm relationships and engage service users with dignity and respect, alongside a sound understanding of the specific challenges faced by people with SCI. This requires not only clinical expertise, but also genuine connections, empathy and a commitment to problem-solving. While not every clinician can innovate to the extent seen in the program, they could at least adopt its staff's dogged pursuit of existing solutions.

The findings also point to clear implications for service managers. Recruiting for, and actively cultivating, these interpersonal approaches shape program outcomes and workplace culture, with flow-on effects for staff satisfaction and retention.

However, many services face structural and cultural constraints that limit the extent to which these interpersonal approaches can be realised. Unlike the case study program, which had the unusual opportunity to build a team from the ground up, most services must work within entrenched staffing structures and workplace cultures. In hospital settings, staff also operate within deeply embedded professional boundaries between staff and patients, and these norms can make it challenging to enact the kind of warm, flexible, relational approach that people with SCI valued.

From actionable insights to challenges in doing so

The constraints identified above signal a shift in the discussion, as they are examples of wider constraints on the sector that may make the insights discussed in this chapter challenging to adopt. Addressing the thesis aim of providing practical guidance to support rehabilitation to move towards an explicit and intentional focus on well-being, the chapter has identified a range of insights for program design and delivery.

Yet the ability of program designers and services to adopt these insights will be influenced by their context. Just as the case study program was influenced by its context, so too are rehabilitation services. The discussion now shifts away from the case study findings, to consider the systemic challenges that frame the thesis as a whole and may limit the application of its insights.

10.6 The reality of constraints – and the need for change

Contextual challenges bookend the thesis, which opened with challenges the research sought to address and now closes with challenges that may limit the application of the thesis insights. While the first chapter focused on the rehabilitation context, the discussion here broadens to the Australian policy environment that influences community-based disability and rehabilitation services, with particular attention to the constraints it places on reform efforts. I identify challenges that may constrain change, reflect on what may underly them, and suggest that they make an explicit focus on well-being even more important – not only to guide better practice, but as a framework for advocacy and reform.

10.6.1 The contrast reveals there is a long way to go

Studying a program described as “an oasis from the barriers out there in the world” highlights an alternative way forward, but also demands attention to the surrounding landscape. The dark side of the case study findings is that while the program meets the needs of people with SCI and enhances well-being, people report face significant barriers outside of it. When describing positive outcomes participants often noted that these were rare, had not been experienced since their injury, or stood in contrast to their usual experiences.

Interviewees, most of whom had lived with SCI for many years, were not despairing, and they demonstrated the resilience and resourcefulness other studies with this population have found [12, 104, 105, 106]. Yet they still appreciated barriers being addressed rather than constantly needing to adapt to them. Stories about people with more recent injuries, drawn from documents and staff interviews, suggest the struggle and contrast were even greater for many people.

While the case study findings show a way forward, they also beg the question: *Why is there such a contrast?* Why do beach lovers go 15 years without feeling sand or water? Why are some positive emotions so rare? Why are other environments still so difficult to navigate? Why is expertise so hard to access elsewhere? What about all the people who can't access the program?

The case study findings explore significant reimagining and expansion of what is offered to people with SCI, but also highlight how far there is to go. I write this chapter somewhat soberly, conscious the insights might seem idealistic or unattainable in this context. But this does not mean the program is aiming too high; it exposes how far the context falls short. A theme throughout the findings is that what seems luxurious or ambitious is actually essential for many people with disability.

10.6.2 An expansive approach while policy tightens

The thesis also promote a more expansive approach in a context of constrained – and changing – funding. The NDIS policy and administration changes, which are still unfolding as I finalise the thesis, make for an uncertain and challenging context. Policy decisions are complex and the aim here is not to assess each one, but to highlight a tension and examine what might lie behind it.

The Productivity Commission, Australia's independent advisory body on public policy including the NDIS, provide a helpful framework for this discussion: the *Wellbeing framework for considering costs and benefits* [107]. Balancing costs and benefits is a central challenge for any policy, and the framework identifies the factors to be considered in service of an overarching aim of improving well-being.

The framework identifies cost levers – eligibility, scope, and administration efficiency – and argues they should be used in balance with the scheme's benefits: independence, social and

economic participation and family and community engagement. Seeking this balance, the *Independent Review of the NDIS* [108] recommended a holistic reform agenda that included maintaining the scheme's foundational rights-based principles [109, 110], while introducing sustainability measures. Crucially, the Review emphasised these recommendations needed to be taken together as an integrated package [108]. The Productivity Commission similarly positions sustainability not as an end in itself, but as a means of ensuring the scheme can continue to deliver on its rights-based and well-being objectives over time [107].

However, critics are concerned that reforms have prioritised cost containment in ways that risk eroding this balance [111, 112], particularly through an over-reliance on narrowing scope rather than engaging all three cost levers. As well as impacting NDIS participants, this imbalance creates the tension between the thesis's expansive well-being orientation and the policy conditions it sits within. To understand why such imbalances exist, it is useful to return to the constraining values and attitudes identified at the outset of the thesis. As well as limiting rehabilitation, neoliberal and ableist logics constrain the broader policy context, based on low expectations about the lives disabled people are expected to lead and the supports deemed appropriate to enable this. These policy dynamics, and their implications for applying the thesis findings, are examined next.

Dominant neoliberal values that constrain funding to the 'basics'

Policies tasked with balancing costs and benefits are commonly underpinned by neoliberal and rights-based values. Within the NDIS, these values formed an unusual alliance in shaping and justifying the scheme: rights were linked to economic benefits, and market mechanisms were intended to deliver choice and control [113, 114, 115, 116]. However, fundamental conflicts remain between these paradigms [117] and the balance increasingly appears to be tilting in favour of cost containment. Scholars highlight aspects of the current context that suggest the dominance of neoliberal values: an emphasis on value for money over other forms of benefit; supports that are frequently inadequate and framed as generosity [110, 111, 113, 114, 115]; and reform proposals that prioritise standardisation and efficiency in ways that risk undermining rights [118]. The dominance of these values is also evident in decisions about aged care funding, where cost pressures justified the exclusion of older people with a newly-acquired disability from the NDIS [119, 120], despite the detrimental impacts on people with significant disability [48, 121, 122, 123].

Through a neoliberal lens, well-being might be construed as an optional extra or luxury beyond what the public should fund [124], despite it ostensibly being an overarching aim of the NDIS [107, 108, 125] and grounded in rights-based frameworks [126, 127, 128]. This distinction between well-being and the 'basics' conflicts with the case study findings, which showed that many of the outcomes – identity, positive emotions, regaining losses, and family relationships – are not add-ons but fundamental human needs. The challenges of disability can turn even 'luxuries' like having a break into fundamental requirements, and make 'basic' supports essential to overcoming the related barriers.

Yet in a context of constraint, policy logic can harden into these simplistic categories. Scarcity can also force this false distinction for people with SCI, who would otherwise understand their own well-being as more complex and essential. When people need to make decisions about how to ration limited funds, well-being might understandably fall into the 'nice to have' category. And when some people lack funding for even the essentials of getting through the day, such as adequate equipment or personal care, talk of pursuing a good life might feel ludicrous.

Ableism and low expectations that resist programs that are 'too nice'

Challenges in the policy context can't be explained by neoliberalism alone: scholars have highlighted the pervasive influence of ableism [129, 130], which shapes low expectations irrespective of cost considerations. These attitudes may explain why experiences perceived as 'too nice' for people with disability may attract resistance even when they cost taxpayers or funders no more. This is a reason the program downplays its 'resort-style' features even though they were charitably-funded – an example of adapting to, rather than challenging, contextual constraints.

The influence of these attitudes is also evident in the recent changes to NDIS respite policy, which provide a useful illustration of how policy decisions can reflect and reinforce low expectations, even if some aspects may be otherwise defensible. While the continuation of respite funding importantly recognises the needs of family carers, it also reflects troubling expectations about the amount of unpaid care they are expected to provide. By limiting eligibility to participants who receive at least six hours of informal support per day [131], the policy excludes families providing substantial but lesser amounts of care, and normalises intensive informal care arrangements instead of interrogating them as a marker of unmet need. This approach echoes a crisis-based model of support – precisely the model the NDIS

was intended to move beyond through earlier, preventative investment in sustaining well-being [132]. Since a crisis-based model fulfils neither the rights-based nor economic imperatives, it appears there are other factors that tilt the scales of this policy toward constraint.

Ableism may at least partly explain the changes. It is evident in the way the policy positions people with disability as burdens [133], an ableist framing that disability activists and scholars have long worked to dismantle [130], and its explicit exclusion of skill-building as a potential benefit to the person of staying away from home [134]. In fact, the policy is notably vague about any potential benefits to people with disability, which, alongside the family benefits of a shared break, is in opposition to the case study findings.

The findings signal a clear imperative for advocacy. However, if the tension between the thesis and its context reflects a deeper clash of values, addressing it will be difficult, even in settings not directly affected by respite policy.

The influence of taxpayer sentiment

The *Wellbeing framework for considering costs and benefits* identifies taxpayer support for the NDIS as another policy driver, and The Productivity Commission report noted that what taxpayers are willing to pay ultimately determines the effective 'cap' on the scheme [107].

Public sentiment about policy both shapes, and is shaped by, media and public discourse [135, 136], in which the NDIS has featured prominently in recent years. Commentary most accessible to the public often presents the NDIS in reductive or negative terms, likely fostering negative public sentiment [124, 137, 138]. The media has increasingly framed the scheme as an unfair burden on taxpayers, with unexpected costs often attributed to participants and providers [139]. This reflects similar trends in discourse about disability support in other contexts [140, 141], especially in contexts of austerity [142]. Although Australia is not an austerity context in policy terms, the media commentary frequently invokes a sense of fiscal urgency around the NDIS.

This public sentiment is likely to reinforce the tightened policy context described above, and reflects similar values and attitudes about disability support [143]. This context may make programs reluctant to adopt more expansive or innovative approaches, instead favouring designs that minimise political risk and exposure to public criticism.

Recognising the influence of taxpayer sentiment, The Productivity Commission emphasised demonstrating the scheme's benefits to the public [107], and below I consider how this may be supported by well-being outcome data. However, this task should arguably extend beyond justification to include challenging problematic attitudes and rhetoric. The same tension between working within existing boundaries and seeking to challenge them was evident throughout the case study. The extent to which boundaries are questioned ultimately depends on the vision, priorities, and willingness of those involved – and these differ across programs and policy actors.

Conservatism that resists innovation and novelty

A deeper cultural divide may also shape the thesis context. A prevailing conservatism may be one reason unconventional models can be difficult to 'sell' or align with funding rules. When novelty and creativity are viewed as risks rather than opportunities, this constrains innovation and narrows the vision of what support can achieve [144], making progress toward more expansive, life-enhancing models difficult. Similar dynamics have been observed in the *schools as community hub* models, where relational and well-being-oriented work is often undervalued or questioned by funders accustomed to more conventional models [79, 80, 81].

The case study findings also suggest the culture of funders may have shifted over time. While the charitable model of disability has historically been critiqued for paternalism and framing support as discretionary [130], philanthropic funders were the stakeholders who adopted the most progressive, expansive approach in this case study. Their values and freedom from bureaucratic constraints were what enabled the program's innovative, life-enhancing model. The flip side of charitable funding is that it often reflects individual priorities rather than systemic needs, with less widely recognised vulnerable to being overlooked, and such funding was limited even for this program.

The importance of – and challenges to – a clear well-being focus in this context

I conclude by returning to the clear, explicit focus on well-being promoted at the start of the thesis, and consider how the policy context both reinforces and challenges this impetus. A key theme in the findings is the importance of stakeholders who "get" well-being aims, and this principle extends to those who influence policy or funding decisions. The case study findings suggest that a clear, shared vision of what that entails would create a more supportive context.

However, the constraining values explored above work against this clear, shared vision, which is further hampered by the broad, subjective nature of wellbeing. As noted earlier, scrutiny of well-being aims and outcomes is appropriate and necessary. Yet when ambiguity about the meaning of well-being intersects with a constrained policy environment, programs that explicitly seek to enhance wellbeing may encounter scepticism or hostility, and risk being dismissed outright [124] instead of carefully examined. Programs in this context, especially integrated models that are already poorly understood, may understandably respond by downplaying their well-being focus.

Yet making a well-being focus clear and open to scrutiny may in fact be the way forward in this context, especially if the thesis insights are applied. The overarching well-being aims of the NDIS give providers a mandate to target it, and programs that thoughtfully reflect on what this entails and how it can be addressed, then communicate this in language that resonates with stakeholders, are more likely to meet a sympathetic audience.

However, the context also requires these insights to be applied with nuance and discernment. The thesis argues for a well-being focus that propels programs beyond the 'basics' of traditional approaches, for which aspirational terms like 'a good life' or 'flourishing' may be helpful. However, it may be strategic in constrained contexts to return to the term 'quality of life', which is already embedded in NDIS language, and may better frame it as a fundamental need rather than a refinement. And while tangible program offerings may most resonate when communicating with service users, they may sit uneasily within funding and policy frameworks, especially if they are perceived as a luxury. For these stakeholders, the language of program outcomes – particularly when linked to 'basic' needs – may be more persuasive and defensible.

The planned introduction of *The Disability Wellbeing Index (DWI)* [145], referred to by the National Disability Insurance Agency (NDIA) as the *Measure of Wellbeing for People with Disability* [146], has the potential to support this outcomes-focused approach, and provide much-needed clarity and guidance to the sector more generally [147]. What is currently known about its development is promising: it has been supported by the NDIA, co-designed by people with disability and researchers, captures a broad range of well-being domains, has been feasibility-tested (including an Easy Read version), and is intended for broad use across the disability sector [145, 147].

The way the measure is implemented will be critical to its influence, and the NDIA are in the process of exploring how it could be applied within the scheme [146]. The intention of the measure is for any disability service providers to routinely evaluate performance and outcomes [147], yet the scheme currently lacks mechanisms that require or support providers to report outcome data. While the measure would provide important validation and guidance for well-being focused programs, they may need to develop their own reporting systems and consider their audience.

It is also unclear whether the NDIA intends to aggregate and report this outcome data at a system level, and they are still examining the measure's suitability for all participants [146]. System-wide reporting would provide a powerful means of sharpening the scheme's focus on well-being, strengthening accountability, and communicating its value to the public.

10.6.3 Conclusion

This thesis set out to identify how rehabilitation can move towards a more explicit and intentional focus on well-being by providing practical guidance for program design and delivery. The systematic and scoping reviews clarified how well-being is currently conceptualised and addressed in practice, while identifying key gaps in its definition, intentional targeting, and translation into service delivery. The case study responded to these gaps through an in-depth examination of an intentionally designed program, offering insight into how well-being can be supported in practice.

This discussion chapter drew these strands together and returned to the central aim: to identify a range of actionable insights for program design and delivery. These insights included how theory of change can support adaptation of the case study findings across contexts; how services may formulate and communicate explicit well-being aims; how well-being theory can inform intentional program design; the characteristics of occupations that appear to most strongly support well-being; and how rehabilitation services and clinicians can better support the long-term pursuit of a good life.

At the same time, the broader policy and service context places constraints on how these insights can be applied, while reinforcing the importance of maintaining a clear and explicit focus on well-being in practice and reform.

The findings of the thesis suggest that a stronger, more explicit focus on well-being is not only relevant, but demonstrably possible, and increasingly necessary in the context. While programs operating in this landscape may still question whether prioritising well-being is attainable amid constraint, this context arguably makes such a focus more vital, not less. A clear commitment to well-being offers both inspiration and conceptual clarity for working within – and, where possible, challenging – constrained systems.

It also has the potential to inform and energise program design that, like the case study, questions the status quo, reimagines what might be possible, creatively mobilises resources, and pushes boundaries. The gap between the case study and other offerings does not mean it represents a luxury, and lowering the bar even further is not the answer. The thesis findings are compelling about the life-changing impacts programs can have when they prioritise and focus on living well with disability, and are willing to ask difficult questions of existing systems.

I hope the thesis encourages others to adopt the approach to facing hurdles modelled by the case study: not to ask whether the answer must be no, but to insist that *the answer should be yes. And how are we going to make it a yes?*

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APPENDICES

Appendix A: Determinants of well-being identified by people with SCI in qualitative research

Well-being determinants described in Hammell [50]	**Key elements of each well-being determinant, as identified in Hammel [50] and later qualitative research [22, 51-59]**
Sense of loss *Negative changes and psychological consequences from SCI*	• Sadness, depression, distress, despair, devastation [22, 50, 52, 53, 55-57] • Wanting to give up [53] or die [52, 54] • Being overwhelmed [50, 53, 56], experiencing multiple challenges and problems at once [51] • Worthlessness [54] and helplessness [52] • Loss of previous life, roles, identity and occupations [22, 50, 55-58] • Dependence on others: sense of burden, impact on privacy and relationships [50, 51, 53-57] • Lost/changed/uncertain future [50, 51, 53, 57] • World became small [50] • Stagnation [55], being in limbo [57] • Challenges of transitions e.g. discharge [51, 54] • Being gradually worn down by chronic pain [52] • Inability to see the good [52] • 'Why me?' [52], 'am I being punished?' [52, 59] • Adjustment takes time and effort [51, 53] • Well-being fluctuates [22, 50, 53] and new challenges arise over time [57] • Challenges for loved ones [55, 56, 59]
Body problems *Difficulties associated with impaired body functions*	• Pain [50-52] • Fatigue [50-52] • Bladder and bowel problems [50, 51, 57] • Sexual function [51] • Spasticity [50] and spasm [57] • Pressure injury [50, 51] • Respiratory issues [51] • Secondary health conditions e.g. kidney problems [51] • Insomnia [51] • Need for, and side effects of, medication [52] • Impact on valued occupations [50] • Personal care routine: inflexible, energy- and time-consuming [50, 51, 53, 54] • Slower and limited mobility, reduced endurance [53, 57] • Lack of control, spontaneity and ability [50] • Changed/new body, body less resilient, no control over body [50] • Body problems worsening with ageing [52, 53, 57] • Any improvements are valued [57, 58]
Occupation	• Continuing/resuming pre-injury occupations [22, 57]

"The things people do in their daily lives" [50,p.131]	• Changed or new occupations [51] • Importance of work/education [22, 50, 56, 57] making contributions to others [50, 51, 56], and activities perceived as normal or valued by society [53] • Symbolic meaning of doing and achieving [22, 50] • Doing what you want do to [50] • Occupations contribute to a sense of purpose [50] roles and identity [50] and coping [51, 53] • Being busy and active, occupying time, not being bored [50, 51], being productive [50] • Creativity [50] • Health benefits [50] • Doing things differently [22, 50, 52, 57] • Focusing on abilities [50] • Danger of doing too much, ignoring vulnerabilities and limitations, or finding value solely in being productive [51, 53]
Responsibility and control *People with SCI assuming responsibility for their own lives; self-determination and decision-making*	• Responsibility for own well-being and progress [50, 52, 53] • Responsibility to take care of self and manage limitations [51, 53] • A conscious decision to take responsibility [50] • Determination, perseverance, persistence [22, 51-53, 57-59] • Struggle and determination provided meaning [58] • Making the best of it [50, 53] • Trying things, not being passive or saying no [57] • Asking for help, being able to direct others [50] • Assertiveness [50] • Freedom [51, 53] • Self-determination [50] • Power [50] • Deinstitutionalisation [50] • Finding a way [50] • Sense of control over life [50, 58], sense of ownership [52] • Taking responsibility for physical activity [53] • Making choices and decisions [50, 57] • Careful planning [50], establishing a routine [57] • Prioritising needs and activities [53, 57] • Control through driving and mobility [50, 51, 53, 57] • Own priorities and perspectives should be heard and valued [58] • Lack of control over body [50] • Accepting loss of control [50]
Values and perspectives *Values and priorities which inform the lives of people with SCI*	• Redefining disability and normality [50, 56] • Re-evaluating life generally [51, 52, 56], new outlook [50] • Changed mindset about the situation [22] and the future [52, 59] • Acceptance [22, 51, 55], letting go [51], adapting [52, 56, 57], moving forward [59] • Positive appraisal and attitude [22, 50-53, 55-57, 59] • Constructive inner dialogue [53, 57, 58] • Changed or retained self-identity [50, 55] • Continuation of pre-injury values and goals [22, 57] • Redefined/new values [50, 52, 56-58] • Making changes where possible, accepting situations that can't be changed [22] • Carefree attitude [51], being flexible [53]

	• Gratitude for life and everyday things [50-53, 55, 56, 59] • Optimism, hope [51-53, 56, 57, 59] • Realism, pragmatism [51] • Wisdom [51] • Patience [51] • Resilience [52, 55, 59] • Pursuing realistic goals [53, 56] • Challenging expectations [51] and stereotypes [50] • Comparison to worse situations [52, 53, 56, 57, 59] • Seeing injury as a random event [55] • Spirituality facilitated coping and growth. SCI may have tested and/or enhanced spirituality [52, 56, 59]. • Coping strategies [22] e.g. not dwelling on problems, keeping occupied [51], humour [53] • Seeing problems as a challenge to be overcome [22, 53, 57], and confidence in ability to cope and meet challenges [22, 57] • Importance of pre-injury resources, character and personality traits [22, 51, 53, 57], but also the need to develop these post-SCI [22, 51] • Danger of 'positivity myth' while ignoring external factors [51] • Recognition that everyone has good and bad days [22, 50, 51] • Less impact then expected [22, 50], realising potential in the future [22] • Embracing and journeying through difficulties [51, 59] • Injury was a turning point [50] • Injury facilitated personal growth and positive life changes [22, 50, 51, 55, 56] • SCI provided unique opportunities [22, 50, 56], although some needed to adjust expectations from early post-SCI [57] • Changed attitudes, values, expectations and priorities [50, 56, 57, 59] • Increased meaning [50], purpose and focus [50-52, 55] and direction [22, 56] • Overcoming challenges [22] • No regrets, not missing anything [51] • Increased maturity [22, 56] • A sense of having a 'second chance', feeling lucky to be alive [56, 59] • 'Best thing that could have happened to me' [51] • New perceptions about well-being [50] • Focusing on deeper or more important thing, less superficiality [50, 51, 56]
Self-worth *A sense of being valuable*	• Developed/restored/retained sense of self [50, 56] • Self-esteem [50, 56], confidence [50, 53] • Being competent and productive [50] • Being comfortable in own skin [22] • Understanding self, insight [56] • Achieving goals [50] • Self-satisfaction [50] • Became a better person [56] • Realising strengths [50] • Being able to contribute [50] • Pride [50] • Meaningful roles [50] • Feeling useless [50]
Self-continuity	• 'Getting back on track' [50] • Engaging in previous interests and roles [50, 52] • Less change than expected [50]

Continued or restored sense of self and biography	• 'I'm the same' [22, 50], 'core character remains' [56] • Viewed as the same by others [22] • Return to normality [22, 52], re-establishing previous life as far as possible [57], reconnecting with past life [52] • Reconstructing self [50, 56], identity integration [55] • Linking past to present [50] • Not feeling disabled, focusing on capability and competence [50] • Not being defined by SCI [22, 50, 59] • Coherence [50, 55] • Importance of relationships for self-continuity [52]
Relationships *Relationships with family members, partners, friends, carers and peers; mutual support and contribution*	• Vital importance of friendships and loving relationships to well-being [51-53, 59] • Social, emotional and practical support [22, 50-59] • Social interaction [50, 53] and shared activities [51, 53] • Empathy [50] • Fun and humour [53] • Encouragement and optimism [22, 56, 57, 59], motivation [52, 53] • Role models [53] • 'Fighting' together against problems [58] • Contribution to identity [50], being valued [50] • Stability [53] • Interdependence [51], contributing to others [50, 51, 59], encouraging others [51, 53, 56] • Peer learning, support and comparison [22, 50, 53, 56, 59] • Importance of relational virtues e.g. patience, gratitude, mutual giving [51]; these virtues developed post-SCI [51, 56] • Strengthened relationships [51, 59] • Helpful attributes of significant others including consistency, love, willingness [52]; caring had positive impacts on character of carers [51] • Challenges to relationships, relationship breakdown, impact on caregivers [51, 53, 55, 56, 59] • Negotiating relationships and need for assistance [51, 53]
Environment *Dimensions of the physical, economic, political and legal, social and cultural environment that either constrain or enable well-being*	• Physical barriers e.g. transport, accessibility [50, 53, 54] • Social supports [22, 50, 51, 53] • Social barriers e.g. stigma, discrimination [50, 51], negative attitudes and low expectations of rehabilitation staff [51, 58] • Support, motivation, encouragement and expertise of rehabilitation staff [51, 53, 54, 57] • Enabling policies e.g. income support [50, 51] • Limitations in health and support systems [51, 54, 57] • Bureaucracy [50] • Transport [50] • Housing [50] • Finances, funding, insurance, lost income and living costs [50, 52, 54] • Care assistance [50] • Cultural expectations and ideals [50] • Equipment [50] • Lack of control over environment [50]

Appendix B: Description of studies included in the systematic review

Authors and location	Aim	Methods	Sample	Intervention	Conception of well-being
Brillhart & Johnson 1997 [69] USA	Explore experiences in rehabilitation (particularly nursing interventions) which affected coping, from the perspective of people with SCI.	Individual interviews	12 adults with SCI 6 with paraplegia, 6 with tetraplegia 8 months – 21 years post-SCI 18-77 y.o.	Inpatient SCI rehabilitation	Not defined. Coping linked to QoL.
Chemtob et al. 2018 [70] Canada	Explore perceptions of mentees with SCI about peer mentoring (in reference to self-determination theory)	Semi-structured telephone interviews	13 adults with SCI 54% had paraplegia 77% with traumatic injury Mean 15.3 years post-SCI Mean age 49.3	Peer mentoring	Not defined. Peer mentoring linked to QoL.
Cotner et al. 2018 [71] USA	Examine quality of life for participants of a vocational program.	Mixed-methods: Pre-test/post-test design. Face-to-face semi-structured interviews.	151 veterans with SCI interviewed (from 213 in quantitative sample) Mean age 51	Individual Placement and Support (IPS) aiming to secure employment in the open market	Well-being linked to WHO definition of health. Employment linked to QoL.
Ekelman et al. 2017 [72] USA	Understand the experiences of participants of a fitness program for people with SCI and perceived influences on well-being, (particularly in relation to occupational science concepts).	Semi-structured individual interviews, observation	4 men with SCI C3-C5 tetraplegia 3 with traumatic injury 1-22 years post SCI 26-49 y.o.	Accessible fitness program at a community wellness center	As defined by Wilcock [102]: Physical well-being (health status and beliefs, and ability to perform valued activities); mental well-being (positive mood, self-esteem, coping, problem-solving, decision-making, meaning); and social well-being (relationships and making contributions). Well-being linked to occupations and physical activity.

Hitzig et al. 2013 [73] Canada	Compare the effects of a FES-assisted mobility intervention to a non-FES exercise program, in relation to quality of life and participation.	Mixed methods: Parallel group RCT. Individual interviews with participants from both groups	16 people with SCI interviewed (from 34 in quantitative sample) T12-C2 (incomplete) 8-10 years post-SCI Mean age approx. 55	Treatment: Functional Electrical Stimulation (FES) and mobility training with physiotherapist Control: resistance and aerobic training with kinesiologist	QoL was a key outcome of interest, but not defined. QoL, self-confidence and community participation, positive mood, self-confidence, and self-efficacy were stated as domains of well-being. QoL and well-being often used interchangeably.
Houlihan et al. 2003 [74] USA	Explore the self-reported benefits of internet use for people with SCI, resultant impacts on social participation and health-related quality of life, and perceived risks.	Mixed methods: Pilot study pre-test/ post-test design. Monthly semi-structured telephone interviews.	23 people with SCI living in the community 18-63 y.o.	Provision of internet access and hardware	Health-related QoL was primary outcome of interest, but not defined. Improved QoL was a key finding.
Lai et al. 2016 [75] USA	Explore the feasibility, potential effects (including well-being) and acceptability of a tele exercise program for people with SCI.	Mixed methods: single cohort pre-post study, Individual interviews	4 adults with SCI T1-2, T2-3, T10-11 and C4-5 Mean 25.8 years post-SCI Mean age 43.5	Tele exercise program	Subjective well-being an outcome of interest, but not defined.
Luchauer & Shurtleff 2015 [76] USA	Identify meaningful components of exercise and adaptive recreation for people with SCI, and explore relationships to performance, capacity and participation.	Focus groups and individual interviews.	17 people with SCI 7 paraplegic, 10 tetraplegic 1.5-37 years post-injury Mean 11.7 years post-SCI Aged in 20s to 50s	Existing involvement in regular physical activity (PA) through local organisations	Not defined. Improved capacity and performance linked to QoL.
Maddick 2011 [77] Australia	Evaluate a music therapy program, including participant and practitioner experiences.	Semi-structured individual Interviews face-to-face or telephone. Focus group with practitioners.	13 men with SCI 9 had tetraplegia 17-59 y.o.	Music therapy with music therapist and social worker during inpatient rehabilitation	Themes of quality of life for people with SCI described by Manns and Chad [78]: physical function and independence, physical accessibility, stigma, emotional well-being, relationships and social function,

					spontaneity, occupation, finances and physical well-being.
Mattar, Hitzig & McGillivray 2015 [79] Canada	Gain an in-depth understanding of how people with SCI use IT, and understand how IT may be used to support health and well-being.	Individual, semi-structured interviews.	10 people with SCI 6 with paraplegia, 2 complete and 2 incomplete tetraplegia 6 with traumatic injury 2.5-26 years post-SCI 20-75 y.o.	Existing use of IT and specialized access equipment/software; input from specialist AT service	Well-being (physical, mental and social) was the topic of interest; not defined. Background includes benefits of IT to well-being.
Ramakrishnan et al. 2016 [80] Australia	Explore the experiences and perceptions of people with SCI about an early intervention vocational program.	Semi-structured individual interviews – telephone or face-to-face.	13 adults with SCI L4-C3 (9 incomplete) 7-21 months post-injury 19-60 y.o	Pilot early intervention vocational rehab (VR) program	Not defined. Employment linked to QoL and subjective well-being.
Semerjian et al. 2005 [81] USA	Assess the effects of adapted exercise on quality of life and body satisfaction of people with SCI.	Mixed methods: Single cohort pre-post study, field observations, semi-structured individual interviews	12 adults with SCI T5-C5 1-30 years post-SCI Mean age 34	Adapted exercise program	QoL defined as “an individual’s assessment of their level of satisfaction in several components of their lives” [73,p96]; this subjective assessment as defined by Noreau & Shepherd as “the gap between an individual’s aspirations and current achievements” [14].
Tamplin et al. 2014 [82] Australia	Explore participant experiences of group music therapy.	Qualitative results of a mixed-methods study. Semi-structured individual interviews.	24 adults with SCI T1-C4 Mean time since injury 13 years 27-70 y.o. (mean 45 y.o.)	Treatment: Group singing and respiratory training Control: Group music appreciation and relaxation	Improved well-being was a finding, but not defined. Socialisation and physical activity linked to well-being. Discussion includes link between music and flourishing.

Taylor & McGruder 1996 [83] USA	Identify meaningful components of sea kayaking and examine processes that may underlie perceived positive changes.	Ethnographic individual interviews, observation.	3 adults with incomplete SCI around C6: non-ambulatory with some UL function. All with traumatic injury 3-10 years post-SCI 23-38 y.o.	Sea kayaking expedition led by a recreational therapist	Not defined. Engagement in activities, particularly those related to leisure and physical activity, linked to QoL and life satisfaction.
Veith et al. 2006 [84] USA	Explore peer mentoring from the perspective of mentees with SCI, including areas of adjustment and aspects of the relationship.	Individual telephone interviews	7 adults with SCI 5 paraplegic, 2 tetraplegic All with traumatic injury Mean age 40	Peer mentoring program during inpatient rehabilitation	Not defined. Social support linked to QoL and well-being.
Verdonck et al. 2014 [85] Ireland	Explore from a user perspective what it is like to use ECS, and the potential of ECS in mitigating participation restrictions and activity limitations.	In-depth, individual interviews	6 people with high-level tetraplegia (C3-C5) 5 with traumatic injury 3-35 years since discharge from inpatient rehabilitation. 22-65 y.o.	8 week loan of a customized ECS 'starter pack' enabling control of home appliances	Not defined. ECS use linked to and QoL.
Verdonck et al. 2018 [86] Ireland	As above [85]. This study reports additional findings.	As above	5 adults with high-level tetraplegia (C3-C5) At least 3 years since discharge from inpatient rehabilitation 22-55 y.o.	As above	As above.
Wangdell et al. 2013 [87] Sweden	Explore effect of reconstructive hand surgery on everyday life, particularly perceived changes.	Semi-structured individual interviews, 7-12 months post-surgery	11 adults with tetraplegia (C4-C7) Mean 3 years post-SCI 22-73 y.o.	Reconstructive hand surgery to improve grip	Improved QoL (not defined) would be an expected outcome of improved hand function. Improved self-efficacy (main finding) was linked to QoL.

Ward & Price 2007 [88] USA	Explore the social and occupational participation of people with SCI, and their perceptions about occupation-based interventions in achieving these outcomes.	Semi-structured individual interviews	3 adults with SCI 2 paraplegic, 1 tetraplegic 2-5 years post-SCI	Occupation-based occupational therapy interventions (inpatient and community settings)	Not defined. Maintenance of daily activities linked to life satisfaction.
Zinman et al. 2014 [89] Canada	Evaluate the effectiveness of a community reintegration program for promoting well-being and community participation post-SCI.	Mixed-methods study: single cohort pre-post study. Semi-structured individual interviews with 12 of the participants.	21 people with SCI 12 had tetraplegia 14 with traumatic injury Mean 3.6 years post-SCI. 12 had tetraplegia Mean age 46	Self-management program, facilitated by OTs and social workers	Hypothesis was the program would improve psychological, emotional and social WB, but these terms were not defined. Coping strategies linked to QoL.

Appendix C: Well-being determinants in which people with SCI reported positive changes in the systematic review

Study	Intervention	Well-being determinants								
		A sense of loss	Body problems	Engaging in occupation	Responsibility / control	Values / perspectives	Self-worth	Self-continuity	Relationships	Environmental context
Brillhart & Johnson [69]	Inpatient rehabilitation, nursing	x	x	x	x	x	x	x	x	x
Chemtob et al. [70]	Peer mentoring program	x	x	x	x	x	x		x	x
Cotner et al. [71]	Individual Placement and Support for employment	x	x	x	x	x	x			x
Ekelman et al. [72]	Community fitness centre	x	x	x	x	x	x		x	x
Hitzig et al. [73]	FES and treadmill walking/ exercise training	x	x	x			x		x	x
Houlihan et al. [74]	Internet access		x	x	x	x			x	x
Lai et al. [75]	Tele exercise program		x	x					x	x
Luchauer & Shurtleff [76]	Regular physical activity - adapted recreation		x	x	x	x	x	x	x	x
Maddick [77]	Music therapy program	x	x	x		x	x	x	x	x
Mattar et al. [79]	Existing use of IT and specialist access equipment		x	x	x				x	x
Ramakrishnan et al. [80]	Early intervention vocational program	x	x	x	x	x	x	x	x	x
Semerjian et al. [81]	Adapted exercise program	x	x	x		x	x	x	x	x
Tamplin et al. [82]	Group singing / music appreciation	x	x	x	x	x	x	x	x	
Taylor & McGruder [83]	Sea kayaking expedition with recreational therapist	x	x	x		x	x	x	x	x
Veith et al. [84]	Peer mentoring program	x	x	x		x	x			
Verdonck et al. [85]	Loan of environmental control system			x	x	x	x	x	x	x
Verdonck et al. [86]	Loan of environmental control system	x	x	x	x	x	x	x	x	x
Wangdell et al. [87]	Reconstructive hand surgery	x	x	x	x	x	x	x	x	x
Ward & Price [88]	Occupation-based OT interventions	x		x	x	x	x	x	x	x
Zinman et al. [89]	Self-management education program	x	x	x	x	x	x	x	x	x

Appendix D: Characteristics of studies included in the systematic review

Study	Location	Aim	Methods	Sample	Intervention	Conception of well-being
Beauchamp et al., 2016 [76]	Canada	Explore the perspectives of mentees with SCI about peer mentoring (in reference to transformational leadership concepts)	Semi-structured individual interviews	15 people with SCI Aged 25-69 14.5 (SD 16) years post-injury	Peer mentoring	Background included literature about link between peer mentoring, transformation leadership, well-being and life satisfaction. Improved 'overall well-being' was a finding but not defined.
Bernet et al. 2019 [91]	Switzerand	Evaluate patient perspectives and experiences of a nurse-guided education program	Semi-structured individual interviews- shortly before discharge and 5-6 months post-discharge	10 people with SCI Aged 19-67 L2-C3 injury	Nurse-led individualised education program in inpatient setting	Improved well-being was a finding, but not defined.
Block et al. 2010 [78]	USA	Evaluate outcomes of a capacity-building program, in terms of self-efficacy, ability to set and achieve goals, and independent living status	Mixed-methods: Non-randomised controlled trial Semi-structured individual interviews	35 people with long term neurological impairment in broader study (16 with SCI), 19 were interviewed (10 with SCI) Mean age 44	Community-based capacity-building program Control groups: wait list or no intervention	Background included literature about link between well-being, goal setting ability and self-efficacy.
Brillhart & Johnson 1997 [82]	USA	Explore experiences in rehabilitation (particularly nursing interventions) which affected coping, from the perspective of people with SCI	Individual interviews	12 people with SCI 6 with paraplegia, 6 with tetraplegia Aged 18-77 10 (2-21) years post-injury	Inpatient SCI rehabilitation	Background included literature about contribution of effective coping to QoL.

Chemtob et al. 2018 [77]	Canada	Explore perceptions of mentees with SCI about peer mentoring (in reference to self-determination theory)	Semi-structured telephone interviews	13 people with SCI Mean age 49.3 54% with paraplegia 15.3 years post-injury	Peer mentoring	Background included literature about link between peer mentoring and QoL.
Conti et al. 2020 [100]	Italy	Identify barriers and facilitators to education provided during SCI rehabilitation.	Focus group interviews	22 people with SCI Mean age 49 14 with paraplegia, 8 with tetraplegia 4.5 years post-discharge	Education provided throughout rehabilitation journey	Self-management programs aim to improve QoL. Background discussed need to identify how these programs can better increase well-being.
Cotner et al. 2018 [67]	USA	Examine quality of life for participants of a vocational program	Mixed-methods: Pre-test/post-test design. Face-to-face semi-structured interviews	151 people with SCI interviewed (from 213 in quantitative sample) Mean age 51	Individual Placement and Support (IPS) aiming to secure employment in the open market	Well-being linked to WHO definition of health [101]. Background included literature about contribution of employment to QoL.
Ekelman et al. 2017 [62]	USA	Understand the experiences of participants of a fitness program for people with SCI and perceived influences on well-being, (particularly in relation to occupational science concepts)	Semi-structured individual interviews, observation	4 men with SCI Aged 26-49 C5-C3 tetraplegia 7.4 (1-22) years post-injury	Accessible fitness program at a community wellness center	As defined by Wilcock [102]: Physical well-being (health status and beliefs, and ability to perform valued activities); mental well-being (positive mood, self-esteem, coping, problem-solving, decision-making, meaning); and social well-being (relationships and making contributions). Well-being linked to occupations and physical activity.
Folan et al. 2015 [68]	Austra-lia	Understand the experiences of clients trialling assistive technology for computer access during rehabilitation	Semi-structured individual interviews	7 men with tetraplegia (C4-5). Aged 20-60 21 (6-29) months post-injury	Inpatient trial and practice of assistive technology (AT) for computer access	Discussion included literature about contribution of computer access, and engagement in meaningful occupations to QoL. A finding was improved self-efficacy "therefore improved well-being".

Hall et al. 2021 [32]	USA	Explore the experience of people with SCI, to inform a new rehabilitation continuum of care.	Semi-structured individual interviews	10 people with SCI Aged 29-65 1-20 years post-SCI		Described various factors affecting quality of life, including determinants identified by Hammell (2007). Discussion included need for rehabilitation to focus more on wellness.
Hitzig et al. 2013 [63]	Canada	Compare the effects of a FES-assisted mobility intervention to a non-FES exercise program, in relation to QoL and participation	Mixed methods: Parallel group RCT. Individual interviews with participants from both groups	16 people with SCI interviewed (from 34 in quantitative sample). C2-T12 (incomplete) Mean age approx. 55 8.75 (8-10) years post-SCI	Treatment: Functional Electrical Stimulation (FES) and mobility training with physiotherapist Control: resistance and aerobic training with kinesiologist	QoL was a key outcome of interest, but not defined. QoL, self-confidence and community participation, positive mood, self-confidence, and self-efficacy were stated as domains of well-being. QoL and well-being often used interchangeably. Improved well-being was a finding.
Houlihan et al. 2003[74]	USA	Explore the self-reported benefits of internet use for people with SCI, impacts on social participation and health-related QoL, and perceived risks	Mixed methods: Pilot pre-test/ post-test study Monthly semi-structured telephone interviews	23 people with SCI living in the community. Aged 18-63	Provision of internet access and hardware	Health-related QoL was primary outcome of interest, but not defined. 'Improved QoL' was a key finding/theme. Discussion included contribution of leisure activities to life satisfaction.
Hutchinson, Loy & Dattilo 2003 [83]	USA	Explore how people use leisure as a coping resource after a traumatic injury or chronic illness	Semi-structured individual interviews (face-to-face or telephone)	Qualitative data from two broader studies, interviews with 16 people with disabilities (12 with SCI) Aged 24-63 7 with tetraplegia, 5 with paraplegia	Engagement in leisure activities (including involvement of therapeutic recreation services)	Main focus of this paper was coping, the description of which shared similar domains to WB. An aim of the broader study was to explore subjective WB (not defined). Discussion linked coping to positive psychology.

Labbé et al. 2018 [75]	Canada	Explore the benefits of adaptive recreational leisure activities to health and social participation, (particularly quality of participation), and barriers and facilitators to participation.	This paper reports the qualitative results of a mixed-methods study. Semi-structured individual interviews, focus groups, observation	19 people with disabilities (4 with SCI), 9 volunteers and 8 staff members of a community-based recreation program Mean age 48.5	Adapted recreational leisure activities (RLA) program	Low social participation adversely affects WB. RLA may target this issue. Quality of participation was key topic of interest (conceptualised by Ginis et al as autonomy, belonging, challenge, engagement, mastery and meaning); thought to have more impact on WB than frequency of activities. Choice and control linked to WB.
Lai et al. 2016 [103]	USA	Explore the feasibility, potential effects (including well-being) and acceptability of a tele-exercise program for people with SCI	Mixed methods: single cohort pre-post study, Individual interviews	4 people with SCI Mean age 43.5 T1-2, T2-3, T10-11 and C4-5 25.8 (20-30) years post-injury	Tele-exercise program	Subjective well-being an outcome of interest, but not defined.
Lape et al. 2018 [73]	USA	Identify factors that influence participation in community-based adaptive sport programs	Focus groups	17 people with disabilities (including 4 with SCI, 10 wheelchair users). Aged 21-63 Median 22 (5-52) years post-injury/diagnosis	Community-based adaptive sports program	Background included literature about contribution of adaptive sports to life satisfaction. Findings included benefits to physical well-being.
Luchauer & Shurtleff 2015 [69]	USA	Identify meaningful components of exercise and adaptive recreation for people with SCI, and explore relationships to performance, capacity and participation	Focus groups and individual interviews	17 people with SCI. Aged in 20s to 50s. 7 with paraplegia, 10 with tetraplegia 11.7 (1.5-37) years post-injury	Existing involvement in regular physical activity (PA) through local organisations	Background included literature about contribution of improved capacity and performance (as defined in ICF) to QoL.

Lucke 1997 [104]	USA	Describe the process, meaning and consequences of nurse caring during rehabilitation from the perspective of people with SCI	Semi-structured individual interviews throughout rehabilitation	15 people with SCI Mean age 48 8 with paraplegia, 7 with tetraplegia	Nursing care interventions at two SCI rehabilitation centres	A desired implication of the study is to design interventions to improve problem-solving, well-being and QoL. Improved well-being was a finding, but not defined.
Maddick 2011 [64]	Austra-lia	Evaluate a music therapy program, including participant and practitioner experiences	Semi-structured individual Interviews face-to-face, or telephone. Focus group with practitioners	13 men with SCI Aged 17-59 9 with tetraplegia	Music therapy with music therapist and social worker during inpatient rehabilitation	Introduction includes themes of quality of life for people with SCI described by Manns and Chad [105]: physical function and independence, physical accessibility, stigma, emotional well-being, relationships and social function, spontaneity, occupation, finances and physical well-being.
Mattar, Hitzig & McGillivray 2015 [81]	Canada	Understand how people with SCI use information technology (IT), and ways IT may be used to support health and well-being	Individual, semi-structured interviews Data also collected about quality of life (WHO-QoL BREF) and self-efficacy (Moorong Self-Efficacy Scale)	10 people with SCI Aged 20-75 6 with paraplegia, 2 complete and 2 incomplete tetraplegia. 10.5 (2.5-26) years post-injury	Existing use of IT and specialised access equipment/software	Well-being (physical, mental and social) was the topic of interest; not defined. Background includes research about benefits of IT to well-being through access to telehealth services, on-line resources, and peer support.
Nygren-Bonnier et al. 2018 [85]	Sweden	Describe and explore the experiences of people with tetraplegia learning and using glossopharyngeal breathing	Semi-structured telephone interviews. Participants of an earlier intervention study [106]	26 people with tetraplegia Mean age 47 C8-C4 21 (2-51) years post-injury	Training in glossopharyngeal breathing by a physiotherapist	Improved well-being was a finding, related to physiological improvements, positive emotions and reduced stress and anxiety. Discussion included literature about contribution of autonomy to quality of life.
O'Dell et al.	UK	Evaluate a peer support program, and its role in	On-line survey, semi-structured	100 people with SCI, their family	Peer support program for people with SCI,	Background included literature about contribution of social support to QoL.

2019 [86]		multidisciplinary support for people with SCI	telephone interviews, and focus groups	and friends, peer support officers.	family, friends and healthcare providers	
Ramakrishnan et al. 2016 [80]	Austra-lia	Explore experiences and perceptions of people with SCI of an early intervention vocational program	Semi-structured individual interviews	13 people with SCI Aged 19-60 L4-C3 14 (7-21) months post-injury	Pilot early intervention vocational rehab (VR) program	Background included literature about contribution of employment to QoL and subjective well-being.
Semerjian et al. 2005 [66]	USA	Assess the effects of adapted exercise on quality of life and body satisfaction of people with SCI	Mixed methods: Single cohort pre-post study, field observations, semi-structured interviews	12 people with SCI Mean age 34 T5-C5 6 (1-30) years post-injury	Adapted exercise program	QoL defined as "an individual's assessment of their level of satisfaction in several components of their lives" [p96]; this subjective assessment as defined by Noreau & Shepherd as "the gap between an individual's aspirations and current achievements" [107] p229.
Singh et al. 2018a [108]	Canada	Understand perceived impacts of a mobility training intervention on the lives of people with SCI, and their experiences of the intervention	Semi-structured interviews	7 people with SCI Mean age 57.3 T8-C4 incomplete injury 4 (3-6) months post-injury	Intensive outpatient locomotor training conducted by a physiotherapist	Findings were summarised as improvements to physical and psychological well-being.
Singh et al. 2018b [109]	Canada	Long-term follow-up from above study: Explore perceived long-term effects on function and community living	Semi-structured telephone interviews Follow-up interviews 1-2 years after earlier study (above)	6 people with SCI Aged 49-65 T8-C4 incomplete injury 2 (1.9-2.7) years post-injury	As above	Some findings (changes to mood and sense of self) were reported as 'changes in psychological well-being'.
Swaffield et al. 2021 [110]	Canada	Explore perceptions of people with SCI about activity based therapy (ABT)	Semi-structured interviews	Ten people with SCI Median age 28.5	Community-based ABT targeting motor and sensory function	Background included literature about contribution of ABT use to QoL. Improved well-being and QoL reported in results.

				6 with tetraplegia, 4 with paraplegia Median 7.3 (2.5-23) years post-SCI		
Tamplin et al. 2014 [88]	Austra-lia	Explore participant experiences of group music therapy	Qualitative results of a mixed-methods study. Semi-structured individual interviews	24 people with SCI Aged 27-70 (mean 45) T1-C4 Median 9 (1-26) years post-injury	Treatment: Group singing and respiratory training Control: Group music appreciation and relaxation	Improved well-being was a finding, but not defined. Linked to socialisation and physical activity. Discussion about contribution of music to flourishing.
Taylor & McGruder1996 [72]	USA	Identify meaningful components of sea kayaking and examine processes that may underlie perceived positive changes	Individual ethnographic interviews, observation	3 people with incomplete SCI around C6: non-ambulatory with some UL function. Aged 23-38 5 (3-10) years post-injury	Sea kayaking expedition led by a recreational therapist	Background included literature about link between life satisfaction/QoL and engagement in activities, particularly those related to leisure and physical activity.
Veith et al. 2006 [87]	USA	Explore peer mentoring from the perspective of mentees with SCI, including areas of adjustment and the mentoring relationship	Individual telephone interviews	7 people with SCI Mean age 40 5 paraplegic, 2 tetraplegic	Peer mentoring program during inpatient rehabilitation	Background included literature about contribution of social support to QoL / well-being.
Verdonck et al. 2011 [89]	Ireland	Explore contribution of an environmental control system (ECS) to participation in everyday life	Focus groups	15 people with high level tetraplegia (C3-C5) 20-57 years old. 10 (1-31) years since discharge from inpatient rehab	Existing or imagined use of an ECS	Background included literature about contribution of ECS use to QoL. Discussion linked the themes of this study (and earlier research) to various elements of well-being and quality of life.

Verdonck et al. 2014 [90]	Ireland	Explore user perspectives of ECS, and the potential of ECS in mitigating participation restrictions and activity limitations	In-depth, individual interviews	6 people with high level tetraplegia (C3-C5). Aged 22-65 13 (3-35) years post-discharge	8 week loan of a customised ECS 'starter pack' enabling control of home appliances	Background included literature about contribution of ECS use to QoL.
Verdonck et al. 2018 [70]	Ireland	As above [90]: This study reports additional findings	As above	5 people with high level tetraplegia (C3-C5). Aged 22-55 At least 3 years post-discharge	As above	As above. Discussion included literature about contribution of doing everyday things to quality of life.
Wangdell et al. 2013 [79]	Sweden	Explore effect of reconstructive hand surgery on everyday life	Semi-structured individual interviews, 7-12 months post-surgery	11 people with tetraplegia (C4-C7) Aged 22-73 3 (2-6) years post-injury	Reconstructive hand surgery to improve grasp	Introduction: Improved QoL would be an expected outcome of improved hand function. Discussion: Findings were summarised as improved self-efficacy, which is linked to QoL.
Ward & Price 2007[71]	USA	Explore the social and occupational participation of people with SCI, and perceptions about occupation-based interventions in achieving these outcomes	Semi-structured individual interviews	3 people with SCI 2 paraplegic, 1 tetraplegic 2-5 years post-injury	Occupation-based occupational therapy interventions (inpatient and community settings)	Introduction included literature about link between maintenance of daily activities and life satisfaction.
Wellard & Rushton 2002 [111]	Austra-lia	Explore the perceptions of people with SCI about nursing practices for pressure ulcer management, particularly in relation	In-depth, unstructured interviews	15 people with SCI Family members also involved in 8 of the interviews	Nursing care for pressure ulcer management in inpatient SCI service	A major finding was the influence of spatial practices on physical, emotional and social well-being (not defined). Mostly these had a negative impact on well-being.

		to spatial practices and environment				
Williams et al. (2014) [65]	UK	Synthesise qualitative research about leisure-time physical activity (LTPA) for people with SCI, including, and propose improvements to LTPA promotion	Systematic review of 18 qualitative studies about LTPA for people with SCI, from 2000-2012	Community-dwelling people with SCI	LTPA programs	Well-being defined as "optimal physiological function and experience" including subjective WB (SWB) (life satisfaction and happiness), psychological WB (PWB) (psychological growth and development; and social WB- flourishing and function in social life).
Zinman et al. 2014 [84]	Canada	Evaluate the effectiveness of a community reintegration program for promoting well-being and community participation post-SCI	Mixed-methods study: single cohort pre-post study. Semi-structured individual interviews with 12 of the participants	21 people with SCI. Mean age 46 3.6 years post-injury 12 tetraplegic	Self-management program, facilitated by OTs and social workers	Hypothesis was the program would improve psychological, emotional and social WB, but these terms were not defined. Discussion included literature about contribution of coping strategies to QoL.

Appendix E: CASP checklist – scoping review

First author	CASP section	1- Aims	2- Methodology	3- Design	4- Recruitment		5- Data collection						6- Relationships	7- Ethical issues			8- Data analysis				9- Findings	
	CASP hints	Clear statement of aims?	Qualitative methodology appropriate?	Research design appropriate/justified?	Explained participant selection?	Discussion of recruitment issues?	Setting/methods clear?	Methods justified?	Methods explicit e.g. interview guide?	Discussion of modification of methods?	Form of data clear?	Data saturation discussed?	Examined own influence on recruitment, design?	Adequately informed consent?	Discussion of ethical issues raised by study?	Ethical approval	In-depth description of analysis, reporting?	Clear how themes derived from data?	Sufficient data?	Critical examination of own bias/influence ?	Findings explicit, related to research questions?	Methods to enhance credibility?
Beauchamp		+	+	+	+	?	+	+	-	?	+	-	-	+	?	+	+	+	+	-	+	+
Bernet		+	+	+	+	?	+	+	-	?	+	-	-	+	?	+	+	+	+	-	+	+
Block		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	-	+	+
Brillhart		+	+	+	-	?	+	+	-	?	+	-	-	+	?	+	+	+	+	-	+	+
Chemtob		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	+	+	+
Conti		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	+	+	+
Cotner		+	+	+	+	?	+	+	-	?	+	-	-	?	?	+	+	+	+	-	+	+
Ekelman		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	+	+	+
Folan		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	+	+	+
Hall		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	-	+	+
Hitzig		+	+	+	+	?	+	+	-	?	+	-	-	+	+	+	+	+	+	-	+	+
Houlihan		+	+	+	+	+	+	+	+	?	+	-	-	+	?	?	+	+	+	-	+	-
Hutchinson		+	+	+	+	?	+	+	+	+	+	-	-	?	?	?	+	+	+	-	+	+
Labbé		+	+	+	+	?	+	+	+	+	+	-	-	+	?	+	+	+	+	+	+	+
Lai		+	+	+	+	?	+	+	+	?	+	-	-	+	+	+	+	+	+	-	+	+
Lape		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	-	+	+
Luchauer		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	-	+	+
Lucke		+	+	+	+	?	+	+	-	?	+	-	-	+	?	?	+	+	+	-	+	+
Maddick		+	+	+	+	+	+	+	+	?	+	-	-	?	?	N/A	-	+	+	+	+	+
Mattar		+	+	+	+	+	+	+	+	?	+	+	-	+	?	+	+	+	+	-	+	+
Nygren-Bonnier		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	-	+	+
O'Dell		+	+	+	+	?	+	+	-	?	+	-	-	+	?	+	+	+	+	-	+	-
Ramakrishnan		+	+	+	+	-	+	+	+	?	+	+	+	+	?	+	+	+	+	-	+	+
Semerjian		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	-	+	+	-	+	+
Singh a		+	+	+	+	?	+	+	+	?	+	-	+	+	?	+	+	+	+	+	+	+
Singh b		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	-	+	+
Swaffield		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	-	+	+
Tamplin		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	-	+	+
Taylor		+	+	+	+	?	+	+	+	?	+	-	-	+	?	?	+	+	+	-	+	+
Veith		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	-	+	+
Verdonck 2011		+	+	+	+	+	+	+	+	?	+	-	-	+	?	+	+	+	+	+	+	+
Verdonck 2014		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	+	+	+
Verdonck 2018		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	+	+	+
Wangdell		+	+	+	+	?	+	+	+	+	+	-	-	+	?	+	+	+	+	+	+	+
Ward		+	+	+	+	?	+	+	+	?	+	-	+	+	?	+	+	+	+	-	+	+
Wellard		+	+	+	+	?	+	+	+	?	+	-	-	+	?	+	+	+	+	-	+	+
Zinman		+	+	+	+	?	+	+	+	?	+	+	-	+	?	+	+	+	+	-	+	+

+ reported
- not reported
? not reported, but may have been N/A

Appendix F: Service activities of studies included in the scoping review

Delivered by	Authors	Intervention type	Intervention description
Adapted recreation/ sports service	Hutchinson et al. 2003 [83]	Adapted recreational leisure activities	• (Six participants with disabilities) therapeutic recreation program in a rehabilitation hospital, with individual and group therapy • (Ten people with SCI) leisure engagement: intervention (if any) not described
	Labbé, Miller and Ng 2018 [75]	Community-based adapted recreational leisure activities (RLA)	• Community-based RLA program for people with disabilities, run by a non-profit organisation, in community/council facilities and a rehabilitation centre • Programs include sailing, paddling, hiking, gardening, wood crafting, music, creating assistive technology, social/information gatherings
	Lape et al. 2018 [73]	Adapted sports	• Community-based adapted sports program, affiliated with a rehabilitation hospital network • Sports include cycling, sailing, rowing, golf, yoga, kayaking, dance, Nordic skiing
	Luchauer & Shurtleff 2015 [69]	Regular physical activity - adapted recreation	• Local community organisations providing accessible physical activity
	Taylor & McGruder 1996 [72]	Sea kayaking expedition with recreational therapist	• Sea kayaking through an outdoor experience organisation for people with disabilities • In-pool training, including rescue and water exit drills, • Sea kayaking expeditions with recreation therapist • Preparatory contribution of OTs in analysing problems and adapting seatings systems and paddles.
	Williams et al. 2014 [65]	Leisure time physical activity	• Physical activities engaged in during spare time, e.g. recreational sport, gym exercise
Peers with SCI	Beauchamp et al. 2016 [76]	Peer mentoring program	• Formal peer mentoring program of two NGOs • Trained peer mentors provide information and support related to living with SCI • Support ranged from 1-2 meetings, to more than a year

	Chemtob et al. 2018 [77]	Peer mentoring program	• Peer mentoring program of a provincial organisation • Mentoring provided by employees with basic training, in inpatient and/or community settings • Mentoring activities included conversations about living with SCI, family member discussions, resource provision and outings • Informal mentoring at events run by the organisation
	O'Dell et al. 2019 [86]	Peer support program	• Peer support program of a spinal injury association • Training by peer support workers for healthcare practitioners
	Veith et al. 2006 [87]	Peer mentoring program	• Peer support program of inpatient rehabilitation unit • Matching of trained peer mentors to mentees (similar injury level, gender and age) • 1-5 face-to-face meetings
Nurses	Bernet et al. 2019 [91]	Nurse-led inpatient education program	• Assessment, collaborative goal setting/review and joint development of structured program • Education program (focused on attainment and application of knowledge and skills, gradual increase in responsibility) involving written information, seminars and workshops, application of skills to practical tasks • Peer counselling
	Brillhart & Johnson 1997 [82]	Inpatient rehabilitation, particularly nursing	• Inpatient rehabilitation (not described in detail) with provision of nursing care • Education and skills training
	Lucke 1997 [104]	Nursing care during inpatient rehabilitation	• Provision of nursing care during impatient rehabilitation (not described in detail)
	Wellard & Rushton 2002 [111]	Inpatient pressure ulcer management	• Inpatient admission from the community and treatment of pressure injury • Focus was the type and use of space in which nursing care was provided, including the way staff adjusted the environment to influence an activity, as well as impacts of the existing spatial arrangements on practice

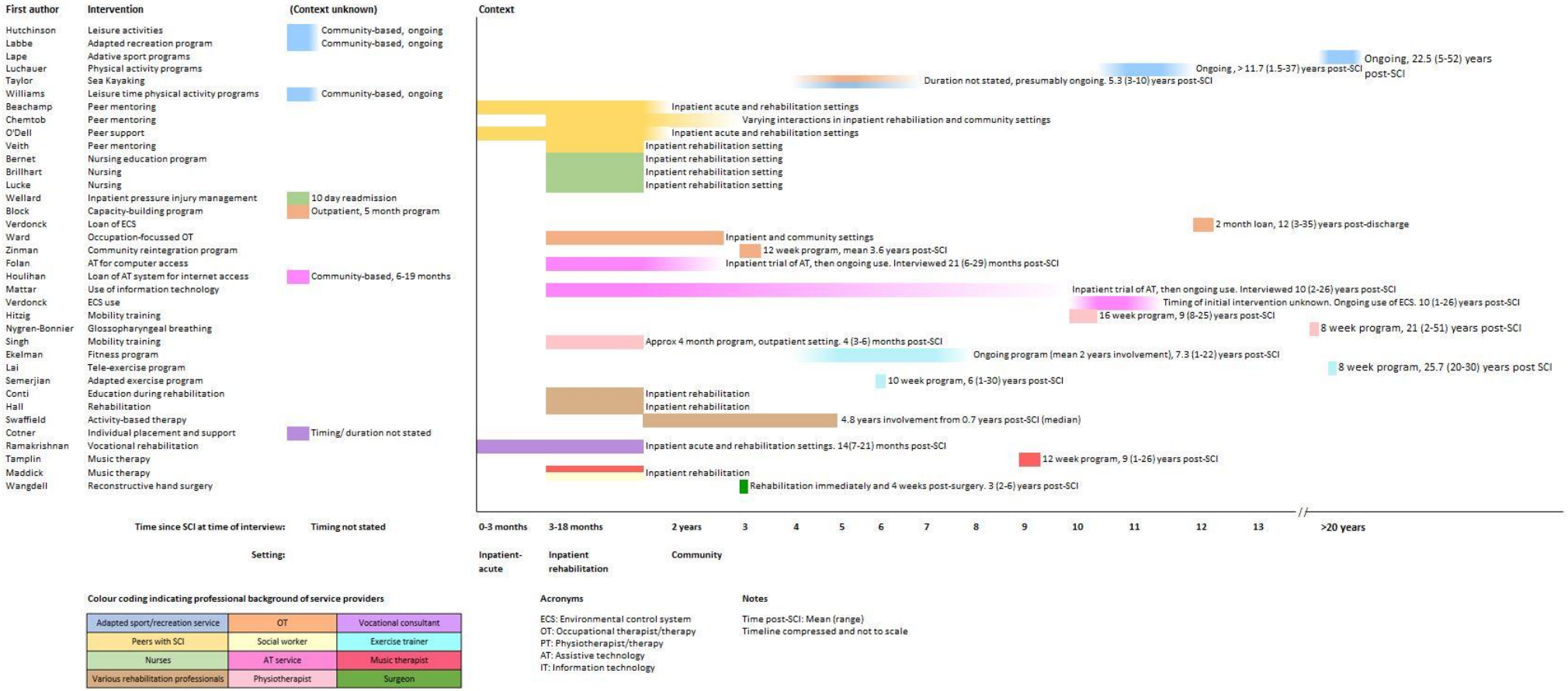
Occupational therapist	Block et al. 2010 [78]	Capacity- building program	• 10 group meetings over 5 months • Morning seminars: • Lectures, group discussion and activities, role play • Topics (tailored to participant interests) included communication, self-advocacy, adaptive equipment and health promotion • Individual goal-setting; provision of strategies (e.g. information about local resources) and peer support for attainment • Afternoon: indoor and outdoor physical or recreational group activities, in various community-based settings • Case co-ordination and peer counselling through a partner organisation • Described further in a companion study [112]
	Verdonck et al. 2014 [90] and 2018 [70]	Loan of environmental control system (ECS)	• 8 week loan of a customised ECS 'starter pack' • ECS enabled control of telephones, lamps, fans, AV equipment and a personal alarm, via a switch-operated remote control • Customisation, assembly and training provided by an OT researcher
	Ward & Price 2007 [71]	Occupation-based OT interventions	• Occupation-based OT interventions (assessment, goal-setting and intervention focused on valued occupations) • Inpatient (n=2) and community rehabilitation (n=1) settings • Intervention activities included: practising valued occupations e.g. shopping and cooking, skills training, escorted outings and facilitated family outings, environmental modifications linking with community-based organisations
Occupational therapist and social worker	Zinman et al. 2014 [84]	Self-management education program	• Weekly, 12-week education program facilitated by an OT and social worker at a SCI rehabilitation hospital. • Focus on self-efficacy, self-management, community integration and well-being • Education activities included lectures, reflection, group discussion and activities, written information, homework tasks to reflect on and apply learning • Topics included self-care, adjustment, stress management, problem-solving, emotions, self talk, communication, energy and pain management, and well-being • Individual goal-setting, and group monitoring/facilitation of goal attainment • Community outing

			• Guiding principles were cognitive behavioural therapy, adult learning, goal-setting, client-centred care, Canadian Model of Occupational Performance.
Assistive technology service (background not specified)	Folan et al. 2015 [68]	Assistive technology (AT) for computer access	• Exposure to AT for computer access as part of a SCI rehabilitation service (clinician role not described) • AT included speech recognition software, trackball and mouth joystick devices, finger splints. • Computer tasks include internet browsing, social media, letters and email, online books, banking, shopping, school work, work tasks and games.
	Houlihan et al. 2003 [74]	Internet access	• Free internet access for 6-19 months • WebTV hardware- TV monitor and wireless keyboard • Installation, basic instruction, technical assistance by researchers and product support hotline
	Mattar et al. 2015 [81]	Existing use of IT and specialist access equipment	• Some participants had input from assistive technology departments in SCI rehabilitation • Involvement of staff not otherwise described, and some of the problems identified suggest a lack of expert involvement
	Verdonck et al. 2011	Existing or imagined use of environmental control system	• Specific intervention activities not described. ECS systems included specialised environmental control units and one mainstream home control system (X-10)
Physiotherapist	Hitzig et al. 2013 [63]	Functional electrical stimulation (FES) and treadmill walking/ exercise training	• Mobilisation on a body-weight supported treadmill. Graded support of body weight using a harness. • FES stimulation to both legs, manually triggered by a physiotherapist or (rarely) the participant. Manual assistance by up to 3 assistants if needed, to facilitate walking pattern • Control group – exercise program with resistance and aerobic training supervised by kinesiologists.
	Nygren-Bonnier et al. 2018 [85]	Glosso-pharyngeal breathing training	• Training in glossopharyngeal breathing by a physiotherapist • The 8-week intervention, as described in companion paper [113], involved a training video, written information and supervised practice of the technique.

	Singh et al. 2018a [22] and 2018b [23]	Mobility training program	• Four 90-minute sessions/week, continued until progress plateaued. • Program began within 4 weeks of discharge from inpatient rehabilitation • Step training on body weight supported treadmill, overground walking
Exercise trainer	Ekelman et al. 2017 [62]	Community fitness centre	• Community fitness center designed for people with SCI • 1:1 personal training • Accessible and specialised equipment e.g. body-weight supported treadmill, FES exercise machine, standing frame
	Lai et al. 2016 [103]	Teleexercise program	• Eight-week, 3x/week exercise program using upper body ergometer • Real time coaching and monitoring by an exercise trainer via tablet computer and biometric monitors • Written instructions, visual targets for each session • Initial setup conducted in-person
	Semerjian et al. 2005 [66]	Adapted exercise program	• Ten-week individualised exercise program • Wheelchair-accessible weight machines, arm and leg ergometer (active and/or passive movement), standing frame with passive leg movement controlled by active arm movement, and body weight supported treadmill
Various rehabilit-ation profession-als	Conti et al. [100]	Education	• Skill training and education • Home visits, overnight leave, community outings
	Hall et al 2021 [32]	Rehabilitation	• This study reported mostly limitations in specific rehabilitation activities • Peer groups and support • Most positive reports related to support of significant others, and own psychological resources
	Swaffield et al,, 2021 [110]	Activity based therapy	• Functional electrical stimulation, task-specific practice, weight-bearing exercises, locomotor training. • Can be delivered by occupational therapists, physiotherapists, kinesiologists and rehabilitation assistants.

Vocational consultant	Cotner et al. 2018 [67]	Individual Placement and Support for employment	• Individualised job support e.g. workplace accommodations • Liaison with clinical team to foster integration vocational goals into general rehabilitation, ongoing support after employment
	Ramakrishnan et al. 2016 [80]	Early intervention vocational program	• Vocational rehabilitation program provided by a vocational consultant in acute and rehabilitation setting • Vocational assessment and intervention • Collaboration with clinical team, integration of vocational rehabilitation into general rehabilitation program
Music therapist and social worker	Maddick 2011 [64]	Music therapy program	• Individual sessions with a music therapist, including song writing, relaxation, singing, voice therapy, playing instruments • Weekly group sessions with social worker and music therapist: song writing, relaxation, music discussions. • Social worker facilitated group processes and peer support. • Can be delivered in various settings. This study focused on community-based delivery.
Music therapist	Tamplin et al. 2014 [88]	Group singing / music appreciation	• Treatment: 12 weeks of active music therapy, involving group singing using Neurologic Music Therapy Techniques, respiratory and vocal exercises. • Control: group receptive music therapy involving music appreciation and discussion, musical games and relaxation • Both interventions conducted in an outpatient setting, and facilitated by a music therapist
Surgeon	Wangdell et al. 2013 [79]	Reconstructive hand surgery	• Reconstructive surgery to restore grasp • 5 days of rehabilitation immediately and 4 weeks after surgery

Appendix G: Service timing and context of studies included in the scoping review



Appendix H: Valued aspects, limitations and perceived outcomes of studies included in the scoping review

Authors, service type	Valued aspects	Limitations	Perceived outcomes
Beauchamp et al. 2016 [76] Peer mentoring program	• Motivation: encouragement, realistic optimism, high expectations • Role modelling:- trust, setting an example, setting expectations • Caring behaviours: empathy, understanding, individualised support • Empowering: advice, problem-solving strategies, reframing problems	Not reported	• Increased motivation, hope, self-confidence, acceptance, "overall well-being" • Increased social participation
Bernet et al. 2019 [91] Nurse-led inpatient education program	• Information about relevant and real-life situations, written information for later use • Practical application of knowledge/practice of skills (including opportunity to experiment and practice alone) • Goal-setting and collaboration • Opportunities for discussions with peers • Flexibility in provision e.g. around rest periods • Interpersonal skills of staff: understanding, individualised care, motivation	• Need more 'mental preparation' for challenges when returning home: new realisation of limitations, more time and space to think, and environmental barriers outside of 'ideal' ward environment	• Self-confidence • Improved skills and capability
Block et al 2010. [78] Capacity-building program	• Support for goal attainment • Information about rights, and increased recognition of the need for self-advocacy • Role playing provided opportunities to practice skills e.g. self-advocacy • Peer support – advice, sharing concerns, positive examples/success stories • Changed perceptions about their potential • Increased awareness of accessible activities and community resources	• Social, financial and access barriers still limited participation/goal attainment for some participants • Barriers to self-advocacy still existed e.g. perspective not being listened to by health professionals, discomfort in doing so	• Improved community access and participation • Attainment of independent living goals • Engagement in, or working towards, new occupations e.g. paid and voluntary work, education, recreation activities

	• Increased awareness of importance of environment (vs impairments) to participation • Learning a new mindset towards problems, problem-solving strategies • Program attendance provided opportunities for socialisation and new friendships		• Improved physical activity, weight loss, decreased medication • Decreased isolation
Brillhart & Johnson 1997 [82] Inpatient rehabilitat-ion – particularly nursing	• Nurses taking every opportunity to teach skills • Influence of peers: role models, positive examples, problem-solving, resources. Having the opportunity to contribute to others in the same way • Being treated as an individual and with dignity: being listened to, warm interactions, 'homey' environment and casual dress of staff, being treated as a 'regular average person', staff spending time with them, having their personal appearance attended to, matter-of-fact attitudes of nurses during personal care procedures. • Having their own expertise respected and encouraged: assessing and solving own problems • Continuity/consistency of staffing • Pursuing long term goals and resuming previous activities • Positive expectations of others about potential (including family members) • Elimination of environmental barriers, access to resources to promote independence • Other facilitators included own problem-solving, support of significant others, having important roles.	• Feeling reluctant to leave perceived safety of the rehabilitation setting • Platitudes • Questions being discouraged • Being provided with unnecessary assistance • Fear of risks (e.g. falling) and use of analgesic medication limited independence	• Self-esteem, confidence, continued/resumed sense of self • Accomplishment of important tasks and participating in valued roles • Realisation life isn't over, "*I still had all these opportunities to live yet*". (p.253) • Perspective about, and adjustment to, situation (often took 1-3 years) • Positive attitude about self, which influences attitudes of others
Chemtob et al. 2018 [77] Peer mentoring program	• Being involved in the decision-making process, feeling in control of the mentoring sessions • Content and style of sessions tailored to individual needs and personality • Being able to ask questions and be listened to • Flexibility in session timing, mentors approachable and available • Care, empathy, comfort, reassurance, friendship	• Goals not being supported, or actively discouraged • Not feeling understood • Events and activities too far away or too late at night	• Autonomy, competence • Positive expectations • Emotional benefits • Expanded networks

	• Sensitivity and understanding from shared experience • Role modelling, an example of what is possible and methods for achievement • Realism about situation, problems and prognosis • Advice and reassurance provided to family members		
Conti et al. 2020 [100] Education provided during rehabilita-tion	• Self-management strategies helped with motivation and applying education • Able to engage in education programs once they accepted a long term change in their life • Goal setting and planning to pace and prioritise education • Own psychological strengths, especially motivation and determination • Support of family in overcoming barriers • Peer support and interaction • Home visits and overnight leave in preparation for discharge • Opportunities to engage in community and leisure activities while in hospital (rare)	• Not ready to receive, value or understand information in early stages • Lack of energy to learn and apply information • Need more time to learn skills and information, including beyond inpatient admission. Timing perceived to be based on service needs. • Lack of continuity between inpatient and community services • Lack of specialist knowledge in community-based services	• Outcomes not discussed
Cotner et al. 2018 [67] Individual Placement and Support for employment	• Many participants reported that the job seeking activities yielded positive outcomes (e.g. increased confidence, purpose) even if employment not yet obtained. • Authors hypothesised positive outcomes may have related to intervention activities such as goal setting, community access, increased social networks, individual support and encouragement	Not reported	• Contributing to society – giving back, sense of pride • Financial independence • Improved mood, confidence, self-esteem, purpose, hope • New goals set once employment obtained e.g. promotion, increased hours.

Ekelman et al. 2017 [62] Community fitness centre	• Supportive community of peers – socialisation, support, acceptance, empathy, understanding, encouragement, motivation, positive examples • Comfortable and non-judgemental environment for sharing personal and sensitive information, asking questions, advice • Trainers: close relationship, positive attitude, provision of resources and advice, feeling like 'more than just a client'. Compared this relationship favourably to rehabilitation experience. • Opportunity for (even small) ongoing improvement	• Limited opportunities for interventions and improvement after inpatient rehabilitation: the fitness center was a rare opportunity, and the only one of its kind in the state	• Managing, reducing and preventing body and health problems • Improved mood, hope • Sense of control, moving forward, routine, accomplishment • Social well-being, sense of belonging and acceptance
Folan et al. 2015 [68] Assistive technology (AT) for computer access	• Exposure to technology they would not have otherwise encountered • Recommend early introduction to AT, to show its potential and integrate into rehabilitation • Opportunities to practice skills and gain familiarity	• Previous inexperience and negative attitudes towards technology- these perceptions gradually changed. • Initially slow and frustrating learning process	• Independence in valued tasks and roles, leading to a sense of control, meaning • Coping with injury, adjustment • Sense of 'normality' and self-worth • Social interactions • Enjoyment and fulfilment from learning something new
Hall et al. 2021 [32] Rehabilitat-ion	• Support of family/friends to navigate and access the rehabilitation system, as supports during rehabilitation, and for community participation and reintegration • Own positive mindset, hope, self-advocacy, perspective • Encouragement and support of rehabilitation providers	• Inadequate preparation for discharge • Inadequate skills training for community participation, no practical training • Lack of indvidualisation • Low expectations of health professionals, lack of understanding • Too short, lack of follow up, difficulty accessing programs or funding, lack of	• This study mostly reported experiences (mostly negative) of rehabilitation: specific outcomes not reported, but some participants described living a good life.

		specialist services in the community • Ongoing environmental barriers limiting community access and participation	
Hitzig et al. 2013 [63] FES and treadmill walking/ exercise training	• Valued aspects listed without detail: staff, socialising, program helps the SCI community, organisation of the program. • Peer support, for education and motivation	• Program interfered with other activities e.g. work • Travel time inconvenient • Program too short	• "Gave me back my life" (p.251) • Improved community mobility, social participation • Greater independence in daily activities • Confidence • Improved mood, less fear e.g. of falling
Houlihan et al. 2003 [74] Internet access	• Using the internet was an entertaining and interesting pastime, especially compared to previous passive activities e.g. watching TV • Able to research information, e.g. about condition, job seeking, transport • Internet enabled connections with others, opportunities for meeting new people, staying in touch with existing networks, sharing with others, learning	• 'Addictive' nature of internet	• Improved mood • Increased meaningful activity options, learning new skills • Social connection, support, sharing
Hutchinson et al. 2003 [83] Adapted recreational leisure activities	• Enjoyable activities were valued in a hospital setting: diversion, sense of continuity early after injury, sense of personhood (vs being a 'patient'), increased motivation for rehabilitation program • Opportunities to leave the hospital/room e.g. attending a music event, going to a different area to smoke and socialise • Meaningful, enjoyable and expressive activities valued, particularly when they restored a sense of self, connection to past identity/values, and connection to others • Both passive and active leisure activities important	• Not feeling competent was a barrier to leisure participation: effort and embarrassment • Social encounters were a negative experience for some	Data analysis focused on coping efforts: • Buffer from stressors: escape, relaxation, distraction/ diversion, sense of connection to the past (identity and activities), escape (physical and symbolic), adjustment • Motivation to sustain ongoing coping through leisure activities:

	• Activities based on a common interest were valued, and took focus away from disability. Shared activities with disabled peers also fostered a sense of belonging for some • Importance of engaging in activities that foster a sense of competence, particularly in the absence of roles/identity usually valued by society (e.g. employment)		hope and optimism, structure, purpose, belonging, connection, acceptance, sense of competence and independence, positive identity self-continuity, maintenance of health. • Greater community and social participation
Labbé, Miller and Ng [75] Community-based adapted recreational leisure activities (RLA)	• Feeling adequately challenged was important: a secure environment to push limits and develop new skills • Activities that were enjoyable, challenging, meaningful and creative were particularly valued • Opportunities to socialise with peers, staff/volunteers, and family/friends during the activities • Information provision from program and peers • Contact with nature during outdoor activities • Importance of planning and customisation of activities for accessibility and safety • Low cost, variety of programs, links between the program and other community organisations, availability of specialised equipment • Expertise and personality of staff members and volunteers	• Logistical issues e.g. booking process • Transport challenges • Limited programs in local area • Worried/closed minded family and friends	• Recovery, adjustment • Sense of continuity • Freedom and escape • Autonomy: control, independence, making choices • Improved mood, relaxation and flow, physical health benefits • Belonging and acceptance, reduced social isolation • Reduced stereotypes, positive image • Further engagement in other leisure activities and volunteering/employment
Lai et al. 2016 [103] Teleexercise program	• Overcoming barriers to exercising at local fitness centres (inaccessible facility or equipment, lack of staff expertise, high costs, limited transport) • Convenience, less time taken, flexibility in timing • Coaches provided motivation, expertise, monitoring, feedback, and accountability. • Technology mostly simple and intuitive	• Few opportunities for exercise outside of program • Tablet screen used for too small, internet instability (in rural areas)	• Increased strength and endurance, less fatigue • Increased ability to perform meaningful activities, particularly physical activities
Lape et al. 2018 [73]	• More engaging than exercising at a gym • Staff expertise, planning/problem-solving and equipment facilitated safe participation and manage risks	• Risks of injury, overexertion and exposure (winter sports)	• Benefits to physical function, including strength, balance, weight maintenance

Adapted sports	• Taking risks and facing challenges was a source of enjoyment and pride • Social relationships with peers and staff: motivation, role models, inspiration, information sharing, opportunity to contribute to others • Contact with nature, being outdoors • Raised awareness of possibilities by exposure to peers • Planning ahead to manage finances, time and energy for participation	• Transport consumed energy, time and financial resources • Preconceived ideas and low expectations initially limited participation • Lack of general awareness of possibilities • Lack of awareness about program amongst health professionals • Limited program resources • Participation limited by personal finances and time	• Improved mood • Improved function for daily activities • Positive identity, transcending disability, self-continuity • Confidence, self-efficacy • Further engagement in other sports • Expanded world, getting out, making the most of every day
Luchauer & Shurtleff 2015 [69] Regular physical activity - adapted recreation	• Improvements in body functions were a motivator to continue participating • Interactions with peers: learning, skill sharing, connection, understanding, socialising • Services provide a rare opportunity to engage in accessible physical activity (particularly with access to specialised equipment) • The opportunity to work towards something and set goals	• Need some level of acceptance of injury in order to participate in adapted sports • Support from family/friends required to participate (motivation, transport, logistics) • Funding required for participation • Active recreation perceived to be inadequately addressed in rehabilitation: lack of priority, low expectations	• Improved strength, fitness and energy • Increased ability to participate in daily activities, do enjoyable tasks, decreased burden on families • Activities less straining, less risk of injury • Improved sense of self, acceptance • Social connection
Lucke 1997 [104]	• Individualised • Caring relationship: listening, encouragement, reassurance, humour, mutual respect, interaction/interest on a personal level	• Inexperienced or casual staff less willing to be flexible, take risks	• Reintegration of self • Improved mood, hope

Nursing care during inpatient rehabilitation	• Risk-taking and 'breaking the rules' to meet individual needs (this required knowledge and experience) • Being respected as a partner in rehabilitation process, trusted to make decisions and take risks • Training and opportunities to practise skills, graded independence • Thoughtful decisions about when to try a new task, reduce assistance, try a difficult task again, cease an activity, and provide rest breaks • Acting as a consultant as the person gained autonomy, e.g. freedom to experiment with new techniques, advising about risks, creative problem-solving	• Providing individualised care sometimes required 'breaking rules' or going against procedures • Defensiveness from some staff about people with SCI trying their own methods/solutions • Existing caring relationship was not always considered when staff were assigned to patients • Developing a caring relationship takes time, which is usually limited	• Greater independence in activities
Maddick 2011 [64] Music therapy program	• Music was an accessible, enjoyable, relaxing activity, and a welcome distraction. Participants looked forward to sessions. • Music facilitated expression of feelings, an emotional outlet for negative thoughts/ feelings; this was particularly beneficial for adjustment and relationships • Safe, non-threatening environment • Group setting with people they could relate to, shared experience and support, expanded musical experiences. • Privacy in individual sessions also valued • Opportunity for creative expression, realisation of talents	• Opportunities for group support were not otherwise provided in rehabilitation • Limitations of program not reported	• Confidence, self-esteem • Greater ability to perform activities, new accessible activities related to music, sense of pride and achievement • Improved mood • Adjustment, hope • Improved relationships, benefits to families • Pain management • Physical gains e.g. finger function, voice/breathing • Greater participation in other rehabilitation therapies

Mattar et al. 2015 [81] Existing use of IT and specialist access equipment	• Equipment and modifications enabled access to IT e.g. mounts, adapted mouse devices, voice recognition software. • IT became invaluable, kept close at hand • Used for managing schedules, researching information, work tasks, planning events and activities, researching and managing health and physical activity. • Facilitated connection with existing and new networks, providing socialisation, information, support, motivation • AT departments in rehabilitation exposed people to devices and access options	• Not all IT devices were accessible, use sometimes caused pain / fatigue • Previous negative experiences with old technology, frustrations e.g. voice recognition • Concerns about future technology: design 'enhancements' can decrease accessibility • Lack of IT experience, training/learning process frustrating • Cost of IT a barrier • Information found on-line not always reliable, sometimes research caused anxiety • Concerns about on-line security • Social media exposure can lead to feelings of exclusion • Concerns about spending too much time using IT, 'dependence'	• Control and independence in activities and routines, community access • Ability to perform tasks from home and more flexibly (e.g. work) • Social connection
Nygren-Bonnier et al. 2018 [85]	•Participants valued learning a new technique, and having increased awareness of, and control over, their breathing •Access to ongoing training and expertise helped with the learning process	• Negative reactions of others when using a non-conventional breathing technique	• Improved lung function (easier, deeper ventilation, more efficient expiration), cough efficiency, voice and sleep

Glosso-pharyngeal breathing training		• Learning the technique was challenging and stressful, with benefits not immediately obvious: cost vs benefit was questioned (at least initially) • Side effects included dizziness, fainting, sense of bloating, tingling	• Benefits to balance, fitness, endurance • Physical benefits resulted in improvements to mood, sense of agency, hope, greater endurance for activities
O'Dell et al. [86] Peer support program	• Shared experience: role model, inspiration, demonstrating possibility of a good life post-SCI • Legitimacy for challenging conversations • Information provided in a way they could identify with • Health professionals felt peer support supplemented their own interventions, and also valued training they received from the peer support workers • Family members valued advice too, and were sometimes willing/ready to talk before the person with SCI	• Occasional personality clashes • Some uncomfortable asking intimate questions of a peer of opposite gender • Not always ready to talk or knowing what to ask early on • Post-discharge support valued but lacking	• Reduced isolation of the person with SCI and their family/friends • Greater awareness of the situation and possibilities • Increased knowledge
Ramakrishnan et al. 2016 [80] Early intervention vocational program	• Most valued early timing of intervention: awareness of options, direction, more likely to be interested • Advocacy to employers • Integration of employment goals into general rehabilitation • Care, compassion, innovation and efficiency of vocational consultants • Provision of information and resources	• Some felt ICU/acute setting was too early: not a priority, 'invasive', dealing with health and lots of other information, too much uncertainty • Wanted better communication about the role of vocational consultants • Need for services later on if not ready to pursue work early after injury	• Hope early after injury, adjustment • Early positive expectations, confidence and motivation • Improved mood, distraction from problems • Feeling empowered • Inspiration and direction to work on other goals e.g. driving • Self-esteem, continuation of a vocational identity

Semerjian et al. 2005 [66] Adapted exercise program	• Particularly valued the body-weight support system which facilitated standing and walking • Some found the aerobic exercise trainer (active passive trainer) enjoyable "I get in the flow, you know, the zone… seems like you can go on forever" p102.	• Inability to get set up on/ use some equipment independently due to impaired grasp • Self-consciousness in harness, especially as it emphasised 'gut' (lack of abdominal tone) • Wanted opportunity to continue after sessions/program	• Increased strength, endurance, energy, better gait and trunk control, increased/less spasticity • Increased satisfaction with appearance • Increased capacity to perform activities, maintain activities with less fatigue, go out more • Improved mood • Emotional benefits of (supported) standing and walking: fun, sense of self and normality, sense of perspective and height when standing near others, dignity • Sense of hope from warding off problems, being in a position to take advantage of future treatment advancements
Singh et al. 2018a [108] Mobility training program	• Valued opportunity for higher intensity training, compared to existing outpatient rehabilitation: desire to maximise potential/gains early on. • Program customised to individual needs • Educational component – increased knowledge • Valued having a structured program/routine soon after discharge • Rapport and collaborative relationship with the clinicians: looked forward to attending, sense of friendship and belonging • Development of measurable goals to monitor progress • Supportive equipment setup e.g. treadmill harness enabled a safe environment to learn skills and take risks • Transfer of skills from treadmill to real outdoor environments	• Limited opportunities for ongoing intervention outside of the research • Balancing time of program with other valued/ important tasks • Long travel distances to program, reliance on carers for transport • Extra support needed for participants with incontinence • Wanted greater transfer of skills to real world environments	• Hope • Increased strength and endurance, resulting in improved mobility and independence in activities • Sense of empowerment and control from increased knowledge • Improved mood • Greater confidence, self-efficacy

		• Wanted more flexibility and challenge once skills were mastered • Need for falls education • Some felt the intense program was exhausting	
Singh et al. 2018b [109] Mobility training program – long term follow up from above study	• Structure and routine eased transition home • Emotional support from clinicians • Resources provided about longer term opportunities and home exercise programs	• Sense of disappointment when program ended, desire to engage in ongoing opportunities (limited) and develop new routines • Long term desire to continue making gains and preventing decline – mostly this was through community gym or home-based exercises	• Increased strength, resulting in greater independence • Able to engage in activities without overexertion • Confidence • Better sleep • Worsened mood and hope when program ended, but this eventually improved for most participants
Swaffield et al [110] Activity based therapy	• Sense of normalcy: setting was 'like a gym' • Sense of community and acceptance, opportunity to interact with others with SCI • Clinicians focused on possibilities rather than limitations; were open to experimenting and new ideas, but were also realistic about potential • Appreciated the high intensity, individualised programs • Some participants found ways to engage in similar activities outside of the clinic e.g. at local gym, although ability to progress and social interaction were lacking	• Participants reported a lack of priority for this type of therapy in rehabilitation, which focused on compensatory interventions and exercises above the level of injury • Mental effort required was tiring and frustrating (although seen as necessary) • Time commitment was challenging, but seen as a priority. • Few services available.	• Improved independence in activities, ability to live alone, community and social participation • Improved neurological function e.g. strength, sensation • Improved health e.g. cardiovascular fitness, and decreased secondary health conditions • Active lifestyle • Improved mood, reduced stress and depression • Confidence, positive outlook • Hope

		• Cost of therapy, insurance funding not always available • Varying levels of skill amongst the clinicians • Some injuries reported • Lack of awareness/referral from rehabilitation professionals; negative outlook/low expectations	• Improvements a part of a gradual and long term process; rehabilitation seen as lifelong
Tamplin et al. 2014 [88] Group singing / music appreciation	• An enjoyable, accessible and meaningful activity • Socialisation, sharing and peer support in groups; sense of safety, support, belonging and inclusiveness • Sessions provided a reason to access community, and get out of bed earlier.	• Greater insight into voice issues were initially challenging • Nervous singing in front of others • Meeting in a group with others with a disability was a confronting reminder of disability for some	• Improved mood • Confidence, hope • Greater appreciation of music and its effect on mood, reconnection to past interests • Improved energy, relaxation, sleep, pain • Experience of flow • Improved vocal quality and breathing
Taylor & McGruder 1996 [72] Sea kayaking expedition with recreational therapist	• The experience of being in nature • A fun, relaxing, enjoyable activity • Social interaction with peers with SCI, with a focus on a shared activity rather than disability. Support and encouragement, new friendships • Novelty of the activity was positive and helped with ‘moving on’ • Overcoming initial low expectations, meeting challenges, redefining limits and self-perceptions • An opportunity to apply skills learnt in rehabilitation setting	• Rehabilitation focused on regaining old activities not on engaging in new ones, which could be confronting/frustrating • Lack of awareness amongst rehabilitation staff about non-traditional activities • Desire for more opportunities to engage in similar activities	• Increased social interaction and new friendships • Coping, adjustment, stress management • Meaning and routine • Self-esteem, confidence • Improved strength and endurance • Improved mood

Veith et al. 2006 [87] Peer mentoring program	• Information, role modelling and inspiration to counter initial fears, uncertainty and low expectations • Detailed practical information that was not provided by professionals • Downward comparisons helped foster a sense of appreciation • Most appreciated having a mentor who was slightly older, of the same gender and with an equivalent injury level • Aspects of the relationship: informal, casual relationship with a social and friendly mentor, humour and positive outlook • Shared experience meant the mentor was a trusted and credible source of information. Sense of understanding, equality, acceptance; normalising their experience and reactions	• Mentoring appeared less important for people with an internal locus of control, and/or strong family support • Logistical issues meant people had less meetings than desired • Significant age differences affected mentoring relationship for some	• Hope, positive expectations • Reduced distress and fear
Verdonck et al. 2011 [89]	• Percieved outcomes were discussed, not experiences of the intervention itself	• Not reported in this study. Half the participants did not yet have access to an ECS "as a result of circumstance (not choice)" p272.	• Time alone: privacy, space • Changed relationship dynamics: less dependence, able to contribute, less perceived annoyance • Reduced care hours for some participants • Less worry for carer and people with SCI • Feeling more confident to be at home/go out alone
Verdonck et al. 2014 [90] Loan of environmental control system (ECS)	• The intervention provided new opportunities to participants with long-term SCI, who had accepted their need for assistance and had not initiated seeking alternatives • With practice, effort and experimentation, participants learnt to use the system • Using ECS enjoyable and addictive • Surprise about their ability to use the system, its potential, and the enjoyment of engaging in new tasks	• Adjusting to the new system required effort, required new routines and habits • Frustrations with the system included complexity/inefficiency of switch scanning (vs asking a carer for help) and technical issues	• Positive emotions • Engagement in new roles • Ability to engage with others in a fun and spontaneous way • Increased control and choice • Independence and privacy

		• ECS not routinely considered in rehabilitation, funding limitations	
Verdonck et al. 2018 [70] Loan of ECS	• Even small gains in independence had a big impact on life and emotions, in the context of being able to do very little otherwise • Simple everyday tasks were valued e.g. changing TV channel, turning on a light, answering phone calls • Independence in these tasks was pleasurable and had symbolic meaning • Increased independence in some tasks, and ability to call for assistance, meant that carers could be more distant • Able to accomplish tasks which would have otherwise been neglected in an attempt to reduce perceived carer burden	• Carers still needed to be readily available • Participants accustomed to assistance of other people, and did not feel confident or safe to reduce hours of care	• Reclaiming previous abilities • Improved ability to make spontaneous choices, sense of freedom • Reduced reliance on assistance resulting in improved relationship dynamics: reduced frustration (and perceived reduction in frustration for carers), reduced sense of burden and obligation • Increased privacy, able to be alone, enjoy own company and 'peace and quiet' • Increased sense of safety and security • Improved mood, positive emotions • Enhanced sense of self
Wangdell et al. 2013 [79] Reconstruct-ive hand surgery	• Positive outcomes were discussed, not experiences of the intervention itself	• Researchers asked about negative experiences but few were reported • Some reported thumb stiffness affecting grasp soon after surgery	• Improved self-efficacy in hand control, leading to enhanced independence • New activities made possible, mobility and exercise activities easier (e.g. grasping gym equipment), tasks 'smoother' and quicker, less reliance on compensatory methods, less impacted by environmental barriers

			• Improved participation • Reduced reliance on assistance: able to be alone longer, reduced care hours, able to perform a task rather than waiting for help • Privacy, enjoying own company, able to carry out private tasks without assistance • Confidence and control, self-esteem • Regained identity as active, independent, social and equal • Reclaiming part of the body they missed • Improved relationships from increased ability to engage in activities, less need for assistance, ability to contribute, reduced sense of burden, and a shared experience of hope and improvement (vs shared sense of loss after injury) • Initial successes led to seeking out further challenges and new occupations
Ward & Price 2007 [71] Occupation-based OT interventions	• Identifying and practising valued occupations which were related to previous interests, self-identity and roles • Experiencing performing valued occupations helped participants (and family) realise they could still engage in these occupations, even if in a different way • Involvement of family and friends in therapy sessions were valued by both parties, and family/friends were a source of motivation	• Not reported	• Ability to engage in valued occupations, maintain roles and contribute to the community • Retained/restored sense of identity • Positive mindset and expectations

	• Therapy sessions (and related occupations) were an opportunity for self-expression, enjoyment, interest, engagement and escape. Sessions felt like 'real life' rather than therapy. • Collaborative problem-solving, teaching problem-solving skills, exposure to a range of techniques and solutions • Positive 'can do' attitude of staff, which countered initially low expectations • Exposure to varying, real environments provided a helpful experience and mindset for ongoing participation in the community • Provision of information about community-based resources for longer-term/specialised support e.g. adapted skiing organisation • Providing practical support and follow-up for unfamiliar tasks e.g. applying for social security • Facilitation of community occupations through home and vehicle modifications and skills training: these occupations were particularly valued, providing a sense of escape, socialisation and identity as a community member/contributor		• Self-efficacy in solving own problems • Increased community and social participation
Wellard & Rushton 2002 [111] Inpatient pressure ulcer management	• Access to windows and outdoor areas helped patients feel more connected to the outside world • Social activities facilitated by staff enabled time with family/friends outside of the ward environment	• Space less flexible and personalised than at home, limiting independence • Spatial practices were perceived to prioritise efficient use of resources over patient interests/experience • Lying in bed increased a sense of dependence and helplessness • Distance from home to hospital, limited, inflexible visiting hours, and lack of space for visitors impacted	• Reduced independence, compared to home environment • Reduced sense of personhood, redefined identity as 'sick, disabled other' • Negative impacts on mood: sense of confinement and dependence, depression • Reduced social connection, impact on family relationships

		families: drain on energy and finances, some members unable to visit, family members left out of information and decisions • Unpleasant physical environment affected mood • Lack of privacy (shared rooms) for personal conversations, personal care routines • Feeling disconnected, confined, punished • Lack of opportunity for social connected (limited access to telephone) and intimacy • Fear of these negative experiences often delayed the decision to seek treatment for pressure injury	
Williams et al. 2014 [65] Leisure time physical activity	• Key motivators for participation included a desire for greater independence, less need for assistance, being in a position to take advantage of future treatments/cure, fulfilling valued roles and contributing to society. • Participating with peers with SCI raised awareness and expectations, and was an opportunity for learning and socialisation. • Information about accessible opportunities mostly provided by peers, and occasionally health professionals (who learnt about these opportunities from their patients) • Experience of supported walking/standing was enjoyable, provided dignity, and a momentary return to 'normality'	• Low levels of subjective well-being and social participation (e.g. reduced confidence, fear of exclusion) were barriers to physical activity • Environmental barriers to participation included finances, high cost of participation/equipment, lack of accessible facilities, cold weather for outdoor	• Improved subjective well-being (e.g. mood), psychological well-being (outlook, purpose) and social well-being. • Improved body functions (e.g. pain, strength, fitness) • Improved body-self relationship, identity, sense of self • Positive cycle: these positive outcomes acted as motivators for ongoing participation

		activities, transport, dependence on assistance of others to exercise (and lack of this assistance) • Body problems (e.g. fatigue, fear of injury) were barriers to participation • Lack of information about accessible opportunities (including amongst health professionals) • Limited time, energy and motivation outweighed the limited benefits for some people • Perceived negatives of disabled sports: some did not enjoy modified versions of their previous sports, inability for able-bodied friends to participate, some women felt in the minority, and some associated it with unhealthy masculine behaviour • Authors caution against: overemphasis on individual responsibility for physical activity while ignoring environmental barriers, overemphasis on sport at the expense of other expressions of self and masculinity, and potential	•

		negative outcomes if hope for cure/recovery is the sole motivator for participation.	
Zinman et al 2014. [84] Self-management education program	• Greater understanding of the role of self, need for assertiveness and advocacy • Adjustment facilitated through greater insight into own limitations, need to accept limitations and communicate these to others, and understanding of potential • Knowledge gained through education and group interaction, skill acquisition, self-management strategies, access to resources • Implementing and practising skills during supported community outing • Experience of goal-setting and pursuit led to new goals being set • Group dynamics and supportive environment with peers: sharing experiences and knowledge, comparisons, able to relate to each other.	• Wanted longer and more sessions and a follow-up service	• Development of post SCI identity improved self-esteem, confidence • Adjustment, positive outlook, hope, gratitude • Increased community participation •

Appendix I: Interview guide – people with SCI

Tell me about how you came to stay at Sargood?

What stands out to you when you think about your stay/s at Sargood?

How would you describe the experience at Sargood?

What do you think Sargood is aiming to do?

Think about your journey and experience with services since your SCI. How do you think Sargood fits into that? Anything that is different/contrasting?

Is there anything you would suggest or change about Sargood?

How do you think your experience at Sargood has impacted you, during your stay and in the long term?

What was your experience with Sargood staff?

What was your experience with other Sargood guests?

(if relevant) How do you think Sargood has impacted people who stayed with you, or people back at home?

(If they haven't brought up well-being): I am interested in the concept of well-being, and how Sargood might contribute to well-being, or a good life. Do you think that is a relevant concept for Sargood, and if so, how do you think Sargood might contribute to well-being?

Appendix J: Interview guide - staff

Tell me about Sargood.

- What do you think they are trying to do?
- What makes Sargood unique?

Thinking about the Sargood guests. Why do they come to Sargood?

Tell me about your role here at Sargood?

- Thinking about your role with Sargood guests. What are you aiming to achieve for them, and why?
- Thinking about your professional background, training, or other work experiences. Is there a philosophy or conceptual framework or an approach that guides you in your work with Sargood guests?
- Recognising the interdisciplinary nature of Sargood. What do you uniquely do to contribute to that aim?

What helps you to do your job? *Probes: Tools, people.*

Are there things that get in the way? How do you work around those things?

Are you happy to share a story that you think captures/illustrates what you've been telling me? *Probes: Goal, focus, tools, other people involved, who did what, what supported/ what constrained*

I'm interested in the broader concept of well-being. How do you think this relates to what is being done and achieved at Sargood?

<u>Additional/alternative questions if needed</u>

What are you most proud of about your work at Sargood? Why?

Why do you work at Sargood? What makes Sargood unique?

Appendix K: Participant information statement

(1) What is this study about?

You are invited to take part in a research study about the experiences of guests of Sargood on Collaroy, and their families and friends. We are interested in finding out about your experience at Sargood. We would like to learn about the activities and programs you chose to participate in and ask what the experiences were like for you.

You have been invited to participate in this study because you have participated in activities at Sargood. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

[Student] is conducting this study as the basis for the degree of Doctor of Philosophy at The University of Sydney. This will take place under the supervision of [supervisors].

(3) What will the study involve for me?

You will be invited to participate in two interviews. The interviews will involve questions about your experiences of, and perceptions about, your participation at Sargood. A second interview will be conducted 6-12 months later to understand any changes or new insights.

The interviews will be conducted in a location that is convenient to you (e.g. your home). Interviews may also be conducted by telephone or on-line video call. An audio recording will be made of the interviews, for record-keeping purposes. The interviewer may also take written notes.

Significant others (e.g. family, friends) who stayed with you at Sargood, or who may have been impacted by your participation at Sargood, can also be invited to take part in an interview. The researcher will discuss potential additional interviewees with you, and you can provide consent on the consent form to invite additional interviewees connected to you.

(4) How much of my time will the study take?

The interviews are expected to take 60-90 minutes each.

(5) Who can take part in the study?

- People with spinal cord injury who have stayed at Sargood on Collaroy
- People with physical disabilities who are members of the community-based "Club Sargood"
- Family members, friends and significant others who have stayed at Sargood or who may have been impacted another person's participation at Sargood

Study participants need to be able to communicate sufficiently to participate in an in-depth interview. Alternative forms of communication (e.g. AAC devices) may be used during the interview.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney or Sargood on Collaroy.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by notifying the researcher at any point, including at the time of the second interview.

You are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

(7) Are there any risks or costs associated with being in the study?

You will be asked questions about your current and past experiences related to having a spinal injury. You may find it uncomfortable to share personal experiences. You can decide what you want to share about your experiences.

Other than giving up your time, there are no costs associated with taking part in this study.

(8) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study.

We hope the results of the study will help to understand better the experiences of Sargood guests, in order to refine the program, and help others (e.g., therapists) better understand how their interventions may impact well-being.

(9) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

A third-party transcription service will have temporary access to interview recordings; these recordings will be de-identified and the transcription service will not be provided with your personal information.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings and verbatim ('word-for-word') interview quotes may be published (journal articles, student thesis, conference presentations and university teaching materials), but you will not be individually identifiable in these publications.

We will keep the information we collect for this study for five years, and we may use it in future projects. By providing your consent you are allowing us to use your information in future projects. We don't know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.

You may be provided with your interview audio recording or transcription on request.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if I would like further information about the study?

When you have read this information, [student] will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact [student university phone number and email address]

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback about the results of the study by ticking the relevant box on the consent form. This feedback will be in the form of a one page 'layman' summary. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (Project number 2019/989). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep

Appendix L: Consent form

I, ... agree to take part in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney or Sargood on Collaroy now or in the future.
- I understand that I can withdraw from the study at any time.
- I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.
- *I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.*
- I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

I consent to:

- **Audio-recording of interviews** (will not be published) YES ☐ NO ☐
- **Being contacted about future studies** YES ☐ NO ☐

I would like to review my interview transcripts YES ☐ NO ☐

I would like to receive feedback about the overall results of this study YES ☐ NO ☐

If you answered **YES**, please indicate your preferred form of feedback and address:

☐ Postal: _____

_____

☐ Email: _____

.....

Signature

....

PRINT name

.....

Date

Appendix M: Documents reviewed

Sources	Documents	Type of information
Sargood on Collaroy: internal	Evaluation framework Booking form data from a two year period (exported into a spreadsheet and deidentified) Covidence – wiki-based intranet site with procedures and guides related to equipment, reception, hotel and building operations, room guides, safety and risk, staff, and the weekly activity program (n=117) Risk assessments (n=3)	Aims, policies, procedures, guides, training documents, demographics of guests
Sargood on Collaroy: external	All pages of the website (n=22)	Description of various elements of the program, information about the facility including a virtual tour, information about packages and funding, information about the history and structure of Sargood on Collaroy activity programs and descriptions, guest testimonials, videos and photographs
Royal Rehab (administrators of the program)	Website pages about Sargood on Collaroy (n=10) Royal Rehab (n.d.) *Sargood on Collaroy brochure* Retrieved Royal Rehab Annual Reports, Retrieved • *(2015-16) Annual Report* • *(2016-17) Annual Report* • *(2017-18) Annual Report* • *(2018-19) Annual Report* • *(2019-20) Annual Report* • *(2020-21) Annual Report* • *(2021-22) Annual Report* • *(2022-23) Annual Report* • *(2023-24) Annual Report* • *(2024-25) Annual Report*	Description of various elements of the Sargood on Collaroy program Sections about Sargood on Collaroy in annual reports

Sargood Foundation	All pages of the website (n=18) *11th annual report Sargood Foundation 2022-23*. Retrieved Sargood Foundation (n.d) *Constitution of the Sargood Foundation*. Retrieved Australian Charities and Not-for-Profits Commission (ACNC) *The Sargood Foundation*. Retrieved	Description of the Foundation and their work, description of various elements of Sargood on Collaroy, information about the history and structure of the Foundation and Sargood on Collaroy, information about funding support, demographics of Sargood on Collaroy guests, guest and supporter testimonials, videos and photographs Annual report Financial reports
The Sargood Centre	Australian Charities and Not-for-Profits Commission (ACNC) *The Sargood Centre*. Retrieved	Summary of activities, financial reports
Insurers	NDIS (2025) Operational guideline - reasonable and necessary supports NDIS (2025) Operational guideline - short term respite NDIS (2025) Crackdown on dodgy STA providers helps save $132 million in NDIS funds. Media release NDIS (2022) Operational guideline - short term accommodation and respite. NDIS (2024) Frequently asked questions about legislation. icare (2023) Sargood on Collaroy: Information for Case Managers. Retrieved icare (2023) Sargood on Collaroy: Information for participants and workers. Retrieved icare (2016, December 2) New world-first facility for spinal cord injury opens in Collaroy. Media release. Retrieved icare (2019, November 8). Winners of the CASE Awards 2019 announced. Media release icare annual reports and financial statements, Retrieved: • Annual report 2015-16	Policies Information for stakeholders Media releases and articles Annual and financial reports (reviewed for information related to Sargood on Collaroy)

- Annual report 2016-17
- Annual report 2017-18
- Annual report 2018-19
- Annual report 2019-20
- Annual report 2020-21
- Annual report 2021-22
- Annual report 2022-23
- Financial statements 2017-2018
- Financial statements 2018-2019
- Financial statements 2019-2020
- Financial statements 2020-2021
- Financial statements 2021-2022
- Financial statements 2022-2023

Local government website	Warringah Council (2012) Meeting minutes (28 August 2012). Retrieved Warringah Council (2012) Annual Report 2011-2012. Retrieved Warringah Council (2015) Annual Report 2014-2015. Retrieved Northern Beaches Council (2017) Disability Inclusion Action Plan (DIAP) 2017-2021. Retrieved Northern Beaches Council (2022) Disability Inclusion Action Plan (DIAP) 2022-2026. Retrieved DIAP Progress report 2017/18. Retrieved DIAP Progress report 2018/19. Retrieved DIAP Progress report 2019/20. Retrieved DIAP Progress report 2020/21. Retrieved DIAP Progress report 2021/22. Retrieved Northern Beaches Council (2017) Collaroy Beach Now More Accessible For All (4 August 2017) Media release Northern Beaches Council Major projects: Collaroy Accessibility Precinct. Retrieved Northern Beaches Council (2018) Southern end of Collaroy Beach set for an upgrade (17 January 2018) Media release Northern Beaches Council (2018) New inclusive Collaroy Beach amenities block opens (20 December 2018) Media release	Media releases Project reports Disability inclusion plan and progress reports Annual reports (reviewed for information related to Sargood on Collaroy and Collaroy accessibility precinct)

Federal government websites	Falinski, j. (2016, November 28). Sargood on Collaroy. Speech given to the House of Representatives, Australia. Retrieved Falinski, J. (2021, March 25) Health Care. Speech given to the House of Representatives, Australia. Retrieved McLucas, Jan (2012, 18 October) Finalists announced for National Disability Awards. Media release	Speeches
News websites	Angelelli, C. (2023, August 30). Rethinking SCI rehab. New Mobility. Bedo, S. (2019, September 16). Unremarkable act leaves man quadriplegic. news.com.au Besley, J. (2017, March 7). Royal Rehab teaming up with Sargood on Collaroy for a world-first accessible resort. Manly Daily Browne, R. (2012, March 25). Access all areas. The Sydney Morning Herald. Clancey, D. (2023, n.d.). Former governor-general praises special camp for brave children. A Current Affair Clark, A. (2016, December 2). Beach resort to cater for people with spinal cord injuries. SBS News Collaroy leads inclusive tourism. (2023, May 31). Northern Beaches Advocate Deare, S. (2014, September 23). New all-abilities playground will cater to children with disabilities at Collaroy Beach Manly Daily Dengate, C. (2014, August 28). Construction to start on spinal cord rehabilitation facility Sargood Centre in Collaroy. Manly Daily Dunn, C. (2023, Dec 3). International Day of People with a Disability. Breakthru: You empowered. Editorial Team (2022, March 30.) Family fun made easy at Sargood. Travel Without Limits Geddes, J. (2018, June 13). Rugby identities give $60,000 boost to spinal injury victims. Manly Daily	Newspaper articles, recordings of television news segments.

Godfrey, A. (2021, February 12). This resort is so good – no-one wants to leave. Family Travel

Han, E. (2019, April 16). Ashlee can't move her legs but she's a certified scuba diver. Sydney Morning Herald

Hunter, B. (n.d.) Katrina Ford Sargood on Collaroy interview. Female.com.au

Kick back at the Sargood on Collaroy. (2020, July 2023). Travel without Limits

Morcombe, J. (2014, September 26). Collaroy Beach has always been a top spot as a safe family spot. Manly Daily

Morcombe, J. (2016, November 11). Sargood, Nuffield donations for children's convalescent home at Collaroy. Manly Daily

New 3D printing technology. (2019, September 7). [7News Australia video Tweet] Twitter

Patterson, R. (2016, November 28). World-first resort and health spa for people with spinal cord injuries Sargood on Collaroy set to open. Manly Daily

Sargood on Collaroy – a world first in medical innovation. (n.d.) Hunter and Bligh

Sargood on Collaroy celebrates two-year milestone. (n.d.). Freedom2Live

SBS (2017, February 3). Sargood on Collaroy. Vimeo

Sargood on Collaroy open day. (2019, n.d.). Events.com

Sargood on Collaroy SCI career workshop. (2019, May 7). Freedom2Live

Sargood resort a community triumph. (n.d.) Beaches Covered

Spinal Cord Injuries Australia. (n.d.). Sargood on Collaroy launches internship program for people with SCI. SCIA

Spinal Cord Injuries Australia (n.d.) NeuroMoves is coming to Sargood on Collaroy this May! SCIA

Spinal Cord Injuries Australia (2019, July 24). Sargood Foundation launches travel grants. Freedom2Live

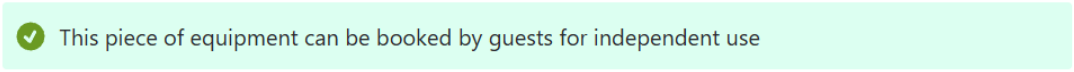
	Spray, T. (2024, December). Fletcher is unstoppable. Peninsula Living Storrie, O. (2018, August 10). Resort caters to wheelchair rugby team. Vacations and Travel Swain, S. (2017, September 16). The world's first holiday resort for people with spinal cord injuries has opened in Collaroy. Manly Daily Tarbert, K. (2018, August 1). The hotel changing the way people with disabilities can go on holidays. Yahoo Lifestyle The extreme X8 enabling resort visitors to explore the great outdoors. (n.d.). Magic Mobility Williams, S. (2017, October 16). Community saves $30 million prime beachfront hospital site in Collaroy from developers' clutches. Domain Williams, W. (2017, March 1). The Sargood effect – revolutionising holidays for people with disability. ProBono Australia	
Blogs and social media	Cross, P. (n.d.) Dream to reality: coastal retreat for people with SCI. Christopher and Diana Reeve Foundation blog Harrison, M. (2018) When accommodation is made accessible – feels like home. Sitting Low, Reaching High Nott, L. (n.d.) Sargood. My C5 Life Sargood on Collaroy – accessible accommodation Sydney. (2017, March 18). Have Wheelchair Will Travel RAD RollinAllDay (2023) THE BEST Accessible Accommodation In Australia... SARGOOD ON COLLAROY. YouTube Sargood on Collaroy turns 2. (n.d.) Travability Surf's up at Sargood on Collaroy. (n.d.) Have Wheelchair Will Travel Swain, K. (2018, March 28). Sargood on Collaroy with Elana Hand. Kate Swain- the Wheel Life Assistive Tech Stuff (2021) RC with adaptive controls for disability. YouTube	Blog posts and videos about their experience of the program

Travel websites and accommodation listings	Sargood on Collaroy. (n.d.) Get Aboutable Sargood on Collaroy. (n.d.) Pantou Sargood on Collaroy. (n.d.) Trip Advisor Sargood on Collaroy (2021, March 10). Wheel Easy	Details about the program, reviews
Design and construction sites	Australia by Design (2017, November 2). Sargood. Vimeo Rider, N. (2017, June 6). The best architecture and design from the 2017 Good Design Awards. Architecture and Design. Sargood. (n.d.) Brand Culture Sargood on Collaroy – branding. (n.d.) Fresco Creative Sargood on Collaroy (2017). Good Design Awards. Sargood on Collaroy (n.d.) Lisu Surfaces Sargood on Collaroy (n.d.) Novati Constructions Sargood on Collaroy – branding. (n.d.) Oculus Sargood on Collaroy (n.d.) WMK Architects WMK Architecture – Sargood on Collaroy-Sydney Australia. (n.d.) IDN World	Articles, videos and project reports about the design of the facility and program
Sargood on Collaroy Facebook page	All Facebook posts and comments Mentions by other Facebook accounts	Text, photos, videos, comments
Sargood on Collaroy Instagram page	All posts and comments Tagged posts by other Instagram accounts	Photos, videos, captions, comments
Competition sites	Listenable Podcast (2022, October 17). You could win 7 nights accommodation at @SargoodOnCollaroy in one of their beautifully appointed ocean view rooms, with a bottle [photograph]. Instagram Spinal Injury Project (2024) Fundraise and win. Retrieved Estara (2023, January 19). We are thrilled to share photos from Dawn who used a PQSA grant to fund a trip to Sargood On Collaroy [photograph]. Instagram.	Articles Information about funding grants

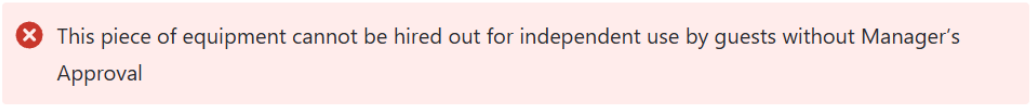
Appendix N: Sample of review notes from a policy and procedures database

Overview/impressions

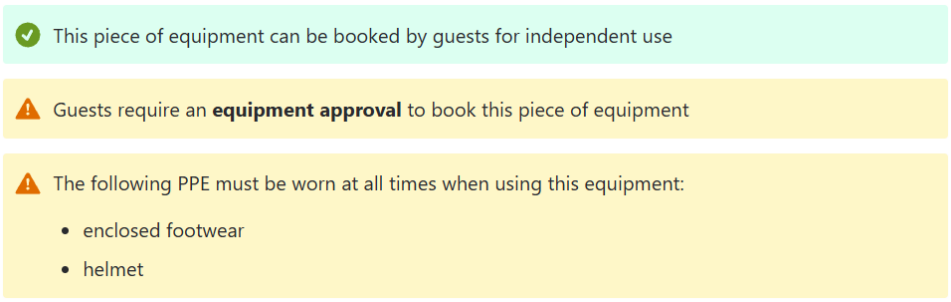
- Complex esp SCI specialty – much more than a hotel. Throughout, it illustrates the complexity of operating a hospitality X clinical service
- A lot to know to be able to offer the program with its various and specialised elements
- High stakes if something goes wrong
- Helpful resource for training – simple, clear layout, images and videos
- Supports for non-clinical staff in clinical matters related to booking and check-in
- Evidence of specialty and solutions beyond usual SCI services e.g. scanning bed controller with voice operation (bespoke solution designed together with a custom electronic AT service)
- Supports for staff to facilitate activities outside of scheduled program e.g. art/craft, games room guide, loan of rec equipment for independent use (highlighted using a label/flag). Procedures/logistics and safety are detailed to enable this to happen safely without relying on clinical staff.



- But facilitating activities is balanced with need to manage risk. E.g. a flag might say



- Risk management throughout e.g. safety information highlighted and with an alert icon. Balance of facilitating activities and managing risks



- Vast amount of detailed knowledge in staff brains – recorded for other staff (and if they move on)
- Not fully complete – some videos/links flagged to insert
- 'Wiki' type site: able to be edited by the group (check what staff roles have editing permissions) – enables collaboration, flatter structure. Authors include management and clinical staff eg rec team leader, OT, clinical managers,
- 'Owner' of the article/page may be one person but there is often a record of updates from another team member - collaboration

- Complexity of booking process to meet billing/funder requirements, arrange care needs and GA roster, booking appointments with allied health staff who may work part time
- Guides reflect the staff approach and culture they want to foster. Shows expectations e.g. check-in guide specifies a friendly welcome, offer to help with luggage
- But also includes principles/procedures re how to manage aggressive or inappropriate behaviour: realistic, interacting with guests is not always friendly and nice
- Activities schedule page– using the schedule, booking in, updating TV display. Shows the logistics required for offering a group/scheduled program and exposing guests to what's available
- Lots of different software systems e.g. booking form and internal system for managing the needs for that stay e.g. equipment, billing, rostering, activities schedule, Royal Rehab P&P, shared drive, processes, to do lists
- Complexity of facilitating insurance funding from a range of funders: detailed and complex process for each
- Equipment use, ordering, maintenance, rental – all complex and part of the risk management requirements. Its complex to offer equipment rental from outside the program
- Policies related to being a facility for people with SCI e.g. no smoking (because of guests with respiratory issues), assistance animals, contacts for local medical facilities (because they don't provide this themselves- managing disability, preventing complications, but not a health service)
- Policies being a hospitality service e.g. Responsible Service of Alcohol. Again, blend of hospitality and disability service
- Offering solutions for people with SCI, making their stay easy – adds complexity e.g. managing the home automation systems in each room, motorised doors. An organisation needs to be committed/motivated to extend their offerings, with the resulting complexity in operations.
- Articles/pages about weekly activity program – who can participate (level of SCI, family, age, weight limit) – this has an encouraging/inclusive slant (vs ruling people out), logistics, contacts (e.g. of external organisations), resources, equipment needed (from Sargood, third parties and guests), logistics like parking bathrooms and access, safety precautions, first aid, emergency contacts. Considers risks throughout: under obvious headings but also in details e.g. list of equipment provided by guest includes sun protection, considers availability of food and water. 'X8s on the Beach' is a good example - pasted below.
- Not just internal – they have information about external organisations and how they facilitate participation of people with SCI. Facilitating access to mainstream community resources, participation with non-disabled people. They have obviously researched these organisations and environments re SCI access and suitability.
- Similarly, there Is detailed information sights/locations in local area (e.g. Narrabeen lagoon trail, lookouts) including accessibility, activities, logistics for taking guests there, risks
- Throughout, there is excellent, detailed knowledge of the local area and considerations for people with SCI