

“It’s a set of scales on a journey”

Living well as young people with vision impairment

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BPsych (hons)

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Abstract

Youth with vision impairment have the right to a life of positive experiences and enriched quality: a life of wellbeing. Educational and rehabilitation services are a key support for this right. Currently, these services focus on the provision of assistive technologies and individual skill instruction, viewing youth as ‘well’ if they handle the functional limitations it is (perceived to) cause, and accept those deemed unresolvable. However, these services inconsistently promote psychological health and quality of life outcomes. I argue that this reflects their incomplete understanding of wellbeing for these young people and need for its continued development. Therefore, this thesis explores the conceptualizations of wellbeing of 21 youth (12-25 years of age), with varying levels and causes of vision impairment, from Victoria, Australia.

This thesis draws upon a participatory research design involving collaboration with these youth over two phases. During phase one, over three data collection encounters, participants discussed their conceptions and experiences of a good life and impacting vision-impairment-related factors. Between sessions, they audio-recorded sound environments and personal reflections of relevant experiences to share in session. The audio-recorded interviews/focus groups and participant recordings were thematically analysed, and resultant themes verified through member-checking focus groups in the second phase.

Themes of balance, sameness, difference and identity were central to participants’ discussions. Living well entailed a personal sense of balance between important elements of life – such as success in their endeavours, close and caring friendships, and feelings of energy – across four domains perceived as valuable to all people: physical health, social

connection, capability and control. Maintaining this balance was important as obtaining each element cyclically supported the maintenance of others, and so experiencing this balance afforded participants an overall sense that their life was going well, even when confronting difficulties around specific elements due to the interactions of their vision impairments with material and institutional environments, and others' negative reactions. Encountering these difficulties also led participants to distinctly value and attain these important elements, as did other intersecting personal characteristics/circumstances (e.g. age, rural/urban residence). As such, participants' conceptions and experiences of wellbeing were informed by their senses of identity: their traits, values, goals, competencies and position in the world around them. Their identity informed both how they understood what it meant to attain each important element in their life and what constituted a balance between them. Therefore, participants' understandings of their wellbeing occupied a space of 'situated sameness': they described it as simultaneously the same as, and yet different from, that of the general population they envisaged.

This empirical data collection identified implications for vision impairment services. These services must ensure a holistic and relational approach to working with young people. They should actively consider their broader personal characteristics/circumstances and tailor services accordingly. They must also incorporate services directly promoting a young person's experience of fulfilment in multiple life domains; ensuring, for example, peer support and recreation programs are provided alongside assistive technologies and skill development. These measures will better promote the young person's sense of personal balance and thus wellbeing.

General Declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes 0 original papers published in peer reviewed journals and 2 submitted publications. The core theme of the thesis is that youth with vision impairment conceptualize their wellbeing as entailing the personal balancing of multiple domains of life that they find valuable; namely, their physical health, social connection, capability, and control. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Social and Political Sciences Graduate Research Program under the supervision of Dr Narelle Warren, Dr RoseAnne Misajon and Dr Stuart Lee.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

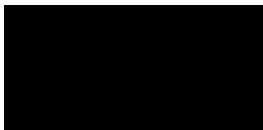
In the case of *Chapters 5 and 6*, my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status (<i>published, in press, accepted or returned for revision</i>)	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
Chapter 5	Exploring wellbeing in youth with vision impairment: Insights for vision rehabilitation	Accepted for review	75%. Designed the project, performed data collection and analysis, wrote the first draft of the paper and was involved its subsequent revision.	1) Narelle Warren: contributed to project design, data analysis, and revision of manuscript. 15% 2) RoseAnne Misajon: contributed to project design and revision of manuscript. 5% 3) Stuart Lee: contributed to project design and revision of manuscript. 5%.	1) N 2) N 3) N

Chapter 6	<p>“You need the more relaxed side, but you also need the adrenaline”: Promoting physical health as perceived by youth with vision impairment</p>	Accepted for review	75%. Designed the project, performed data collection and analysis, wrote the first draft of the paper and was involved its subsequent revision.	<p>1) Narelle Warren: contributed to project design, data analysis, and revision of manuscript. 15% 2) RoseAnne Misajon: contributed to project design and revision of manuscript. 5% 3) Stuart Lee: contributed to project design and revision of manuscript. 5%.</p>	<p>1) N 2) N 3) N</p>
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I have renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Student signature:



Date: 7 Dec 2017

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student’s and co-authors’ contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature:



Date: 7 Dec 2017

Acknowledgements

My research – like all research – occurred in the messiness of everyday life. As such, it was really a “roll with the punches” endeavour and was only made possible with the ongoing presence and support of many people and institutions who deserve special mention.

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I also wish to wholeheartedly thank the not-for-profit and government organizations who supported my work: Vision Australia; Guide Dogs Victoria; Blind Citizens Australia; Retina Victoria (Australia); Blind Sports and Recreation Victoria; the Insight Education Centre for the Blind and Vision Impaired; and, the Statewide Vision Resource Centre. Their support in facilitating recruitment was invaluable. I would particularly like to thank Vision Australia and Guide Dogs Victoria for their provision of alternative formatting services and their centres as venues for study interviews and focus groups. I also acknowledge that the completion of my doctoral research has been supported through an Australian Government Research Training Scholarship.

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*To my amazing mother, Margaret Gladys Anderson, and father, Paul Robert Anderson,
whose trials over the last two years have paled the stressors of the PhD process*

&

My wonderful wife, Brooke Loraine Anderson.

Table of Contents

Abstract	iii
General Declaration	v
Acknowledgements	vii
Table of Contents	xi
List of Abbreviations	xiv
List of Tables	xv
List of Figures	xvi
List of Appendices	xvii
Prologue - My youthful aspiration	1
Thesis Overview	5
Chapter 1 - Wellbeing in youth with vision impairment: Taking in the scenery	11
1.1 Understanding Vision Impairment.....	13
1.2 An Overview of Vision Impairment Services.....	17
Chapter 2 - Problematizing our understanding of ‘living well with vision impairment’	38
2.1 Wellbeing and Disability: An Overview.....	41
2.2 The Assumptions of Vision Impairment Services and Research.....	54
2.3 Challenging the Personal Tragedy Model.....	59
2.4 Rethinking ‘Living Well with Vision Impairment’: Project Aim.....	74

Chapter 3 - Methodology: Collaboration with comrades	80
3.1 My Impairment and My Critical Realist Participatory Approach	81
3.2 Study Design and Methods	90
3.3 An ‘Insider’, an ‘Activist’ or a ‘Friend’?	105
3.4 Power and Positioning in Practice	115
3.5 Evaluating the Quality of the Project	124
Chapter 4 - Vision impairment services in Victoria, Australia	130
4.1 An Overview of the Victorian Services Context	131
4.2 The Focus of Victorian Vision Impairment Services	137
Chapter 5 - The refraction of wellbeing by youth with vision impairment	142
5.1 Paper 1: Exploring wellbeing in youth with vision impairment: Insights for vision rehabilitation	146
5.2 Concluding Remarks on Paper 1	181
Chapter 6 - Both body and energy: An expansion of physical health	184
6.1 Paper 2: “You need the more relaxed side, but you also need the adrenaline”: Promoting physical health as perceived by youth with vision impairment	186
6.2 Concluding Remarks on Paper 2	212
Chapter 7 - Social connection: Closeness, community and capital	214
7.1 The Valuable Capital of Close Bonds and Communities	215
7.2 Living with Vision Impairment and Barriers to Social Connection	231
7.3 Conclusion: Positive Social Connection and Inclusion to Enhance Wellbeing	245
Chapter 8 - Capability and control: More than the performance of tasks	248
8.1 Capability and Control: The Importance of Successful Independence	250

8.2 Difficulties and Differences in Being Capable and in Control	266
8.3 Capability and Control: Managing Psycho-Emotional Disablism.....	279
8.4 Conclusion: Capability and Control as Intersubjective Experiences	293
Chapter 9 - Adaptability and self-reflection: Participant-identified strategies to maintain wellbeing	296
9.1 Moving On: Wellbeing despite Difficulties.....	297
9.2 Adaptability: A Set of Strategies and Resources	302
9.3 Self-management through Self-reflection.....	317
9.4 Conclusion: The Need for Psychologically-focused Services	328
Chapter 10 - Fresh eyes on ‘living well with vision impairment’	332
10.1 The Ongoing Process of ‘Living Well with Vision Impairment’	333
10.2 Implications for Vision Impairment Services for Young People.....	350
References.....	374
Appendices.....	434

List of Abbreviations

DET – Victorian State Government Department of Education and Training

ECC – Expanded Core Curriculum

ICD-10 – International Statistical Classification of Diseases and Related Health Problems

NLTS-2 – National Longitudinal Transition Study 2

O&M – Orientation and Mobility

QoL – Quality of Life

RCT – Randomized Controlled Trial

SES – Socio-economic Status

SF-36 – Medical Outcome Study 36-item Short-form Survey

VI – Vision Impairment

Youth ReACT method – Youth Research Actualizing Critical Thought method

WHO – World Health Organization

UN – United Nations

List of Tables

Table 1.1. VI Severity Levels in the WHO's ICD-10.

Table 1.2. Global Prevalence Rates of VI by Age Group.

Table 1.3. Major Causes of VI in Younger Populations.

Table 1.4. Strategies and Resources Provided to Youths receiving VI Services.

Table 2.1. Eight Quality of Life Domains identified by Schalock and Verdugo (Schalock, 2004; Schalock et al., 2016).

Table 3.1. Differences Between Original and Adapted Youth ReACT Method.

Table 3.2. Descriptive Statistics for Personal Background Information of Participants.

Table 3.3. Step-by-step Description of the First Phase.

Table 4.1. Frequencies at which Participants Reported the Receipt of Different Services.

Table 5.1. Causes of Vision Impairment and Education Levels of Participants.

Table 6.1. Descriptive Statistics for Participants' Education Levels, Causes of VI and Use of VI-related Services.

Table 6.2. Prompting Questions for the Audio-Recording Task Provided to Participants Between Sessions.

Table 6.3. Prompting and Reserve Questions for the Data Collection Sessions.

Table 6.4. The Four Elements Discussed by Participants within the Theme of 'Physical health'.

Table 10.1. Major VI-related Difficulties Encountered by Participants in Each Life Domain by Type.

List of Figures

Figure 1.1. The components of the expanded core curriculum.

Figure 1.2. Three levels of service provision for low vision care proposed by the World Health Organization.

Figure 2.1. A diagram representing the staged model of ‘adjusting with blindness’ proposed by Tuttle and Tuttle (2004).

Figure 5.1. A diagram illustrating the shaping effect over time of the various situating factors at play in the participants’ lives on their conceptions of wellbeing.

Figure 6.1. A flowchart depicting the four sessions participated in by the participants across the data collection and member-checking phases.

Figure 7.1. A diagram depicting the key qualities (subthemes) that the participants identified as contributing to the value they found in their social connections.

Figure 9.1. A diagram summarizing the set of strategies and resources identified by the participants as contributing to their adaptability in responding to the VI-related difficulties they encountered in different situations.

Figure 10.1. The fit of the important life domains identified by the participants with the well-cited eight domain model of quality of life outlined by Schalock and Verdugo (Schalock, 2004; Schalock et al., 2016).

List of Appendices

Appendix A. Project Recruitment Flyers.

Appendix B. Facilitation Guides for Sessions in the First Phase of the Project.

Appendix C. Audio-recording Task Handouts for the First Phase of the Project.

Prologue

My youthful aspiration

Growing up, one of my most long-lived aspirations was to become an architect. I loved drawing from an early age and my Poppy (grandfather) – who had been a professional draftsman and an amateur painter – taught me how to draw from photographs. He would tell me to “draw what you see, not what you think you see” as he erased parts of my drawings. This career goal remained through to my mid-adolescence. I recall standing outside the community recreation centre at which I attended my guitar lessons with my friend’s father – an architect – as he described the various considerations of the architect who had designed the centre. I nodded my way through this conversation, despite being unable to see the elements of the building to which he referred. I was diagnosed with Retinitis Pigmentosa when I was 12 years of age during my final year of primary school.

Reflecting upon this, the longevity of my architectural aspirations beyond my diagnosis – even as my vision deteriorated – stands out to me. Throughout the first three years of secondary school, my mind remained set upon architecture; a fact which I outwardly voiced to my peers and teachers, all of whom knew of my vision impairment. Nonetheless, with continued vision loss, I eventually felt forced to question my confidence in pursuing a career that appeared (at least at the time) highly dependent upon sight. Coming to terms with this entailed many processes, including taking my Poppy’s advice and deliberately drawing “what I saw”, as well as talking to other adolescents with vision impairment regarding their experiences and aspirations. I especially remember several discussions with one friend, Mal (a pseudonym), in which I repeatedly urged him

to self-advocate about his vision at school, despite his staunch reticence to disclose because of the risk of social exclusion. Mal pushed me to stick with my goal of architecture despite my doubts: as I was questioning my aspirations, he held firm in his pursuit of a career in carpentry; another occupation that appeared (again, at least to me) reliant on sight. In the end, I relinquished my drive to be an architect; however, it was through grappling with these experiences and implications of living with my own and my friends' vision impairments that I gained new inspiration. I became determined to pursue a career in psychology and work towards optimizing support for future youth grappling with similar and different issues to those I faced by drawing upon my own personal experiences.

This same motivation has also driven my doctoral research from its inception through to the present moment as I sit writing up my thesis, no longer a youth (technically) by most formal definitions. My research has been inextricably moulded by my own personal understandings of living with vision impairment developed (and still developing) from my own experiences and those encountered through others. This collective lived experience foregrounds for me the complexities inherent in not just living with, but 'living well with vision impairment' as a young person transitioning into adulthood. Reflecting on the contrast between my adolescent self and Mal, brings forth the realization that we both made different decisions regarding where and how to resist and handle potential barriers related to our vision impairments in order to pursue what we considered important. Such complexities are brought to bear throughout this thesis, where I critically explore what living well means from the perspectives of youth with vision impairment in order to illuminate the implicit concept of 'wellbeing' underpinning services to this population that has been exposed to limited interrogation. I examine the goals, values and qualities youth pursue in their conception of the good life, and how they

go about maintaining and promoting them when encountering difficulties associated with their vision or other factors. Through this exploration, I seek to offer useful ways of understanding wellbeing for youth with vision impairment and inform continued research and refinement of supports for this group.

Thesis Overview

In this thesis, I contribute to the theoretical critique of the understanding of wellbeing that underpins vision impairment services for youth. The central narrative of my thesis explores how 21 young people with vision impairment from Victoria, Australia, understood, experienced and maintained a life of quality. Drawing upon this, I consider the implications and insights that can be taken from participants' voices for services looking to promote the wellbeing of youth with VI. In unpacking their accounts, I draw upon larger theoretical discourses regarding the nature of both wellbeing and disability. I argue that the accounts of these young people highlight the need for vision impairment services to ensure they take a holistic and situated approach in working to support the wellbeing of young people. These services should seek to directly support fulfilment across multiple life domains that contribute to their wellbeing, in a way that takes into consideration each young person's particular values, goals, characteristics and other personal circumstances. This thesis includes two papers that were submitted for stand-alone publication as substantive chapters. As such, while efforts have been made to reduce repetition throughout the thesis, some repetition was unavoidable, in particular with regard to study methods.

Chapter 1 sets the scene for the thesis by providing background information regarding vision impairment and the current state-of-play in service provision to young people with vision impairment. In particular, it provides a description of the kinds of educational and rehabilitation services that are generally provided to young people with vision impairment and research findings regarding the effectiveness of these services at promoting the wellbeing of this population. *Chapter 2* then commences my theoretical

critique of current vision impairment service provision and underlines the need for further development of the theoretical understanding of wellbeing that informs service provision to youth. In this chapter, I argue that the implicit working theory of wellbeing that informs contemporary vision impairment services for youth is grounded in the personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000). Consequently, responding to the functional limitations (perceived as) resulting from vision impairment is positioned as the priority in supporting a young person's wellbeing. However, given inconsistent effectiveness of vision impairment services at promoting broader indicators of wellbeing, and empirical and theoretical challenges to the personal tragedy model of disability, I emphasize the need to further develop understandings of wellbeing in youth with vision impairment to inform such services.

Chapter 3 outlines the study design, methodological considerations, and specific methods employed in conducting this collaborative exploration with fellow youth with vision impairment. I outline how reflections upon my own vision impairment led to my adoption of a critical realist participatory approach to my research and detail the specific methods through which this approach was realized. I conclude this chapter by identifying a number of limitations to my work, as well as my efforts to ensure the trustworthiness and quality of this research. *Chapter 4* then describes the specific services, resources and support available to youth with vision impairment in Victoria, Australia, which provides contextualization of the participants' accounts.

Chapter 5 is the first substantive results chapter and is constituted by a publication. This paper presents the overall picture of wellbeing painted by the participants. After providing a brief summary of the four thematic domains of life identified as important to the participants – *physical health, social connection, capability* and *control* – it engages with the themes of balance, identity, sameness and difference

that framed participants' experiences of a good life. I highlight the emphasis that participants placed on maintaining a sense of balance across the elements they considered important in their life that fell across the four domains, and the significance of their sense of who they were – based on their particular circumstances and history of experiences – in guiding how they pursued these elements and what they considered a balance between them. I also highlight how the participants' discussions of their wellbeing located it in a space of 'situated sameness'. That is, they perceived the life elements that they valued as the same as those they felt were valuable to the general sighted population, although how they were experienced was shaped by their experiences of living with vision impairment, and the influence of other intersecting personal characteristics and circumstances.

The three subsequent results chapters engage in discussion of the situated conception and experience of the four major life domains discussed by the participants. Each chapter expounds the participants' discussions of the elements of their lives that they valued categorized within each thematic domain. They also highlight how living with vision impairment impacted upon the participants' experiences within each domain both through the interaction of their limited vision with varied environmental factors to produce practical difficulties, and the psychosocial impacts of others' negative reactions to their vision impairment.

Chapter 6 encompasses a second publication. Contextualized within findings of the reduced physical activity and fitness of youth with vision impairment, this paper presents the participants' reflections related to the domain of *physical health* in order to contribute to existing work developing services and programs targeting the physical activity and health of this population (Furtado, Allums-Featherston, Lieberman, & Gutierrez, 2015). I highlight the participants' emphasis on their maintenance of subjective feelings of energy alongside their bodily integrity and functioning, through their

interrelated engagement in physical activity and relaxation. *Chapter 7* then elucidates participants' understandings of valuable social connection with others, in both close one-on-one relationships and in larger communities, and the barriers they encountered to forming and keeping such social connections. Building on this, *Chapter 8* discusses the participants' desires to be in charge of and successful in their lives that cut across multiple endeavours (e.g. school, sports) that were captured in the closely-interrelated domains of capability and control. In particular, I highlight the importance participants placed on feeling that they could rely on their own skills and resources for their successful participation in these endeavours, and how this needed to be managed in the face of both practical difficulties from environmental barriers and their reduced sight, and the diminishing judgements about their capacities made by others.

The final results chapter – *Chapter 9* – focuses on how participants responded to difficulties in pursuing and attaining the elements that they considered important to the quality of their lives, in order to preserve their personal sense of balance. I highlight, in particular, the importance they placed upon being able to adapt their response to each difficulty encountered in its own context; an ability that necessitated their possession of a broad set of strategies and resources upon which to draw. This included strategies and resources for addressing both the practical difficulties as well as the psychosocial impacts of living with vision impairment. I also highlight the central role of self-reflection in enabling the participants to appraise a difficulty they encountered to determine which strategy or resource to draw on in a given situation in order to best promote their wellbeing.

In the final thesis chapter, *Chapter 10*, I paint the overall picture of what it meant to be 'living well with vision impairment' expressed in the discussions and shared

experiences of the participating youth. I discuss the implications and insights this holds for the provision of vision impairment services to this population.

Chapter 1

Wellbeing in youth with vision impairment: Taking in the scenery

Children and young people with vision impairment have the right to lead a full and well life as reflected in the *United Nations Convention on the Rights of the Child* (Ben-Arieh, 2008; Llewellyn & Leonard, 2010; United Nations, 1990). In contrast to the common perception of vision impairment and blindness as one of the worst forms of disability that can befall a person (Noran, Izzuna, Bulgiba, Mimiwati, & Ayu, 2009; Southwell, 2012), having vision impairment does not inherently preclude a person's capacity to live a life in which they experience wellbeing, as has been found in research among both older and young individuals (Kef, 2002; Kef, Hox, & Habekothé, 2000; Renaud et al., 2010). Thus, people living with vision impairment – including younger individuals – should be afforded the same opportunities as the non-disabled population to pursue and live their life in accordance with their conceptions of wellbeing.

Wellbeing can be understood as what it means for a person to live a life characterized by positive experiences and enriched quality, and not just the lack of – or perhaps even in the presence of – negative factors (Ben-Arieh, Casas, Frønes, & Korbin, 2014; Manderson, 2005; R. M. Ryan & Deci, 2001; Wallander & Koot, 2016). This positivity and quality is judged with reference to certain objectively- and subjectively-valuable criteria (e.g. positive emotions, positive relationships). Due to the ubiquity of this aspiration to wellbeing, wellbeing has come to represent a significant target and evaluation outcome at the level of international and national policy development, as well

as the level of service provision to individuals (Ben-Arieh, 2008; Bickenbach, 2014; Warren & Manderson, 2013). The spread of this “wellbeing agenda” (Marquès-Brocksopp, 2011, p. 51) has not overlooked the area of vision impairment (VI). This is made explicit through services provided to young people with VI, particularly VI education and rehabilitation services. Extending over many years, these broad-range services are provided to individuals with VI to reduce associated impacts on their life (Binns et al., 2012; Markowitz, 2016; P. S. Roberts et al., 2016; B. Ryan, 2014); the goal is not to restore lost vision, but rather to enhance functioning and wellbeing despite VI.

Childhood and youth VI is associated with lifelong hardship due to barriers encountered during the establishment of solid foundations in many areas of life (e.g. employment, social life) as an individual transitions into adulthood (J. E. Brown, 2009). Although childhood causes of VI account for only a small amount of VI worldwide – only 4% of blindness globally – in comparison to other later-onset causes of VI these childhood causes account for the second highest number of years of human life whose quality is affected by blindness, and thus represent a priority (Gilbert & Foster, 2001; Pascolini & Mariotti, 2012). Effectively responding to childhood and youth VI is essential in order to support and promote the wellbeing of young people who experience it, with such an effective response involving multiple components. Numerous global causes of VI in younger populations are preventable (e.g. measles), and the increased prevention of these causes is a core target for the World Health Organization’s (WHO) initiative ‘Vision 2020: The Right to Sight’ (Gilbert & Foster, 2001; Thylefors, 1998). Despite such valuable prevention- and treatment-focused work, many causes of childhood and youth VI are not currently preventable or treatable by medicine, surgery or standard prescription glasses (Gilbert & Muhit, 2008; Rahi & Solebo, 2012). For youth whose VI was not preventable or is not treatable, educational and rehabilitative VI services are crucial to the

alleviation of the immediate and lifelong difficulties that they encounter, and thus their wellbeing.

This thesis focuses on wellbeing and its promotion through VI services for youth, defined here – despite complex and variable definitions across contexts due to historical, social and cultural factors (Ansell, 2016; Furlong, 2013) – as including an intentionally broad range of people aged 12-25 years. In exploring variations of wellbeing, the thesis unpacks the lived experiences of youth with VI from Victoria, Australia, regarding what it means for them to ‘live well’. This exploration is conducted in order to gain insights to guide VI services for this population. In this chapter, I contextualize my exploration of the conceptualizations of wellbeing of youths with VI. I provide epidemiological and aetiological information regarding VI in the first section, before I engage in a more detailed description of VI services. This includes the discussion of research reporting on the inconsistent effectiveness of these services in promoting psychological and broader wellbeing outcomes. I conclude the chapter by flagging the need for greater development of our theoretical understandings of wellbeing among people – including youth – with VI to guide continued development of these services.

1.1 Understanding Vision Impairment

VI – the chronic condition of having limited or no sight – is clinically understood in terms of an individual’s visual function, particularly visual perceptual capacities and the performance of the different eye structures and lower-order cortical visual processing pathways (Colenbrander, 2009; Lepri, 2009; Markowitz, 2006). Several characteristics are assessed on a person’s first contact with VI service providers after initial signs of possible VI, or after signs of potential deterioration of a person’s remaining sight in the case of degenerative conditions. This includes refractive error, stereopsis, colour

perception, and contrast sensitivity¹ (Colenbrander, 2009; Markowitz, 2006; Rahi & Solebo, 2012).

Two particular visual function characteristics that are prominently used in describing VI are visual acuity and visual field. Many different forms of visual acuity can be discussed (e.g. near visual acuity, distance visual acuity), but generally it is the capacity to discern visual detail. Visual acuity is most commonly represented using Snellen ratio notation (e.g. <math><6/60</math>; Markowitz, 2006; Rahi & Solebo, 2012). The numerator indicates the distance from which the person being tested can see an object as clearly as a ‘normally-sighted person’ at the distance represented in the denominator (Rahi & Solebo, 2012); poorer visual acuity is conveyed with a larger denominator and smaller numerator. Meanwhile, visual field refers to the area that an individual can see with their eyes and head sitting still (and forward facing). It is measured in degrees: an average adult eye has a horizontal visual field of 160° and a vertical field of 135° (Rahi & Solebo, 2012).

Visual acuity and visual field measurements are employed to demarcate distinct categories of VI severity in many official definitions or systems of classification, including the WHO’s (2006) International Statistical Classification of Diseases and Related Health Problems (ICD-10) classification system for VI (Table 1.1). They also underlie legal definitions of blindness and are used to determine an individual’s eligibility for VI services. In Australia, for example, criteria for ‘legal blindness’ are a) a best-corrected visual acuity of <math><6/60</math> in each eye, b) a remaining visual field of <math><10</math> degrees in the stronger eye, or c) a combination of acuity and field loss representing equivalent impairment (Australian Government Department of Social Services, 2017). Meanwhile,

¹ Detailed definition and discussion of each of these characteristics is beyond the scope of this introduction. Description of these characteristics can be found in Rahi and Solebo (2012).

the visual function thresholds that young Australians must meet to be considered as having VI in order to be eligible for many VI services in Victoria (an Australian state) are a) a best-corrected visual acuity of <6/18 or b) a visual field of <20 degrees (Statewide Vision Resource Centre, n.d.-b; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015).

Table 1.1

VI Severity Levels in the WHO's ICD-10 (2006)

Clinical Characteristic	Mild or No Impairment	Low Vision		Blindness
		Moderate VI	Severe VI	
Visual acuity	>6/18	<6/18 - >6/60	<6/60 - >3/60	<3/60
Visual field	-	-	-	<10 degrees

Note: VI = Vision Impairment; WHO = World Health Organization; ICD-10 = International Statistical Classification of Diseases and Related Health Problems.

These visual function classifications offer one means of monitoring the prevalence of VI. Recent estimates from 2010 suggest that approximately 285 million people – or 4.2% of the world’s population – have VI worldwide, with approximately 246 million having low vision (<6/18 - >3/60) and approximately 39 million considered blind (Pascolini & Mariotti, 2012). VI is more prevalent in older populations (Table 1.2); nonetheless, its prevalence in younger populations is still salient when considered in light of the life of disadvantage that these younger individuals face. Furthermore, prevalence estimates vary across geographic locations (Gilbert & Ellwein, 2008; Gilbert & Foster, 2001; Gilbert & Muhi, 2008, 2012). It has been estimated that the percentage of children who are blind in Australia is relatively low at 0.03% (Rahi & Solebo, 2012).

In addition to classification based on a person’s remaining level of visual function, VI can also be categorized by its cause. VI in younger populations has numerous causes

that vary in preventability and treatability (Rahi & Solebo, 2012; Schwartz, 2010). Table 1.3 describes major categories of causes of VI that occur in younger populations.

Table 1.2

Global Prevalence Rates of VI by Age Group (Pascolini & Mariotti, 2012)

Age Group	Prevalence	
	<i>N</i> (million)	% (of global population)
50 years or older	186	13.9
15-49 years	80	2.3
0-15 years	19	1

Note: VI = Vision Impairment.

Table 1.3

Major Causes of VI in Younger Populations (Rahi & Solebo, 2012; Schwartz, 2010)

Type of Cause	Brief Description
Refractive Error	This arises due to treatable or correctable differences in the shape of one's eyes or ocular lens.
Retinal-level Causes	This can include retinal damage from congenital/genetic non-preventable and non-treatable dystrophies, or treatable developmental differences/scarring following premature birth.
Corneal-level Causes	This includes preventable and treatable corneal scarring/opacities from diseases or genetic conditions
Optic Nerve or Cortical-level Causes	This can include damage to the visual processing cortical pathways – including the optic nerve – by preventable diseases (e.g. meningitis), or non-preventable and non-treatable congenital/genetic conditions (e.g. Leber's congenital optic neuropathy)

Note: VI = Vision Impairment.

The prevalence rates of these causes also differ by geographic location. For example, in high income countries – such as Australia – inherited or congenital dystrophies or differences in the retina, optic nerve, and cortical visual pathway are the most prominent causes of VI in children (Gilbert & Foster, 2001; Rahi & Solebo, 2012). This is significant as these causes of VI are not preventable or treatable. Thus, educational and rehabilitation services are essential in effectively responding to the immediate and longer-term difficulties associated with childhood and youth VI (J. E. Brown, 2009), and promoting the wellbeing of the children and youth with VI in these countries.

Childhood and youth VI – and VI more generally – varies between individuals by age at onset. It can be present from birth congenitally (e.g. optic nerve hypoplasia) or as a genetic condition, like retinitis pigmentosa (Schwartz, 2010). Alternatively, it can have its onset at any stage during a young person’s life. Adventitious vision loss can occur gradually, as with some disease-related or genetic dystrophies, or rapidly such as through physical trauma (Schwartz, 2010). Further variability arises from comorbidities of VI with other conditions (e.g. hearing impairment, physical impairment) which may also affect a youth’s lived experiences (Erin & Toper, 2010a, 2010b).

Given this variability, each case of VI produces distinct and unique lived experiences for the youth. Available services must therefore account for this complexity.

1.2 An Overview of Vision Impairment Services

Multiple services are provided to promote the functioning and wellbeing for people living with VI, including youth² (Binns et al., 2012; Corn & Lusk, 2010; B. Ryan, 2014); a

² Many of the services described in this subsection are provided to people with VI across the lifespan (e.g. orientation and mobility training, magnification devices) and thus are not specific services provided to youth with VI. Nonetheless, given the focus of this thesis on youth with VI, for the sake of brevity and clarity of writing, I do not continue to explicitly highlight the provision or applicability of these services to younger or older populations, and will just refer to the provision of these services to youth with VI.

snapshot of such services is provided in Table 1.4 (below on page 21). As outlined in this table, these diverse services aim to address the varied difficulties associated with living with VI by providing youth – and, in some cases, their family – with differing strategies and resources (Gordon et al., 2015; Markowitz, 2006, 2016; P. S. Roberts et al., 2016). These services can be provided in a range of settings: inpatient and outpatient clinics; through schools; and, in self-management and group-based programmes (e.g. de Boer et al., 2006; Girdler, Boldy, Dhaliwal, Crowley, & Packer, 2010; Stelmack et al., 2008). Numerous health professionals deliver VI services, including clinical eye specialists (i.e. optometrists, ophthalmologists), general and specialist visiting teachers, occupational therapists, orientation and mobility (O&M) or vision rehabilitation specialists, social workers and counsellors (Binns et al., 2012; Corn & Lusk, 2010; P. S. Roberts et al., 2016; Scheiman, Scheiman, & Whittaker, 2007).

The historical complexity of the development of VI services across multiple spaces and institutions has contributed to this variability of contemporary VI services. Indeed, education, charity or not-for-profit, government, and clinical sectors have all been involved in the development of VI services (Goodrich & Huebner, 2010; Markowitz, 2016; B. Ryan, 2014; Studebaker & Pankow, 2004)

1.2.1 Educational vision impairment services

Education has been an especially important sector for the provision of VI services throughout history, starting with the first instantiation of specialized schools for the blind in the 18th century (Goodrich & Huebner, 2010; Studebaker & Pankow, 2004). Even at the start of the 20th century, no distinction was drawn in these educational institutions

between blindness and low vision³, and most specialist educators believed that preservation of residual vision through non-use was paramount. Consequently, all young people were educated as though they had no functionally usable vision. In contrast, a modern educational or habilitative approach to VI services – which primarily developed and grew to dominance in the second half of the 20th century (Goodrich & Huebner, 2010; Studebaker & Pankow, 2004) – focuses on the instruction of young people with VI in various skills and competencies for learning, interacting and functioning in their daily lives in alternative ways from birth, or in childhood and adolescence within their larger education (Hogg et al., 2017). Taking this approach, such educational services aim to enable children and youth with VI to establish these skills and competencies from early on so that they encounter fewer difficulties throughout their life. In recent decades, many such educational VI services have centred on the expanded core curriculum (ECC; Hatlen, 1996; Sapp & Hatlen, 2010). This is the case, for example, in Victoria, Australia – discussed further in Chapter 4 – where programs or services offered by both government and non-government providers often target the promotion of skillsets represented in the ECC (Hatlen, 1996; Sapp & Hatlen, 2010).

The ECC refers to a set of nine skill categories whose proponents assert within which students with VI should receive instruction in order to enable both their greater engagement with the standard curriculum and better post-secondary school outcomes as they transition into adulthood (see Figure 1.1 on page 23 for a list of the skill categories; Hatlen, 1996; Sapp & Hatlen, 2010). In its first incarnation, Hatlen (1996) described an

³ In the context of the historical development of VI services, ‘low vision’ is used to refer imprecisely to persons with VI retaining functionally usable vision as opposed to people with a complete (or at least functionally complete) lack of sight. No universally accepted definition of low vision exists, despite the use of the term in the WHO’s (2006) ICD-10 classification system for VI (Table 1.1). For a more detailed discussion of this terminology see Corn and Lusk (2010).

initial eight skillsets that he asserted were already well-established as beneficial for children with VI in practice by educators of students with VI, with the ninth skill category of ‘self-determination’ added in the early 2000’s as several academics in the field identified its importance (Agran, Hong, & Blankenship, 2007). The driving premise underlying the ECC – and habilitative VI services more generally – is that these skills are those that sighted children and youth acquire more passively through visual surveying and awareness in the many environments through which they pass (Hogg et al., 2017; Lohmeier, Blankenship, & Hatlen, 2009; Sapp & Hatlen, 2010):

“Sighted people usually select [recreational] activities by visually observing them and choosing those in which they wish to participate. Recreation and leisure skills must be deliberately planned and taught to blind and visually impaired students and should focus on the development of life-long skills” (Hatlen, 1996, p. 29).

By including them in the ECC, it is argued that youth with VI are intentionally and mindfully given these skills understood as important for independent adulthood.

Table 1.4

Strategies and Resources Provided to Youth receiving VI Services (Gordon et al., 2015; Markowitz, 2006, 2016; P. S. Roberts et al., 2016)

Strategy/Resource	Brief Description	Example Services
Information	Includes information both about the youth’s specific VI provided during initial/follow-up eye assessments, and information about other resources.	Information about their specific VI will be provided to the youth as part of formal visual function assessments conducted by clinical eye specialists. Information about additional resources will be provided throughout the provision of many services by many different service professionals. For example, information about and assistance in seeking available education funding may be provided by specialist visiting teachers as part of the educational supports they provide.
Optical Aids/Techniques	Includes behavioural techniques and equipment/technologies which facilitate the youth’s performance of tasks/activities through their adapted use of their remaining vision (e.g. magnification, scene-scanning techniques).	Optical techniques and aids are provided as part of occupational therapy, training in the use of assistive technology/equipment or O&M training: the latter denotes specialized training provided to people with VI to enable their independent travel in society. Predominant professionals involved in instruction around these techniques and aids are O&M specialists, occupational therapists, assistive technology specialists, specialist visiting teachers, dog guide instructors and, to some extent, clinical eye specialists.
Non-optical Aids/Techniques	Includes behavioural techniques and equipment/technologies which do not utilize the youth’s remaining vision, and instead promote their performance of tasks/activities through the use of their other sensory or cognitive capacities (e.g. white cane, echolocation, pneumatic tricks, Braille).	Non-optical techniques and aids are provided as part of the same services as the above optical aids and techniques. Predominant professionals involved in instruction around these techniques and aids are O&M specialists, occupational therapists, assistive technology specialists, specialist visiting teachers and dog guide instructors.

Strategy/Resource	Brief Description	Example Services
Environmental Modifications	Includes proposed changes to regular environments with which youth engage (e.g. tactile indicators, changes to environmental lighting).	These environmental changes are commonly proposed or implemented as part of O&M training, occupational therapy, or educational support services. Clinical eye specialists can also propose some environmental modifications.
Psychosocial Supports and Resources	Includes behavioural/cognitive strategies or skills that enable the youth to respond to the psychological or social difficulties associated with VI (e.g. coping techniques, self-advocacy/social skills). In addition to these individual strategies or skills for the youth, some services and programs seek to provide or refer a younger person to direct resources addressing psychosocial impacts associated with VI,	The promotion of specific strategies or skills for handling the psychosocial impacts associated with VI among youth is targeted through services, such as individual counselling or group skill development programs. Advocacy services can offer youth direct assistance in resolving difficulties. Meanwhile, the connection of young people with peer communities and recreation programs seeks to directly promote their social and recreational activity. Predominant professionals involved in the provision of such resources include advocates, psychologists, counsellors, social workers, recreation officers and specialist visiting teachers.

Note: VI = Vision Impairment; O&M = Orientation & Mobility.

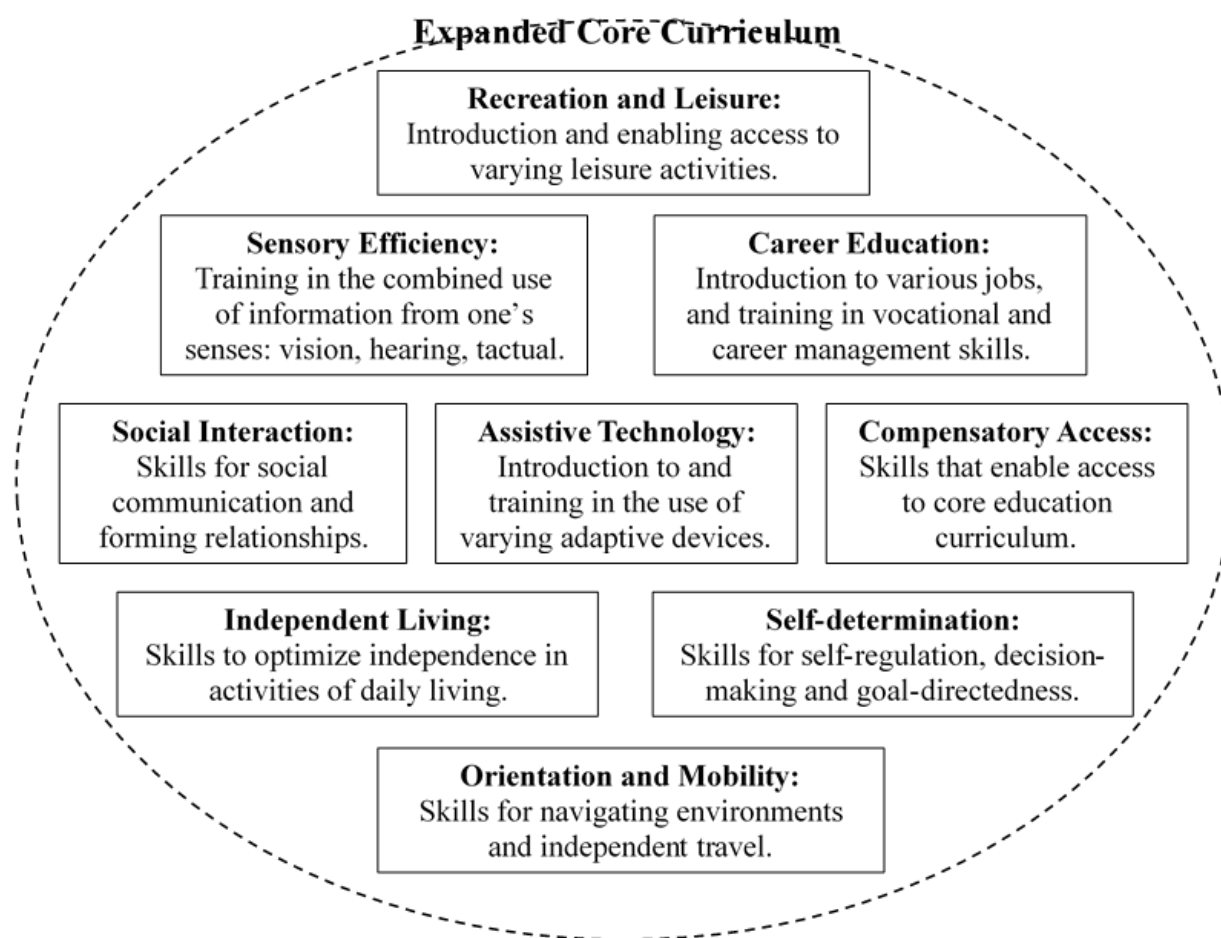


Figure 1.1. The components of the expanded core curriculum (Hatlen, 1996; Lohmeier, Blankenship, & Hatlen, 2009; Sapp & Hatlen, 2010).

The ECC is presented as an essential part of one complete curriculum – along with generic elements of the core curriculum (e.g. literacy, mathematics) – for children and youth with VI (Hatlen, 1996; Sapp & Hatlen, 2010). As such, the ECC positions the provision of VI services as an indispensable part of larger education, ideally occurring primarily within an individual's educational setting, irrespective of its inclusive or specialized nature. Visiting teachers of students with VI or O&M specialists are frequently the primary professionals responsible for ensuring that students with VI receive instruction in all categories of the ECC alongside the general core curriculum; the latter of which is taught by regular class teachers (Lohmeier et al., 2009; Sapp & Hatlen,

2010). Specialist educators facilitate this through multiple means; for example, they may include direct instruction on a skillset or incorporate instruction or practise regarding a skill category into lessons which form part of the general core curriculum. Further education in certain ECC skill categories (e.g. recreation and leisure) may be facilitated through specialized programs attended by the student with VI following a referral by the visiting teacher or O&M specialist. In practice, the visiting teacher or O&M specialist will tailor the strategies to the youth based upon an initial assessment of the student's performance of each skill and educational needs (Lohmeier et al., 2009; Sapp & Hatlen, 2010).

1.2.2 Rehabilitation or clinical vision impairment services

Alongside this provision within the education sector, VI services – often labelled ‘[low] vision rehabilitation’⁴ – are provided within other societal sectors (Goodrich & Huebner, 2010; Markowitz, 2016; B. Ryan, 2014). The distinction between educational VI services and vision rehabilitation is largely a product of their historical development. Vision rehabilitation developed as a field during the 20th century in response to the increasing majority subpopulation of adults with low vision within the larger VI population, following increased traumatic vision loss during the World Wars and age-related vision loss driven by medical advancement⁵ (Goodrich & Huebner, 2010; Markowitz, 2016). Thus, as opposed to educational services which occur from the early years of a person's life, vision rehabilitation was historically provided to individuals with adventitious vision

⁴ Much of the published literature refers to ‘low vision rehabilitation’. Although it is clear in the writing of some authors that they are specifically referring to rehabilitation services provided to people with some remaining sight (e.g. Markowitz, 2016), others also describe services provided to both people who are totally blind and who have partial sight despite discussing ‘low vision rehabilitation’ (e.g. Binns et al., 2012). Given I am referring to services provided to youth with all levels of VI, I use ‘vision rehabilitation’.

⁵ In the 19th and early 20th century, the children experiencing congenital VI represented the majority of the VI population (Markowitz, 2016).

loss to facilitate their reacquisition of functioning previously performed with their greater visual function capacities prior to their vision loss. Although the majority of vision rehabilitation users are still adults with adventitious VI in the contemporary context – due to their greater incidence (Pascolini & Mariotti, 2012) – the complementary and overlapping nature of educational VI services and vision rehabilitation for service provision to younger VI populations is now acknowledged and emphasized (Corn & Lusk, 2010; Gordon et al., 2015).

Vision rehabilitation services can be provided to youth with VI in various settings: community-based charity or not-for-profit organizations; government departments or clinics (e.g. the US Department of Veteran Affairs; Stelmack et al., 2008); and, by private practitioners. The specific services provided within these distinct settings vary in their objectives of focus and intensity. This variability in service delivery is captured within the WHO's three-levelled model of service provision for low vision care depicted in Figure 1.2 (Markowitz, 2016; B. Ryan, 2014; Vasconcelos & Fernandes, 2015). For example, in addition to diagnosis and the provision of medical and surgical treatments of eye conditions, private or public system clinical eye specialists can provide specific low vision rehabilitative services. Located at the secondary-level of the WHO's model, these services are focused on the provision of magnification and advice regarding the visual optimization of specific environments to enable youth with remaining vision to better perform vision-dependent tasks/activities (Minto & Awan, 2004; Vasconcelos & Fernandes, 2015; Wong, O'Connor, & Keefe, 2011). Meanwhile, at the tertiary-level, not-for-profit organizations or government clinics deliver a wider complement of services (listed earlier in Table 1.4 on page 21) to both youth with remaining sight and youth without usable vision. This array of services is provided by a team of specialists, which may again include ophthalmologists or optometrists among many others professionals (B.

Ryan, 2014; Vasconcelos & Fernandes, 2015). The WHO proposed this three-levelled model as a means to enable the comprehensive delivery of eye care and vision rehabilitation services. As depicted in Figure 1.2., each level of service provision fulfils a particular role and meets the needs of particular subpopulations of youth with VI, and is interconnected with the other two levels through processes of referral to ensure that each youth receives the particular level of service provision that matches their needs and circumstances (B. Ryan, 2014; Vasconcelos & Fernandes, 2015).

Despite recognition of the value of this levelled approach to service provision, the multidisciplinary model – positioned as the tertiary-level of the WHO’s model of low vision care (B. Ryan, 2014; Vasconcelos & Fernandes, 2015) – remains commonly identified as the model of best practice for vision rehabilitation (Binns et al., 2012; Corn & Lusk, 2010; Gordon et al., 2015; P. S. Roberts et al., 2016). It has been specifically endorsed for service provision to younger populations with VI (Gordon et al., 2015; Low Vision Services Group - Children's Sub Committee, 2010; Rahi & Solebo, 2012). This is the case in Victoria – and Australia more generally – where vision rehabilitation services are almost entirely delivered at the tertiary-level of the WHO’s model through multidisciplinary teams based in the not-for-profit sector (Wong et al., 2011). Given the prominence of the multidisciplinary model of vision rehabilitation in Victoria, I now provide a brief description of the processes and principles of service provision within this model⁶.

⁶ The trajectory of the service components in the model described in the next subsection is an ideal, and in practice their timings vary and overlap.

Primary-level services focus on:

- Screening for VI, and referral to secondary- and/or tertiary-level services by various community-based professionals (e.g. general practitioners, community outreach centres).
- Providing guidance on basic environmental and optical strategies.
- VI prevention through treatment of eye infections and initiatives, such as vaccination.

Secondary-level services focus on:

- Assisting people with remaining vision who are seeking to engage with print or perform other visual tasks.
- Assessment of visual function and low vision by clinical eye specialists (e.g. ophthalmologists, optometrists, orthoptists).
- Instruction by these clinical specialists in optical, environmental and basic/essential adaptive technology strategies.
- Referral to other educational, financial and/or tertiary-level services where necessary.
- Medical management of some ocular issue (e.g. corneal trauma) and provision of prescription glasses.
- Maintaining contact with tertiary-level service recipients.

Tertiary-level services focus on:

- Assisting people with VI with more sophisticated/complicated needs.
- Holistic assessment of the person with VI: visual function, low vision and other elements relevant to their functioning and wellbeing.
- Provision of a wide range of different but interrelated services by a multidisciplinary team spanning various specialties (e.g. O&M specialists, occupational therapists).
- Provision of optical and non-optical assistive equipment/technologies.
- Referral to and/or collaboration with other education or community-based rehabilitation services.

Figure 1.2. Three levels of service provision for low vision care proposed by the World Health Organization (B. Ryan, 2014; Vasconcelos & Fernandes, 2015). *Note:* VI = Vision Impairment; O&M = Orientation and Mobility.

1.2.3 The multidisciplinary model of vision rehabilitation

Following self-referral, or referral from primary- or secondary-level care providers within the WHO's model (Figure 1.2; B. Ryan, 2014; Vasconcelos & Fernandes, 2015), multidisciplinary vision rehabilitation commences with a multi-staged intake process. An initial consultation assesses the youth's personal, vision-related and larger medical history (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007); depending on age, this consultation may involve parents/guardians. Where relevant, any medical and surgical treatments can then be pursued, while the youth's remaining vision-related difficulties are evaluated through both in-depth visual function and functional vision examinations. Information regarding the youth's visual function and functional vision may also be drawn from assessments performed by clinical eye specialists at the secondary-level of service provision handed over during the referral process. Visual function assessments examine the various clinical indicators used to capture the perceptual or sensory performance of the eye and its multiple structures, while functional vision assessments examine the person's ability to successfully perform tasks and engage in activities recurrent in their everyday life with their remaining visual function (Lepri, 2009; Markowitz, 2006). The latter includes both 'activities of daily living' – that is, the tasks involved in looking after one's self (e.g. preparing food, bathing) – and 'instrumental activities of daily living' – which are tasks directed at environmental interaction (e.g. navigating the community, using communication technology) that are somewhat more discretionary (Scheiman et al., 2007). The person's reasons for and goals in seeking VI services should also be collected during their intake (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007).

The complete information obtained through this intake process is then used to guide the particular set of services provided to the youth with VI. Optical, non-optical and environmental modification strategies are recommended to aid the youth in handling any difficulties in visual function and functional vision they encounter. This may include the provision of both basic and sophisticated optical devices (e.g. light-modulating lenses, magnifiers), as well as other advice regarding, for example, the management of environmental light conditions (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007). It also could involve training regarding aids for mobility, such as white canes and dog guides; devices with electronic screen-reading software that convert print/written text into speech for accessing documents; and, strategies such as Braille labels or tactile markers for greater self-sufficiency with household objects, utensils or appliances (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007).

Depending on the priorities and needs of the youth with VI, other services are incorporated into tertiary-level multidisciplinary vision rehabilitation in order to address broader domains of life beyond the youth's visual function and functional vision (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007). For example, if the youth reported or it is observed that they are encountering psychological, emotional or social difficulties during the initial intake process, then services can be provided to support them. Such services could include individual counselling sessions, group-based therapy, or assistance in accessing available community resources and in sourcing social support (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007). Similarly, and tying in with the educational services and instruction regarding the ECC (Hatlen, 1996; Sapp & Hatlen, 2010), if the youth is encountering difficulties in their participation at school then

a visiting teacher or O&M specialist can be sent to their school to assist the youth in advocating for the supports and accommodations they require (Gordon et al., 2015; Low Vision Working Group, 2007; Markowitz, 2006; Scheiman et al., 2007).

The literature reviewed in this subsection demonstrates that, despite the historical complexity of their development and their remaining diversity, certain features of rehabilitative or habilitative VI services have become established. These services are generally provided by a network of specialist professionals – working alongside and within the larger health and education systems – in order to address the impact of VI across multiple life domains. They are primarily focused on providing individuals with adaptive skills and strategies, but in some cases, do engage in individual-level or political advocacy. The establishment of these overarching features of VI services has also been accompanied by questions regarding their effectiveness. I discuss this research below.

1.2.4 The effectiveness of vision impairment services

In line with the importance placed on ‘evidence-based practice’ in contemporary medicine and healthcare (Craig & Bigby, 2015; Houston, 2001, 2005, 2010), increasing research around VI services has examined the effectiveness of their provision in promoting the wellbeing of people with VI (Binns et al., 2009, 2012; Rees, Ponczek, Hassell, Keeffe, & Lamoureux, 2010). Research on the effectiveness of vision rehabilitation indicates that the success of such services in terms of decreasing recipients’ levels of psychopathology, or their scores obtained for psychometric measures of other psychological (e.g. self-esteem) or quality of life (QoL) outcomes, are inconsistent, especially over the longer-term (Binns et al., 2009, 2012; Rees et al., 2010). Improvements on these indicators are not regularly the focus of research and, where they are discussed, evidence indicates they are poorly understood. More frequent

improvements with regard to psychological outcomes have been obtained from models of service provision that include service components deliberately intended to target psychological outcomes. This has included individual counselling or group programs aimed at bolstering the individual's psychological/internal resources (e.g. problem-solving skills and strategies; Girdler et al., 2010; Horowitz, Leonard, & Reinhardt, 2000; Needham, Acton, & Eldridge, 1992). However, even these programs have been found to be ineffective in recent randomized controlled trials (Rees et al., 2015), and any resultant benefits with regard to psychological health outcomes are increasingly inconsistent at longer follow-ups (Rees et al., 2010). For example, while one non-randomized control trial promoted greater adaption to vision loss for those enrolled in a problem-focused strategy group program compared to both a control group and an emotion-focused strategy group program, it was also associated with increased depression symptoms at a two month follow-up (Wahl et al., 2006).

These inconsistent findings were evident in two recent systematic reviews that compared findings from studies evaluating VI services that differed in terms of: number of health professionals involved; services provided; provision location (e.g. inpatient, outpatient); and delivery format (e.g. group, individual; Binns et al., 2009, 2012; Rees et al., 2010). In their review of 58 studies across all age-groups, Binns et al. (2009, 2012) found that the studies provided reasonable evidence affirming the association between VI services and improved functional outcomes; this did not extend to psychosocial and QoL outcomes. Similar inconsistent findings were found in Rees et al.'s (2010) review of 30 adult studies concerned with psychological and QoL outcomes. The available evidence is therefore suggestive of greater effectiveness for VI services in improving functioning rather than psychosocial outcomes for people with VI.

Where it has occurred, the majority of research evaluating the effectiveness of VI services at promoting psychosocial or QoL outcomes has been conducted in adult or elderly populations. Rees et al. (2010) excluded research in populations younger than 18 years of age, and the majority of studies in Binns et al.'s (2009, 2012) review were conducted among the elderly. A very limited number of studies have evaluated the effectiveness of any VI services in younger populations. Binns et al. (2012) emphasized that, at the time of their review, “no rigorous studies of interventions relevant to children” (p. 57) had been performed, citing only a few studies focused on adaptive technology use and resultant improvements to functional performance in daily life (e.g. reading ability, motor skills; Aki, Atasavun, Turan, & Kayihan, 2007; Corn et al., 2002; Rudduck, Corcoran, & Davies, 2004). Binns et al. (2012) further suggested that the limited research attention paid to children may, in part, stem from a lack of outcome measures for their broader QoL that are specifically sensitive to their experiences. However, although such measures have since been developed (e.g. Khadka, Ryan, Margrain, Court, & Woodhouse, 2010; Rahi, Tadic, Keeley, & Lewando-Hundt, 2011), none of 27 trial studies among younger populations with VI more recently reviewed examined psychological or broader wellbeing outcomes (Chavda, Hodge, Si, & Diab, 2014).

This is not to say that no research has examined, nor offered insight into the services or programs effective at promoting wellbeing – including psychological health – in younger populations with VI. A handful have explored the relationship of particular interventions – including visual perceptual training, peer support and recreation programs – to certain psychological outcomes, finding mixed results (Başakci Çalik, Kitiş, Cavlak, & Oğuzhanoğlu, 2012; Bowen, 2010; Dursun et al., 2015; Goodwin, Lieberman, Johnston, & Leo, 2011). Başakci Çalik et al. (2012) found that participation in three 30-minute attentional capacity training sessions over a six-week period by 10 preteens with

VI was associated with significant improvements in their performance of daily activities (when both objectively- and self-rated); such improvement was not observed among a control group of 10 preteens with VI. However, this attention training program was accompanied by no significant improvement in either groups' self-reported psychological adjustment scores. In contrast, Bowen (2010) reported improvements in self-esteem among four adolescents with VI following the individualized combination of one-on-one mentoring and peer support group programs, and Joshi, Yamagata, Akura, and Shakya (2008) found that teachers of students with VI reported the increased academic self-confidence of these students following their use of magnification aids. Meanwhile, although visual appraisal of self-esteem scores suggested their elevation for some young adults with VI accompanying their regular participation in a martial arts program (Qasim, Ravenscroft, & Sproule, 2014), other research has found a contrasting effect of other recreation programs. Dursun et al. (2015) found that preteen and teenage participants with VI experienced significantly reduced self-esteem after participation in an ice-skating recreation program, as well as poorer social relations; although, these young people also reported significantly reduced emotional difficulties. Finally, qualitative explorations suggest that youth with VI perceive such recreation programs as important for providing them with social relationships with people with similar experiences, a valuable contribution to their sense of self, a sense of competence and autonomy, and a platform through which to resist oppressive beliefs about themselves (Goodwin et al., 2011; Jessup, Cornell, & Bundy, 2010).

In addition to the mixed findings from these individual trials and case studies, a reasonable body of literature exists evaluating the delivery of the ECC or the effectiveness of certain interventions in promoting specific skillsets among youth with VI (Furtado et al., 2015; Haegele & Porretta, 2015; Lewis, Savaiano, Blankenship, &

Greeley-Bennett, 2014). However, this research has primarily focused on the success of such interventions at developing the skillsets among the students with VI, with only a few studies then extending out to determine whether this translates to the promotion of broader psychological or QoL outcomes. Botsford's (2013) meta-analysis of three studies reporting on findings from the National Longitudinal Transition Study 2⁷ (NLTS-2) regarding the later employment or post-secondary education/training of youth with VI represents one example of the latter. It showed a significant positive correlation between social skill instruction and greater achievement of employment or post-secondary education or training; social skill instruction accounted for 6% of variance. Monson (2009) also undertook a secondary analysis of NLTS-2 data to examine the impact of instruction in the ECC categories on post-secondary QoL outcomes. This included indicators of positive feelings and progress in adopting adult roles. They found that those who received ECC instruction in secondary school had significantly poorer post-secondary QoL outcomes; an unanticipated finding that may result from time spent receiving specialized education removed from peers. Those who spent less time in such education had higher post-secondary QoL outcomes suggesting that provision of VI services to youth with VI in specialized settings may actually be unhelpful (Monson, 2009). Monson also found that instruction in different ECC components were differentially associated with post-secondary QoL outcomes. Instruction in some components (e.g. assistive technology, social interaction skills) significantly predicted poorer outcomes. In contrast, instruction in self-determination and independent living were found to be particularly strong and positive predictors of post-secondary outcomes. The difference in direction of these predictions suggests that the relationship between ECC instruction and wellbeing is complex and indicates the need for further explanation

⁷ For further information regarding the NLTS-2 refer to <https://nlts2.sri.com/>

of why certain ECC skill instruction is related to an increase in wellbeing among youth with VI, and others a decrease.

Studies such as Monson's (2009) and Botsford's (2013) not only provide valuable evidence regarding how the provision of VI services to youth is related to their wellbeing, but also highlight several further topics for inquiry regarding these services. For example, while they provide some insight into the longer-term correlates of ECC instruction, questions regarding the concurrent effects of this instruction on youth wellbeing also deserve attention. In particular, Monson's (2009) work identifies the necessary intricacy in providing services to youth with VI and calls on ongoing research to determine the (likely dynamic) parameters of positive VI service delivery: for example, whether it should occur in specialized or 'mainstream' settings. Furthermore, existing findings from research evaluating interventions targeting ECC skill categories more generally suggest that continued work in developing and trialling these interventions is needed (Furtado et al., 2015; Haegele & Porretta, 2015; Lewis et al., 2014). This includes findings that instruction in the categories, provided to young people with VI by specialist educators, often favours certain skillsets over others, due to time constraints and competing demands (Sapp & Hatlen, 2010). The skill categories more removed from general schoolwork (e.g. self-determination, recreation and leisure) receive both less, and more unstructured attention (Agran et al., 2007; Lohmeier et al., 2009; Wolffe et al., 2002).

The need for further research and knowledge development with regard to VI services more generally in light of the reviewed evidence of their inconsistent relationship with improvements in psychological health and wellbeing indicators has been highlighted (Binns et al., 2009, 2012; Rees et al., 2010). In particular, Rees et al. (2010) and Binns et al. (2009, 2012) identified the need for future research to determine the particular interventions or features of service delivery that are responsible for improvements in

wellbeing indicators when they do arise, including the development or identification of useful theory for understanding the mechanisms or factors at play (Binns et al., 2009, 2012; Rees et al., 2010). Although some previous research has found improvements in recipients' levels of psychopathology, self-esteem or self-rated QoL, knowledge of why these improvements have occurred is limited, which in turn makes the transfer of this knowledge across settings difficult. This need for greater clarity and understanding around which particular services, or components of service delivery, are the responsible agents for observed improvements in wellbeing is also aligned with larger critiques of contemporary healthcare service provision (Craig & Bigby, 2015; Houston, 2001, 2005, 2010). Both Craig and Bigby, and Houston argue that, due to their emphasis on evidencing their effectiveness in promoting outcomes desired by their 'consumers', research has centred on trials seeking to demonstrate the predictability of these outcomes following particular services. The primacy placed on evidence of a predictable relationship between a service and the desirable outcome has diminished the research attention devoted to theoretically understanding and explaining the actual relationship, even in the face of conflicting evidence that demands such explanation. In the following chapters, I contend that such a theoretically critical approach is required to advance the development of VI services to enhance their effectiveness in promoting wellbeing for youth with VI.

Chapter 2

Problematizing our understanding of ‘living well with vision impairment’

Much discourse and research regarding contemporary health services, including the VI services discussed in Chapter 1, is focused on their delivery and whether they facilitate the achievement of desirable health outcomes – whatever they may be (e.g. wellbeing, improved daily functioning). This focus is tied to the emphasis on ‘evidence-based practice’ dominant in medicine and broader healthcare disciplines (Greenhalgh, Howick, & Maskrey, 2014; A. Petersen, 2015; Rousseau & Gunia, 2016). Evidence-based practice holds that treatments or services provided by healthcare professionals to ‘consumers’ should be informed by consideration of evidence regarding the effectiveness of the intervention in promoting the particular health-related outcome (Greenhalgh et al., 2014; Rousseau & Gunia, 2016). That is, interventions shown to promote better health, functioning, wellbeing or another outcome of interest, should inform decisions about best practice. While service provision should be guided by evidence, the general processes of determining what services and interventions are supported by evidence privileges certain forms of research evidence over others (Craig & Bigby, 2015; Houston, 2005, 2010). Statistical evidence of an effect obtained through randomized controlled trials (RCTs) is positioned as providing the strongest and most credible support for an intervention’s effectiveness (Haegle & Porretta, 2015; A. Petersen, 2015).

A particular critique of the processes of evidence-based practise – which I argue is especially relevant to my work to develop our understandings of wellbeing among youth

with VI to inform service provision to this population – is that an associated prioritization of evidence from intervention trials means that less attention is given to how the concepts that inform outcomes are defined. One manifestation of the influence of neoliberal ideologies in medicine and health⁸, a reduction in theoretical engagement with and thus development of outcomes – such as ‘wellbeing’ or ‘QoL’ – has been highlighted, because health services are focused on delivery and on achieving these outcomes as implicitly understood (Craig & Bigby, 2015; Houston, 2001, 2005, 2010). These services assume that a common conception of wellbeing – including the mechanisms that support it – applies universally to all people (S. Atkinson, 2013). Furthermore, this limited conceptual consideration hinders the ability of service providers to effectively utilize the considerable research evidence that is produced. With only limited underpinning theory to guide and unite them, too much variation exists across selected outcome measures and, in some cases, the trialled interventions to make any meaningful comparisons and thus conclusions about best practice (Craig & Bigby, 2015; Houston, 2010).

These shortcomings of the focus on evidence-based practice are readily apparent in extant research examining the effectiveness of VI services in promoting wellbeing (Binns et al., 2012; Rees et al., 2010). Within this literature reviewed in Chapter 1, considerable emphasis has been put upon the need for continued trials of different interventions and models of service delivery in order to develop our understandings of how VI services can bolster psychological or QoL outcomes, and thus help rectify

⁸ A broader discussion of the influence of neoliberalism on the health sector is beyond the focus of this chapter or thesis. For an overview of such influences, including the greater marketization of health products and services, the discursive emphasis placed upon the ‘choice’ and ‘responsibility’ of healthcare ‘consumers’, and the formation of active consumer groups regarding specific conditions, please refer to A. Petersen, Davis, Fraser, and Lindsay (2010).

demonstrated inconsistencies in their effectiveness with regard to these outcomes (Binns et al., 2012; Haegele & Porretta, 2015; Lewis et al., 2014; Rees et al., 2010). The importance of further RCTs to develop our knowledge-base is stressed, including several trials underway during my doctoral candidature (Margrain et al., 2012; Rees et al., 2015). For example, B. Ryan (2014) highlighted a then current RCT being done to unravel some of these inconsistencies (i.e. Christy, Keeffe, Nirmalan, & Rao, 2010). She stated: “It is hoped that the randomised controlled trial underway to compare the effectiveness of four different strategies to deliver low vision rehabilitation services, including the addition of homebased rehabilitation, will provide a useful addition to the evidence” (B. Ryan, 2014, p. 211).

In addition, recent systematic reviews regarding interventions for youth with VI targeting their physical health and activity – outcomes commonly connected with wellbeing (Cahill, 2015; Eime, Young, Harvey, Charity, & Payne, 2013; Nussbaum, 2005) – highlighted the difficulty of determining best practice from available research (Furtado et al., 2015; Haegele & Porretta, 2015). Both Haegele et al. and Furtado et al. indicated that a contributor to this inconclusiveness is the limited theoretical grounding of these interventions. Meanwhile, broader reviews of VI services have also highlighted the need for stronger theoretical foundations for interventions targeted at psychological or QoL outcomes (Rees et al., 2010).

VI services are based on an implicit understanding of wellbeing, and the factors and mechanisms that support it. Precisely because they inform service delivery, we need to unpack these assumptions. In order to address the inconsistent evidence regarding the effectiveness of VI services in promoting wellbeing among people with VI, it is important to develop our understanding of wellbeing for these populations. Greater direct interrogation of the concept of wellbeing – by engaging with people with VI qualitatively

and not simply through continued RCTs – will enable us to deepen the theoretical grounding of the services trialled and then provided by VI service organizations, and thus more efficacious service provision (Craig & Bigby, 2015; Houston, 2001, 2005, 2010).

In the remainder of this chapter, I commence this theoretical engagement – the central project of my thesis – in two main ways. First, I elucidate the implicit conceptualization of what it means to ‘live well with VI’ that grounds contemporary approaches to service provision among youth with VI. This conceptualization is embedded within larger discussions of wellbeing among people with disabilities. Therefore, in the first section of this chapter, I provide an overview of the dominant personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000) and the particular approach to understanding wellbeing for people with disabilities it produces. In the second section, I return to the specific context of VI, and demonstrate the presence of this personal tragedy model and an associated understanding of what it means to live well with VI at the heart of VI service provision. Then, I move onto the chapter’s second purpose in the third and final section. I argue that this conceptualization of living well with VI informed by the personal tragedy model does not adequately explain the wellbeing of youth with VI and as such contributes to the inconsistent effectiveness of VI services at promoting this outcome. I conclude by presenting my aim in this thesis of contributing to the development of our theoretical understanding of what it means to live well for youth with VI by capturing the voices of the youths themselves.

2.1 Wellbeing and Disability: An Overview

Wellbeing is a widely-used concept in everyday life, politics, policy and academia; however, despite its pervasiveness, a consistent and clear definition remains elusive

(Cahill, 2015; Dodge, Daly, Huyton, & Sanders, 2012; Wallander & Koot, 2016). Discussions around the definition of wellbeing and related concepts (e.g. ‘the good life’, ‘QoL’)⁹ span many disciplines, such as philosophy, psychology, medicine and economics (Ben-Arieh et al., 2014; Cahill, 2015; Manderson, 2005). A person’s wellbeing is generally the extent to which their life is characterized by positive experiences and enriched quality, and not just the absence of disease, disadvantage or suffering. This vague definition is insufficient to inform policy and practice targeting its promotion. Thus, the question “what precisely constitutes a life of positive experiences and enriched quality?” has been answered by philosophers, social and biomedical researchers, economists, political activists and healthcare practitioners with reference to both objective and subjective understandings of wellbeing (Bickenbach, Felder, & Schmitz, 2014; I. Brown, Hatton, & Emerson, 2013; Parfit, 2003; R. M. Ryan & Deci, 2001).

Subjective theories of wellbeing or QoL hold that no universal criteria by which the quality of each person’s life can be evaluated and compared exist, and instead asserts that wellbeing should be understood and evaluated with regard to the person’s perspective about how satisfied they are with their life in relation to their own personal values and criteria (Diener, Napa Scollon, & Lucas, 2009; Diener & Ryan, 2009; Parfit, 2003). Concepts of hedonic wellbeing capture this approach. In its traditional form, hedonism champions the doctrine that a person who is well has high levels of positive affect (e.g. joy, excitement) and low levels of negative affect (e.g. sadness, anger), with these being the sole outcomes of intrinsic value (Deci & Ryan, 2008; R. M. Ryan & Deci, 2001; R. M. Ryan, Huta, & Deci, 2008). This stance met criticism on the grounds that all human wellbeing and motivations cannot be reduced to the promotion of positive affect and

⁹ The terms ‘wellbeing’ and ‘QoL’ are often used interchangeably, and while some scholars draw a distinction between the two (e.g. Dodge et al., 2012; Lent, 2004), the distinctions they draw are not consistent. Therefore, in reviewing previous literature, I opted to use the terms interchangeably so as to facilitate more comprehensible engagement with work discussing both concepts.

reduction of negative affect (Ryff, 1989; Seligman, 2011). Some people pursue meaning or social relationships despite such pursuits, in some instances, proving arduous. In contrast to such traditional hedonism, modern psychological stances associated with hedonism opt for more inclusive definitions of “pleasure” and “displeasure” (R. M. Ryan & Deci, 2001, p. 144). Acknowledging that people have various values, psychological theories of hedonic wellbeing posit pleasure/satisfaction and displeasure/dissatisfaction as larger concepts encompassing fulfilment of a person’s preferences (R. M. Ryan & Deci, 2001), in order to avoid an ‘expert’-derived prescriptive definition of wellbeing’s constitution (Diener, Sapyta, & Suh, 1998). An individual’s cognitions (i.e. their thoughts about their QoL termed ‘life satisfaction’) and affective states (i.e. the emotions and mood state they experience in response to their life) are considered in the measurement of wellbeing as representations of that individual’s evaluations of the fulfilment of their preferences and values. The overall resultant degree to which a person positively or negatively evaluates their life, it is argued, reflects their level of subjective wellbeing (Diener et al., 2009; Diener & Ryan, 2009; Diener et al., 1998).

In contrast to subjective theories, objective theories of wellbeing or QoL maintain that there are criteria of life quality which are universally applicable to all people (Bickenbach et al., 2014; Parfit, 2003; R. M. Ryan & Deci, 2001; Wallander & Koot, 2016). Thus, the evaluation of wellbeing entails the examination of the level of each of these elements in a person’s life often in comparison to those possessed by others. The model of QoL developed and employed in the work of Robert Schalock and Miguel-Angel Verdugo provides one prominent example of such an objective conception of wellbeing (Schalock, 2004; Schalock, Verdugo, Gomez, & Reinders, 2016). Following a wide review of academic literature regarding QoL across multiple specific areas of study (e.g. intellectual disability, aging), Schalock and Verdugo identified eight key life

domains. These were emotional wellbeing, physical wellbeing, material wellbeing, self-determination, personal development, interpersonal relations, social inclusion, and rights (Schalock, 2004; Schalock et al., 2016); a brief description of each is provided in Table 2.1. This list represents only one published set of domains proposed to constitute QoL. Others have postulated alternative collections of domains (for examples see I. Brown et al., 2013); however, many of the eight domains endorsed by Schalock and Verdugo are commonly identified in other models, including in models developed from the voices of children and youth (Bourke & Geldens, 2007; Fattore, Mason, & Watson, 2009). For example, conducting interviews with young people and youth worker's living in rural Victoria, Australia, Bourke and Geldens (2007) found that the two groups identified key dimension of wellbeing as including their relationships, their emotional wellbeing, their goals and sense of self (i.e. personal development), their physical health, and the characteristics of their social environments (i.e. social inclusion).

Table 2.1

Eight Quality of Life Domains identified by Schalock and Verdugo (Schalock, 2004; Schalock et al., 2016)

Domain	Description of the Domain
Emotional wellbeing	The person's affective experience and cognitive appraisals, including with regard to their self (i.e. self-concept, self-esteem) and their level of stress.
Interpersonal relations	The types and level of social interaction experienced by the person (e.g. familial, friendships, romantic) and the support this provides them.
Material wellbeing	The person's fiscal and housing situation.
Personal development	The person's level of education, their skillsets (e.g. cognitive, practical), and their actual levels of achievement and success.
Physical wellbeing	The person's experience of illnesses or functional limitations, their satisfaction of their bodily needs (e.g. nutrition) and promotion of their fitness, and their engagement in common daily tasks and activities of recreation.
Self-determination	The person's ability to identify and pursue their personal goals and aspirations with autonomy and independence, as well as their level of choice and opportunity.
Social inclusion	The extent to which the person is involved in their community, and the supports available to them through this participation.
Rights	The level to which the person is afforded their human and legal rights.

In addition to these theoretical distinctions between subjective and objective wellbeing, similar debates exist regarding how to measure wellbeing within these different conceptions. In particular, questions about what indicators should be used, and whether these indicators should be measured through objective or subjective means predominate. For example, while self-report measures of life satisfaction and affective

experiences are most prominently utilized, Diener and Ryan (2009) highlighted that diverse indicators – both objective (e.g. physiological signs of emotion) and subjective (e.g. self-reported life satisfaction) – can be used as indicators of a person’s subjective wellbeing. Meanwhile, with regard to objective theories, considerable discussion has occurred around what indicators to use to best tap into the domains postulated to comprise wellbeing or QoL. Such objective models of wellbeing have employed indicators, such as a person’s possession of material resources, their exhibition of certain observable behaviours considered to represent well- or ill-being (e.g. risk-taking behaviours among youth), and the person’s own self-ratings of their wellbeing on psychometric quantitative measures (I. Brown et al., 2013; Cummins, 2005; Wallander & Koot, 2016). The latter questionnaires, although capturing the participant’s subjective perspectives, do in themselves restrict the indicators of wellbeing considered by stipulating the domains within which they ask individuals to rate their wellbeing or QoL, with different measures incorporating different domains. For example, some are predominately intended to capture elements and effects of a person’s physical functioning and health. Others are more holistic in constitution, tapping into physical functioning, social relationships, material and financial commodities, mental health and so on (see Brown et al., 2013, and Wallander & Koot, 2016, for presented comparisons of existing measures). Such questionnaires are the most common method of choice for measuring wellbeing among people with disabilities as discussed further below (Cummins, 2005; Wallander & Koot, 2016; Warren & Manderson, 2013); with these instruments purported to measure what is known as ‘health-related’ or ‘disease-related’ QoL. This is commonly understood to refer to the quality the person experiences in the domains of their life associated with their functioning and health, and thus affected by their disability or illness (Karimi & Brazier, 2016; Wallander & Koot, 2016).

Regardless of the chosen indicators or measures, however, the process of such quantitative measurement brings with it certain assumptions about the nature of wellbeing. Indicators and measures – even self-report questionnaires – assume that wellbeing and its domains can be understood in a way that lifts it out of context, but yet remains measurable or at least amenable to measurement (Warren & Manderson, 2013). This is an issue often discussed in terms of the “equivalence” (Herdman, Fox-Rushby, & Radia, 1997, p. 237) of measures across distinct cultures and languages (Bowden & Fox-Rushby, 2003; Epstein, Santo, & Guillemin, 2015; Herdman, Fox-Rushby, & Badia, 1998). In particular, quantitative measures of wellbeing or QoL generally assume that not only do the same domains comprise these concepts for all people, but also that selected items or scales (the indicators) carry the same meaning or significance for people in different contexts or circumstances; an assumption not necessarily supported. For example, in their research on the QoL of adults who had recently undergone a lower-limb amputation, Warren, Manderson, and Misajon (2008) found through qualitative interviews that many participants experienced significant depression despite obtaining mental health scores equivalent to the general Australian population on the Medical Outcome Study 36-item Short-form Survey (SF-36; Ware & Sherbourne, 1992). This raised questions about whether the items comprising the mental health scale in the SF-36 validly reflected how these participants conceptualized and experienced these mental health symptoms (Warren et al., 2008).

Thus, an ongoing tension runs through discussions and research regarding the concept of wellbeing: a tension between understanding the concept ‘objectively’ – which in actuality represents dominant conception of what comprises a quality life – or ‘subjectively’ based upon each person’s own preferences and values. This continued tension is reflected in the reported consensual recognition that both objective and

subjective indicators should be used in appraising wellbeing (I. Brown et al., 2013; Cummins, 2005; Wallander & Koot, 2016). One important example of this tension for the topic of my thesis is the “disability paradox” (Albrecht & Devlieger, 1999, p. 977): the observation that people with disabilities generally rate their own wellbeing high compared with the lower ratings they receive from objective measures of wellbeing, or when their wellbeing is rated by another non-disabled person (Reinders, 2014). In the next subsection, I examine this paradox in more detail.

2.1.1 Disability as ‘ill-being’ and the disability paradox

The disability paradox, in part, reflects the longstanding cultural perception in Western societies that a life with disability is, inherently, a life of diminished wellbeing (Bickenbach et al., 2014; Prilleltensky, 2009; Warren & Manderson, 2013). Two “erroneous assumptions” held by the majority of non-disabled society have been identified as key in informing this perception of disability (Asch, 2001, p. 300). First, that the disadvantage and difficulty encountered by people with disabilities is a direct result of their disability itself (Asch, 2001; Prilleltensky, 2009). Disability is understood to limit the capacities of those who ‘suffer’ from it, and as such is prominently perceived to present significant barriers to their participation in many valuable social roles, activities and settings. This includes paid employment, local community groups and social events, the attainment of education and training, and the raising of children. In other words, many roles, activities and settings that would be perceived to contribute to the fulfilment of domains of wellbeing or QoL (Schalock, 2004; Schalock et al., 2016). For example, in a recent survey-based study conducted in the US, McDonnall, O'Mally, and Crudden (2014) found that 67% of participating employers could not accurately describe how an employee with VI would perform any of five basic office tasks (e.g. using a computer,

using a photocopier), and this lack of knowledge was associated with their negative attitudes towards hiring people with VI. Similarly, reviewing news articles on parenting published in Australian print media between 2004 and 2008, Fraser and Llewellyn (2015) found that parenting with a disability was rarely covered, implicitly reinforcing the dominant perception that people with disabilities are not parents. Furthermore, in those articles that did report on parents with disabilities, they were portrayed as inactive and incapable due to their disabilities, and thus not up to the task of self-care, let alone caring for and protecting their child.

This first assumption, however, disregards the role of society – represented both in its physical and social construction – in producing the difficulties and disadvantage experienced by people with disabilities through its responses to and interactions with their particular bodily capacities (Shakespeare, 2006; C. Thomas, 2007): a point I return to discuss in section 2.3. In failing to recognize this, the dominant view of disability also fails to understand that such difficulties and disadvantage are, in fact, expressly *separable* from a life with disability. As evidenced by McDonnall et al.'s (2014) findings regarding employers' perceptions of people with VI, due to the powerful cultural image of people with disabilities as incapable (Butler, 1998; Gibson, Carnevale, & King, 2012; C. Thomas, 2007), non-disabled members of society are ignorant of, and unable to envisage the alternative ways through which people with disabilities do participate in many valuable social roles, activities and settings. People with disabilities do find such alternative resources and means that reduce the jarring interaction between their capacities and their societal environment so that they can obtain these desirable ends, and in turn experience a higher level of wellbeing than the non-disabled person would expect (i.e. the disability paradox; Warren & Manderson, 2013).

The second key assumption underpinning disability's synonymy with ill-being is that living with disability is experienced as ongoing distress and disorganization (Asch, 2001; Prilleltensky, 2009). Non-disabled people draw on the experiences of temporary illnesses as disturbances to their own lives in assuming that all disability and illness is experienced in this way. This, again, gives rise to the disability paradox as, in contrast with this assumption, many people with disabilities do not experience such ongoing disruption. For those that do experience a degree of disruption to the life they have mapped out ahead of them due to the adventitious onset of their disability – in short, a biographical disruption (Bury, 1982) – this experience is frequently temporary. Non-disabled people underestimate the ability of people to adapt to the difficulties presented by their disabilities, and instead imagine the distressing and upheaving effect of disability as pervading and persisting throughout a person's life (Ubel, Lowenstein, & Japson, 2005; Warren & Manderson, 2013). For instance, Ubel et al. (2005) found that the diminished ratings of life quality provided by non-disabled people, when considering a life with a disability, were improved following reminders of other times in their own lives that they had adapted to negative events. Furthermore, this second assumption completely discounts the experience of people born with their disability, for whom their disability is not a disruption to their imagined life as it has always been present (Warren & Manderson, 2013), and who thus rate their wellbeing accordingly.

The disability paradox is, therefore, a by-product of what has been variously labelled the 'medical model', 'individual model' and 'personal tragedy model' of disability (M. Oliver, 1990; Prilleltensky, 2009; Shakespeare, 2006; Swain & French, 2000). As suggested above, this model locates disability within the individual, as produced by their bodily or psychological differences in anatomy or functioning. Furthermore, as their body is understood as broken or malfunctioning, and thus as a

barrier to fulfilment in many domains of life, this model further theorizes that having or acquiring a disability is experienced as tragic by the individual (M. Oliver, 1990; Prilleltensky, 2009; Shakespeare, 2006; Swain & French, 2000). Disability *per se* is seen as a reason for distress, depression, frustration and other forms of psychopathology. Thus, in short, such a model of disability – which remains an influential view of disability in contemporary Western societies (M. Oliver, 2013) – presumes that having a disability precludes one from having and experiencing high QoL. Throughout the remainder of my thesis, I use the term ‘personal tragedy model of disability’ due to its better alignment with my focus on the lived experience of youth with VI.

This examination of the disability paradox drives home the unavoidable subjective perceptions that contribute to considerations of wellbeing (I. Brown et al., 2013; Cummins, 2005; Wallander & Koot, 2016), and highlights the imposition, in particular, of dominant cultural (subjective) perceptions of what it means to live and have wellbeing with a disability upon people with disabilities (Prilleltensky, 2009). Recognizing these dominant cultural perceptions is important as they continue to influence the approach to promoting the wellbeing of people with disabilities through service provision, as I discuss below.

2.1.2 The personal tragedy model and disability services

This personal tragedy model has produced deficit-focused policy and practice regarding the wellbeing of people with disabilities that have, historically, been about working to cure or fix their broken and distressing bodies to enable ‘normal’ functioning and their performance of expected social roles (Goodley, 2014; M. Oliver, 1990; Prilleltensky, 2009). Functional difficulties resulting from their bodily impairment are blamed for any negative impacts upon their wellbeing. Appraising and reducing the extent of such

functional difficulties is therefore seen as the priority for promoting their wellbeing. It is for this reason that the majority of psychometric measures of wellbeing and QoL developed for and used with people with disabilities – as described earlier – have focused on their health and functioning, and associated mental state (Warren & Manderson, 2013), reflected in the prominent use of health-related or disease-related QoL measures. These measures have a deficit-focus on the person’s self-rated physical, social and emotional functioning – and, with regard to the latter disease-specific measures, how they are impacted by their particular disability or condition – despite often being interpreted by those who use them as reflecting broader and more positive conceptions of QoL (Cummins, 2005; Cummins, Lau, & Stokes, 2004; Karimi & Brazier, 2016; Wallander & Koot, 2016). Meanwhile, this positioning of individual functioning as the root of wellbeing among people with disabilities has resulted in an approach to health services that prioritizes addressing the functional limitations attributed to the person’s disability (Hammell, 2006; Prilleltensky, 2009; Warren & Manderson, 2008). This includes rehabilitation services, such as those outlined in Chapter 1 (McGrath, Rudman, Trentham, Polgar, & Spafford, 2017).

Rehabilitation services seek to compensate for and address the physical, psychological and social difficulties perceived to be created by disability through the provision of and instruction in adaptive technologies and strategies (Hammell, 2006; McGrath et al., 2017; Warren & Manderson, 2008). Their primary objective is to enable the individual to function as ‘normally’ as they can despite their disability. Inherent in this notion of ‘as normally as they can’, these rehabilitation services not only seek to address a person’s functional limitations through their adaptation in their functioning, but also through their psychological adjustment: that is, to facilitate the person’s acceptance of functional and social role limitations that cannot be compensated for in order to render

them no longer upsetting (Prilleltensky, 2009). In short, the goal is to support the person in moving past the (presumed) experience of tragedy resulting from the functional and social limitations produced by their disability. Underlying this rehabilitation approach is the central idea of trajectory here. Adaptation is positioned as a process running from disruptive events – for example, the onset of their disability, or some fresh and significant impact of disability upon the person’s life – through to their return to normal and thus healthy functioning. This process is most commonly framed in terms of a generic set of stages (e.g. shock, denial, anger, depression) along which a person moves during their adaptation or adjustment towards achieving outcomes like acceptance and positive self-esteem (e.g. Livneh, 2001; Livneh & Antonak, 2005). This underlying trajectory, however, has been criticized by many disability studies and other social science scholars (Elliot & Warren, 2007; Prilleltensky, 2009; Warren & Manderson, 2013). This criticism highlights its presumption that all disabilities are experienced as disruptive to one’s life – as discussed above on page 50, this is definitely not the case for people with congenital or early-onset disabilities – and that all people who do experience disability as disruptive then ‘adapt’ to this disruption in the same way, an assertion that is unsupported by empirical evidence (Gill, 2001).

Dominant cultural beliefs about the pivotal importance of bodily health and functioning, reflected in the personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000), shape the theoretical approach taken to understanding wellbeing among people with disabilities. Despite both broader-reaching models of wellbeing and QoL (e.g. Schalock, 2004), and the recognized importance of people’s subjective perspectives (Cummins, 2005; Diener & Ryan, 2009; Wallander & Koot, 2016), policy and practice regarding people with disabilities has long been influenced by a working model of wellbeing that centres on their individual functioning

and emotional responses to their disabilities. These two elements are prioritized as their presence is perceived as essential to the attainment of other valuable life domains. As McGrath et al. (2017) have argued in the context of VI services for older populations, I argue that this particular approach to wellbeing and its promotion applies in the particular context of youth VI services. I address this below and highlight how this personal tragedy model permeates VI service provision to young people.

2.2 The Assumptions of Vision Impairment Services and Research

The fingerprints of the personal tragedy model of disability are readily evident in contemporary VI services provided to youth with VI (described in Chapter 1). These services predominantly focus on supporting and promoting the ability of individuals to independently perform daily tasks: cooking, washing, reading, moving around, and so on. The provision of means (e.g. strategies, aids, assistive technologies) that will enable the young person to ‘overcome’ functional difficulties, perceived as resulting from their VI, in performing tasks is prioritized; thus, these services typically take a deficit-focused approach. This is reflected in the fact that the majority of research evaluating the success of VI-related interventions among younger populations to date has centred on appraising the benefits of assistive technologies or programs targeting independent living skill development among young people with VI (Barker, Thomas, Rubin, & Dahlmann-Noor, 2015; Chavda et al., 2014; Lewis et al., 2014; R. Thomas, Barker, Rubin, & Dahlmann-Noor, 2015). As highlighted in Chapter 1, in contrast, considerably less research attention has been given to evaluating the effectiveness of services or interventions in promoting psychological outcomes or other domains of wellbeing in younger populations (Binns et al., 2012).

However, this focus on individual functioning in VI services persists even where other domains included within broader conceptions of wellbeing or QoL (Schalock, 2004; Schalock et al., 2016) – such as ‘interpersonal relations’, ‘material wellbeing’ and ‘personal development’ – are the focus. The proposed mechanism for achieving these domains often continues to be the development of the skills and knowledge of the young person to address deficits (perceived as) arising from their VI (i.e. social skill development, recreation skill development; Hatlen, 1996; Sapp & Hatlen, 2010). For example, a recent focus group study with various vision rehabilitation professionals, exploring the optimal approach to promoting successful transitions to employment of youth with VI, found that they stressed the importance of assessing and developing the varied skillsets of youth (e.g. problem-solving skills, independent living skills) from an earlier age (Crudden, 2012). Not discussed by these professionals was the discriminatory employer attitudes regarding VI. These have been identified in other research (McDonnell et al., 2014), highlighting a lack of awareness of or emphasis given to non-individual factors and how these social barriers should be addressed by professionals. In practice, therefore, these broader domains and thus the young person’s wellbeing are still framed in terms of individual functioning, particularly those areas of functioning (perceived to be) negatively affected by VI. This underlying assumption is evident in the justification for the ECC (outlined in Chapter 1); which is underpinned by the rationale that certain skills and knowledge need to be taught to children and young people with VI because their VIs themselves prevent the vicarious or passive environmental acquisition of such skills (Hatlen, 1996; Sapp & Hatlen, 2010). Such an approach to the promotion of wellbeing among people with VI represents the field-specific manifestation of the personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000).

This central position of individual functioning in the conception of wellbeing underlying VI services for young people is further reflected in the psychometric measures that have been developed and utilized for evaluating the effectiveness of these services at promoting wellbeing or QoL. The majority of psychometric measures of wellbeing used among people with VI have focused on the individual's self-ratings of the impact of their VI on their physical and social functioning (Marquès-Brocksopp, 2011). In particular, echoing the aforementioned larger critiques of health- and disease-related QoL measures (Cummins, 2005; Cummins et al., 2004; Karimi & Brazier, 2016; Wallander & Koot, 2016), many measures that have been labelled 'vision-specific QoL' measures conflate self-reported visual function and everyday functional capabilities with the concept of QoL (Binns et al., 2012). This was specifically found in a recent review conducted by Tadic, Hogan, Sobti, Knowles, and Rahi (2013) of the self-report functional vision, and vision-specific or eye-condition-specific QoL instruments developed for use among younger populations with VI. In many cases these measures had been devised by expert clinicians or researchers without contribution from young people themselves. Reviewing 12 existing measures, Tadic et al. (2013) found that many were not accompanied by an explicit description of the construct they measured. Although not as problematic for those intended as self-report measures of visual function and functional vision, this represented a salient concern regarding several intended as QoL measures. Despite adopting the label of vision- or condition-specific QoL measure, several of these instruments primarily contained items regarding the young person's functional capabilities, ignoring broader domains often identified as important to conceptions of QoL (e.g. social relationships, personal success). This, again, demonstrates the central position of individual functioning in the conception of wellbeing for youth with VI in work used to inform VI service provision.

Finally, the influence of the personal tragedy model of disability upon the approach to wellbeing for youth with VI within VI services and related research is also evident in how their psychological and emotional health is discussed. Rooted in ideas of overcoming the distressing and disruptive personal tragedy that is disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000), the promotion of the psychological health of people with VI – including youth – is frequently couched in terms of concepts of adjustment or self-acceptance (Sacks, 2010; Tuttle & Tuttle, 2004). Tuttle and Tuttle (2004), in particular, outlined a staged model of “adjusting with blindness” (p. 5); see Figure 2.1 on page 76 where I engage with this model in more detail. This model resonates with those that have been commonly applied to people with disabilities more generally as described earlier (Livneh, 2001; Livneh & Antonak, 2005). In general, in employing concepts of self-acceptance and adjustment, living with VI is understood to be an experience characterized by heightened distress and loss for (young) people, with the goal of VI services being to support the person to psychologically ‘come to terms’ with the difficulties associated with VI. In line with the personal tragedy model, much of the research literature regarding the psychological health of youth with VI still frames VI as the cause of these problems expected to elevate their negative feelings, and thus the factor to which the youth must adjust (Bolat, Doğangün, Yavuz, Demir, & Kayaalp, 2011; Chai et al., 2009; Datta & Halder, 2012; Datta & Talukdar, 2016; Erol & Ergun, 2013; K. Papadopoulos, 2014). Although – as I discuss further below – this does not reflect all engagement with ideas of self-acceptance and psychological adjustment in research among youth with VI; with many, increasingly, recognizing the role of social forces (e.g. bullying) in producing the negative experiences requiring the youth’s adjustment and acceptance (Garaigordobil & Bernaras, 2009; Huurre & Aro, 1998; Pinguart & Pfeiffer,

2012b; Sacks, 2010). This includes the staged model of Tuttle and Tuttle (2004), as I return to discuss later.

Despite this, an implicit working conception of wellbeing, based in the dominant personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000), remains influential at the heart of VI services for youth with VI and in much related research. To be living well with VI, a young person is conceptualized to be developing and employing adapted skills and strategies in order to function ‘normally’ despite the limitations produced by their VI, and to have psychologically adjusted to and accepted the limitations produced by their VI that cannot be resolved so that they are no longer distressing. This particular working model of wellbeing guides and influences the approaches in policy and practice of these VI services to its promotion. Explicitly problematizing this underlying personal tragedy model of disability and this resultant conceptualization of wellbeing in this way raises a further important question: the question as to whether this is an accurate and appropriate conceptualization of ‘living well with VI’ upon which to base VI service provision. The inconsistent effectiveness of VI services at promoting psychological and QoL outcomes (Binns et al., 2012; Rees et al., 2010) may then suggest a need to further develop our theoretical understanding of wellbeing for people and – in the case of this thesis – youths with VI. Below, I examine the various challenges to the personal tragedy model of disability, and thus associated conceptions of the wellbeing of people with disabilities in terms of individual functioning and adaptation. To demonstrate the applicability of these challenges and critiques to the topic of the current thesis, I draw upon findings from extant quantitative and qualitative research exploring wellbeing among youth with VI.

2.3 Challenging the Personal Tragedy Model

The core tenet that having a disability is inherently debilitating and distressing, and thus diminishes one's wellbeing, at the heart of the personal tragedy model of disability has been challenged by scholars working within the social sciences and disability studies (Goodley, 2014; Prilleltensky, 2009; Shakespeare, 2006; C. Thomas, 2007). These critiques have been based in a combination of contradictory findings of empirical research among people with disabilities, and theoretical and political arguments.

2.3.1 Inconsistent comparisons of wellbeing in youth with and without VI

The disability paradox directly contradicts the notion that disability intrinsically diminishes one's wellbeing, instead reflecting the repeated observation that people living with disabilities are still able to live well (Albrecht & Devlieger, 1999; Prilleltensky, 2009; Warren & Manderson, 2013). Similar inconsistent empirical findings have also been repeatedly obtained in quantitative questionnaire-based research comparing the obtained scores of youth with and without VI on varied wellbeing-related outcome measures.

Studies utilizing psychometric measures for various forms of emotion-related psychopathology have repeatedly found inconsistent results. Greater scores for depression or its symptomatology have been found among youth with VI when compared to sighted adolescents in some research (Chai et al., 2009; Koenes & Karshmer, 2000; Pinguart & Pfeiffer, 2012b), while others have found no such difference (Bolat et al., 2011; Garaigordobil & Bernaras, 2009; Huurre & Aro, 1998; Yoshida, Ichikawa, Ishikawa, & Hori, 1998). Increased levels of other mental health difficulties – anxiety, anger/aggression, internalizing behaviour and melancholy – have also been found in some research (Bolat et al., 2011; Garaigordobil & Bernaras, 2009; Van Hasselt, Kazdin, &

Hersen, 1986). Other studies have in comparison found lower levels of anxiety/depression, worry and attention difficulties among youth with VI when compared to sighted young people, alongside statistically equivalent scores for aggressiveness (Demir et al., 2014; Piquart & Pfeiffer, 2014). Discrepant findings have also been obtained utilizing psychometric measures of adjustment among youth with VI (Kef, 2002, 2005; Kef & Bos, 2006; Lifshitz, Hen, & Weisse, 2007), and among the considerably larger body of research regarding their 'self-acceptance' compared to sighted youth (Augestad, 2017; Datta, 2014). Several studies have found that youth with VI obtain overall self-concept or self-esteem scores that are statistically no different to those of sighted young people (Bolat et al., 2011; Garaigordobil & Bernaras, 2009; Griffin-Shirley & Nes, 2005; Konarska, 2007; Lopez-Justicia, Martinez, & Medina, 2005). However, other research has reported both lower (Beaty, 1991, 1992; Datta & Halder, 2012; Mishra & Singh, 2012) and higher scores (Kef, 2002; Lifshitz et al., 2007; Obiakor & Stile, 1990). These findings suggest that the image of VI as an intrinsic personal tragedy that leads to distress and maladaptation, as is inherent in the personal tragedy model of disability, is not reliably supported by the experiences of the youth with VI themselves.

Turning to studies employing measures related to broader and less deficit-focused understandings of wellbeing (e.g. life satisfaction, personal development, autonomy), findings are again inconsistent with the notion of youth experiencing VI as a tragedy. Some studies have reported no significant differences between the ratings offered by youth with VI of their overall satisfaction in their life when compared to those obtained from sighted adolescents (Kef, 2002; Kef et al., 2000; Piquart & Pfeiffer, 2011). Interestingly, in a two-year follow-up phase of data collection at the same schools specialized in the education of young people with VI, Piquart and Pfeiffer (2012a) reported significantly lower self-ratings of life satisfaction amongst youth with VI. This

difference in finding could be a reflection, in part, of the change in sample as the cohort of young people at the schools changed over time, with some participants graduating and not returning to re-participate, while new students were recruited for this phase. This is in line with the running theme of inconsistency arising across the accounts of youth with VI. At the same time, both adolescents with and without VI obtained equivalent scores for identity exploration and identity formation, which suggested that both groups perceived themselves to have undergone comparable levels of personal growth and development (Pinquart & Pfeiffer, 2013b). This conclusion is further supported by statistically equivalent self-rated levels of engagement in and attainment of adolescent developmental tasks for these two groups (e.g. developing a peer group) as they progress through adolescence regardless of VI status (Pfeiffer & Pinquart, 2011a, 2011b, 2012). Youth with VI also reported significantly greater autonomy from their parents than sighted youth in some cases (Pinquart & Pfeiffer, 2013a). In other cases, they self-reported statistically equivalent levels of autonomy attainment compared with their sighted peers (Pfeiffer & Pinquart, 2011a, 2012; Pfeiffer, Pinquart, & Munchow, 2012), or perceptions of their own reduced self-determination (Robinson & Lieberman, 2004).

One domain of wellbeing for which more consistent differences have been found between youth with and without VI is social participation. Youth with VI consistently present with significantly poorer outcomes on multiple indicators of social wellbeing (e.g. Caballo & Verdugo, 2007; Konarska, 2007). They report fewer friends than their sighted peers and spend significantly less leisure time with the friends that they do have, especially in active social groups/activities (Huurre & Aro, 2000; Kef, 1997, 2002, 2005; Kef et al., 2000; Kroksmark & Nordell, 2001; Lifshitz et al., 2007; Sacks, Wolffe, & Tierney, 1998; Sacks & Wolffe, 1998). They also have significantly smaller social networks than sighted youth more generally (Kef, 1997, 2002, 2005; Kef et al., 2000),

and have fewer romantic and intimate experiences during their adolescence, with their first dating and sexual experiences occurring at an older age (Huurre & Aro, 1998; Kef & Bos, 2006; Piquart & Pfeiffer, 2012c). Furthermore, their parents also report concerns about the social activity of these adolescents (Leyser, Heinze, & Kapperman, 1996; Leyser & Heinze, 2001).

However, this consistent finding of their reduced social wellbeing compared to sighted youth becomes less cemented when the indicators considered to represent those tapping into the subjective experience of social connection of young people with VI themselves are measured. As with the other indicators of wellbeing described above, some research has found that youth with VI report greater loneliness and isolation than those without VI (Hadidi & Al Khateeb, 2013; Huurre & Aro, 1998), but this is not always the case (Kef, 2002; Kef et al., 2000). The appearance of inconsistencies in findings regarding the social wellbeing of youth with VI compared to sighted peers on these subjective indicators aligns with the disability paradox (Albrecht & Devlieger, 1999). That is, ‘paradoxically’, while there is consistent evidence of lower social wellbeing among the youths’ responses regarding (more) objective indicators (e.g. number of friends, number of romantic encounters) and ratings of their social participation offered by others (e.g. parents), some youth with VI subjectively experience a high-level of social wellbeing.

Empirical findings such as those outlined above demand conceptual and theoretical consideration, and particularly indicate the need to critically examine the direct negative relationship that is assumed to exist between disability – such as VI in youth – and wellbeing by models of rehabilitation service provision. Many writers grounded in disability activist and political movements over the past four decades have answered these demands for this critical theorizing (Goodley, 2011, 2014; Shakespeare,

2006; C. Thomas, 2007). Primarily, they have sought to alter the discourse around disability from one of deficient bodily functioning and individual catastrophe – the personal tragedy model – to one of oppression through structural and cultural barriers located in the majority non-disabled society, thus giving rise to socio-cultural models of disability (Goodley, 2011, 2014; Shakespeare, 2006; C. Thomas, 2007).

2.3.2 Extending upon the social model of disability

Social approaches to disability propose an alternative understanding of the factors and mechanisms at play in the relationship between disability and wellbeing. In fact, the original (British) social model offered a redefinition of ‘disability’, drawing a distinction between it and impairment (Goodley, 2011, 2014). From this social model approach, the term ‘impairment’ denotes the physical or mental difference in structure or function that is possessed by a person’s body, leaving the term ‘disability’ to refer to the oppressive barriers that the person encounters to their participation in society because of this difference. These barriers include inaccessible material environments, restrictive institutional policies, and discriminatory cultural attitudes about disability that are enacted by non-disabled people towards people with disabilities. In adopting these specific definitions for these terms, the social model of disability severed bodily impairment from the disability, so that the former’s consideration could be put on the backburner (Goodley, 2011, 2014; Shakespeare, 2006; C. Thomas, 2007). Instead, the priority was to identify and rally for the removal of forms of disablism: that is, the various material, institutional and attitudinal barriers that restrict the participation of people with impairments in societal roles and settings (i.e. employment, community positions), and thus produce the difficulty and disadvantage they face. This refocus represented a significant and necessary step forward in advancing the rights and interests of people living with disabilities;

however, given the emphasis on environmental forces and structures – and the shunting of the individual to the side – the original social model offered no direct critique of the personal experience and wellbeing of these people (Goodley, 2011, 2014; Shakespeare, 2006; C. Thomas, 2007). Subsequent scholarship extending and critiquing the social model of disability has since reasserted the significance of the personal experience and wellbeing of people living with disabilities and replaced it under direct examination. This occurred in two main ways.

Feminist disability studies scholars argued that its focus on these oppressive environmental forces and structures as the problem did not preclude the social model's extension to the lived experience of people with disabilities (Goodley, 2014; C. Thomas, 2007). They argued that research should examine the lived experience of these individuals in interacting with these forces and structures in the difficulties and disadvantage that they encounter. Carol Thomas' (1999, 2007) work – later extended upon by Donna Reeve (2006, 2012) – in expanding the concept of disablism was particularly influential in this. Thomas identified two overlapping yet distinct means through which disablism operated. According to C. Thomas (2007, p. 73), disablism “is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing”. In this definition, Thomas highlighted both the structural disablism – the environmental barriers that limit the participation of people with disabilities in society described above – and introduced the concept of psycho-emotional disablism (Reeve, 2012; C. Thomas, 2007). Psycho-emotional disablism acknowledges that the oppression of people with disabilities is underpinned by dominant cultural values, norms and beliefs that position people with disabilities as abnormal, incapable, inferior and unwanted; and, that interacting with these dominant cultural forces often produced strong

negative emotions and self-evaluations among people with disabilities. Reeve (2012) outlined two ways that people living with disabilities come into contact with these cultural forces. First, they may recognize them in their interactions with forms of structural disablism, known as “indirect psycho-emotional disablism” (Reeve, 2012, p. 81). For instance, a lack of inaccessible class materials may be interpreted by a young person with VI as saying you are not wanted at this school. Second, and more prominently, these cultural forces are enacted towards people with disabilities by others and themselves (after their internalization) in what is known as “direct psycho-emotional disablism” (Reeve, 2012, p. 79). For example, a young person with VI may repeatedly encounter the view from others that they are unattractive because of their wandering eye and may in turn begin to feel this way about their self.

In addition to such examination of the personal experience of disablism, other approaches have been taken to the reinsertion of the personal experience of people with disabilities into literature dominated by the social model (Prilleltensky, 2009; Shakespeare, 2006). These approaches have highlighted that – while it is indeed important to identify and address the many socio-cultural factors and forces that contribute to the difficulties and disadvantage experienced by people with disabilities – we cannot lose sight of the effects of the person’s bodily difference. Employing the language of the social model, the person’s impairment has direct impacts itself – which C. Thomas (1999, p. 42) labelled “impairment effects” – that in part contribute to their lived experiences, including the pain and fear of degeneration that accompanies many disabilities (Hughes & Paterson, 1997; Prilleltensky, 2009; Shakespeare, 2006; C. Thomas, 2007). Undoubtedly, for example, the difficulties encountered by people with the condition of chronic pain will be contributed to by social and contextual forces; for example, scepticism from others about the legitimacy of their condition or inflexible

employment policies (Broom, Kirby, Adams, & Refshauge, 2015). Yet, no social or contextual forces can entirely account for the negative experience of pain and the affect that this has on the person's wellbeing. Nonetheless, it has also been argued that a person's experience of any impairment effects – irrespective of their connection to the person's distinct material body – are still embedded within their social context. For example, how any person experiences pain is influenced by dominant understandings of the meaning of pain they have encountered and internalized from their society and culture into their worldview (Hughes & Paterson, 1997). These discussions have highlighted the arbitrariness of the impairment and disability divide espoused by the original social model, proposing instead more relational models of disability (Shakespeare, 2006; C. Thomas, 2007). Relational models understand disability as arising out of the ongoing interaction of the effects of the person's bodily difference and the impacts of environmental forces.

Such a relational understanding of disability, that acknowledges the role of both structural and psycho-emotional forms of disablism alongside impairment effects, represents a direct theoretical challenge to the personal tragedy model of disability at the heart of the working model of living well with VI that underlies VI services provision (as described above). Despite recognizing the importance of acknowledging impairment effects in the lived experience of people with disabilities, these relational models dispute the assumption that bodily impairment (in social model terms) is the primary cause of the disadvantages and difficulties experienced by people with disabilities, and thus is experienced as distressing (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000). In so doing, they raise questions about approaching the promotion of wellbeing among youth in VI services through primarily addressing the individual-level functional impacts of VI through instruction in the use of specialist skills, technologies and equipment, and

through working to facilitate their acceptance of those impacts that cannot be compensated for in this way. Instead, the working model of 'living well with VI' guiding the provision of these services needs to consider both the youth's VI itself as well as environmental and social forces. This challenge to the personal tragedy assumption underlying VI services is strengthened by previous findings of both quantitative and qualitative research among youth with VI that support the applicability of relational models of disability in understanding their lived experiences and wellbeing. I now briefly review these findings.

Factors affecting the wellbeing of youth with vision impairment. Many studies have examined social or contextual factors that shape the lived experience of young people with VI (e.g. Huurre & Aro, 2000; Kef, 2002; Kef et al., 2000; Lifshitz et al., 2007). Social and contextual factors have also been concluded to be better predictors of indicators of wellbeing than VI-related factors, such as severity or cause (Kef, 2012). In particular, negative interactions and relationships of youth with other sighted people have been found to have significant psychological impacts (aligning with the concept of direct psycho-emotional disablism; Reeve, 2012; C. Thomas, 2007). For example, negative interactions with peers at school can include repeated and unwanted questions about their VI and unsolicited direction or help (DeCarlo, McGwin, Bixler, Wallander, & Owsley, 2012; Hess, 2011; Rosenblum, 2000; Tadic, Hundt, Keeley, & Rahi, 2014; Worth, 2013a). Several qualitative studies involving focus groups and interviews with youth with VI have found that many experience a range of negative feelings regarding their VI (e.g. frustration, shame) which they do not attribute to particular visual symptoms, but instead to feeling excluded, different or special (Chang, 1998; Cochrane, Lamoureux, & Keeffe, 2008; Rosenblum, 2000; Tadic et al., 2014). These youth also describe how feeling

excluded, judged or unvalued by others (e.g. parents, peers, teachers) can lower their own feelings of worth with respect to aspects of or their whole self (Chang, 1998; Tadic et al., 2014).

The school experiences of youth with VI are typified by feelings of social isolation and exclusion due to the actions of their peers, teachers and other support staff (Cochrane et al., 2008; Hess, 2011; Rosenblum, 2000; Salminen & Karhula, 2014; Tadic et al., 2014; Whitburn, 2014a, 2014b). Many report experiencing difficulty in socializing with their sighted peers and forming friendships, often pairing up with other young people who have also been outcast (Cochrane et al., 2008; Hess, 2011; Rosenblum, 2000; Salminen & Karhula, 2014). One particular form of negative social interaction encountered by youth with VI at school is bullying. Young people with disabilities, including VI, experience greater bullying and exclusion by their peers as compared to non-disabled/sighted young people (Carter & Spencer, 2006; Pinqart & Pfeiffer, 2011, 2012a). Youth with VI report both frequent verbal and physical bullying from their peers at school (DeCarlo et al., 2012; Hess, 2011; Rosenblum, 2000; Salminen & Karhula, 2014; Tadic et al., 2014; Worth, 2013a). This bullying can reach quite severe levels. For example, youth with VI interviewed about their school experience in previous research have recounted physical fights between them and their bullies; events with implications for their physical health, as well as psycho-emotional impacts, with some breaking down in tears on returning home from school (Rosenblum, 2000; Sacks & Corn, 1996; Tadic et al., 2014). Resonating with these personal accounts, quantitative studies have found that elevated levels of self-reported bullying are significantly associated with poorer self-perceptions of body image, self-report symptoms of psychopathology, and poorer life satisfaction among youth with VI (Pinqart & Pfeiffer, 2011, 2012a).

Youth with VI have offered some insight into the factors contributing to their experiences of bullying and other negative social interactions with school peers, such as whether they attend ‘mainstream’ or specialized educational settings. Differences in the shared experiences of adolescents across these settings suggest that, while most who attend specialized settings feel more included and respected, these specialized environments are not free of experiences of victimization (Tadic et al., 2014; Worth, 2013a). Nonetheless, as suggested by the accounts of two partially sighted young people interviewed by Worth (2013a), ‘mainstream’ education may be more positively experienced by those with less severe VI as they experience less stigmatization by their peers (i.e. an impairment effect; Lingsom, 2008; C. Thomas, 1999, 2007). This stigma – the devalued social status assigned to the youth by society because they possess a particular characteristic (i.e. VI) to which negative cultural meanings have been affixed (Gill, 2001; Goffman, 1963; Scior, 2016) – is a major factor that youth with VI discuss as contributing to their bullying and negative social experiences (Hess, 2011; Rosenblum, 2000; Tadic et al., 2014; Whitburn, 2014a, 2014b; Worth, 2013a). They assert that their sighted peers have minimal and negative understandings of VI, with some viewing their conditions as infectious illnesses or judging them as incapable or inferior (Hess, 2011; Rosenblum, 2000; Whitburn, 2014a, 2014b; Worth, 2013a). Youth with partial vision further describe a particular manifestation of ignorance of their sighted peers, in that they often fail to grasp why they can perform certain visual tasks but not others; a gap in understanding that they find particularly agitating (Worth, 2013b). This is another example of the direct impairment effect of particular VI-related factors through their interaction with social forces.

Youth with VI attribute their encounters with this stigma, in part, to their need for and use of varying special supports and considerations at school which flag them as

different (Whitburn, 2014a, 2014b; Worth, 2013a). This includes specially-provided transport to school, adaptive learning technologies (e.g. magnifiers) and mobility aids. Consequently, they report resisting use of some of these devices or resources in order to obscure their disability from their peers, which in turn impacts upon their ability to fully participate and independently function (Khadka, Ryan, Margrain, Woodhouse, & Davies, 2012; Salminen & Karhula, 2014; Tadic et al., 2014; Worth, 2013b). Thus, a form of psycho-emotional disablism in turn becomes structurally disabling to the youth (Reeve, 2006). Furthermore, while the support they provide is valued, the accompaniment of learning support aides across large amounts of the school day is particularly identified by youth as further fuel for stigma, and as literally placing a physical (and, thus, structural) barrier between them and their peers (Khadka et al., 2012; Whitburn, 2013, 2014a, 2014b; Worth, 2013a). Finally, according to youth with VI, the inability of mainstream teachers to appropriately adapt their teaching style further contributes to this stigma by accentuating their difference and inhibiting their proper participation in class (Hess, 2011; Rosenblum, 2000; Whitburn, 2014b, 2014c).

In addition to these negative social interactions and thus forms of direct psycho-emotional disablism, other social and environmental factors have been found to impact upon the wellbeing of youth with VI by restricting their ability to perform certain tasks or participate in certain activities. Thus, they represent forms of structural disablism (C. Thomas, 2007). For example, the over-concern or watchfulness of parents, teachers and classroom aides – who frequently make decisions for the youth – has been connected with the reduced ability to independently and autonomously participate at home, school or in other settings (Khadka et al., 2012; Robinson & Lieberman, 2004; Whitburn, 2013, 2014a, 2014b; Worth, 2013a). Leyser et al. (1996) found that parents of children with VI reported that their family environments afford less impetus for personal growth for these

children. Parental overprotectiveness has also been linked to the reduced participation of young people with disabilities in sports and physical activity (Boufous, Finch, & Bauman, 2004). This in turn may deprive them of the psychological benefits that some have found to be associated with physical activity for youth with VI (e.g. Goodwin et al., 2011; Jessup et al., 2010; Qasim et al., 2014; Shapiro, Moffett, Lieberman, & Dummer, 2005). Other social barriers to the participation of youth with VI in physical activity have also been identified, including inappropriate equipment or resources for programs, and poor understandings and negative perceptions of disability held by other participants or the people running the activity (Augestad & Jiang, 2015; Haegele & Porretta, 2015; Shields, Synnot, & Barr, 2012)

The influences of these forms of structural and psycho-emotional disability upon the wellbeing of youth with VI notwithstanding (C. Thomas, 2007), they did not account for all impacts upon the participants' lived experiences and wellbeing. As already indicated at points in the above discussion, despite inconsistent associations between VI clinical characteristics, such as severity, and the scores obtained for youth on indicators of wellbeing (also highlighted by Augestad, 2017), previous empirical research among youth with VI has obtained findings of the direct effects of their VI. For instance, youth with VI report numerous worries about the future derived directly from their VI. These include concerns regarding whether they would pass on their VI to their children (if genetically-based), and whether any remaining vision they possessed would endure if the particular cause of their VI is degenerative in nature (Rosenblum, 2000; Salminen & Karhula, 2014; Tadic et al., 2014). Furthermore, such future concerns seem particularly prominent for young people who experience adventitious vision loss, as the later onset of VI for these adolescents is experienced as an unanticipated and distressing shock (Rosenblum, 2000; Tadic et al., 2014). For these youth, the onset of their VI directly unsettles their

developing sense of self and their future, and thus represent biographical disruptions (Bury, 1982).

The impact of their limited vision on their ability to drive represented one prominent impairment effect identified in previous empirical research among youth with VI. Driving is something many equate with increased independence, and consequently it is something that they wished to be able to do, but many were unable to do due to their VI (Khadka et al., 2012; Rosenblum, 2000). Some adolescents recounted feelings of bitterness and irritation due to their resultant reliance on others for their transportation, as well as feelings of missing out on a significant life milestone (Rosenblum, 2000). Additional impairment effects have also been identified in the discussions of adolescents regarding their use of transportation that present an avenue for travel independence that is an alternative to driving (e.g. public transport; Salminen & Karhula, 2014; Whitburn, 2014b). These barriers include difficulty in accurately identifying a bus they want to catch and thus indicating to the bus driver for them to stop. These latter impairment effects, however, did not produce the transportation difficulty the participants faced alone; rather, in line with a relational understanding of disability (Shakespeare, 2006; C. Thomas, 2007), they represented the interaction between the young people's VI and features of the public transport system. That is, the participants' difficulty in catching the right bus arose out of the interaction of their reduced vision, and both the fact that the bus routes were visually demarcated and did not automatically pick up passengers at each stop (thus, requiring flagging down).

Empirical support is therefore available for the influence of both psycho-emotional and structural disability, and impairment effects in the lives of youth with VI (Shakespeare, 2006; C. Thomas, 2007). Thus, a relational understanding of VI in young people presents a direct challenge to the working theory of 'living well with VI' that

underlies youth VI services rooted in the personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000). Rather than perceiving a life with VI as characterized by diminished wellbeing due to the functional limitations it produces and that must be overcome, this empirical research indicates that the experiences of wellbeing of youth with VI are more complex due to the influence of environmental and social forces. Therefore, the working conceptualization of living well with VI needs to ensure that it reflects this complexity in order to inform more sensitive and relevant service provision.

However, while highlighting the inappropriateness of this current working conceptualization of living well with VI, this critique does not, in itself, offer an alternative conceptualization of personal wellbeing among youth with VI that is useful for informing VI services. Greater recognition of environmental and social forces in understanding disability readily aligns with ecological approaches to conceptualizing wellbeing that consider a persons' wellbeing in terms of indicators across the multiple layers contributing to their situation (Prilleltensky, 2009). In other words, it evaluates their wellbeing by considering factors at their immediate personal level, the level of their local community and at the larger level of the society within which they live. However, such ecological understandings of wellbeing typically propose that action to promote the wellbeing of a group of people must occur at the level of political and social change (Cahill, 2015). While advocating for such political and social change should represent part of the role of VI service providers, understanding wellbeing in this way provides no guidance to service providers on how to more immediately support the wellbeing of the young people with whom they work.

I argue that to move beyond the inconsistent findings of effectiveness of VI services at promoting wellbeing outlined in Chapter 1 (Binns et al., 2012; Rees et al.,

2010), further development of the theoretical understanding that informs these services is required. An alternative working model to the personal tragedy model, that currently underlies these services, needs to be developed of what it means to be living well with VI as a youth. This must not only take into account direct impairment effects but also the disablism they encounter.

2.4 Rethinking ‘Living Well with Vision Impairment’: Project Aim

Very little research has sought to elaborate such an alternative and positive account of what it means to be ‘living well with VI’ for young people. By ‘positive’, I mean an account of what constitutes living well itself for the individual, and not the factors – beneficial (i.e. social support) or detracting (e.g. bullying) – that can affect it. The one significant exception to this observation resides in the work of Tuttle and Tuttle (Tuttle, 1984; Tuttle & Tuttle, 2004) around adjusting with blindness.

As mentioned in section 2.2 above, Tuttle and Tuttle (2004) outlined a staged process model of adjusting with blindness through which they explained that people – including children and youth – with VI maintain self-acceptance and self-esteem; this staged model is depicted below in Figure 2.1 on page 76. Unlike some academics employing the concepts of acceptance and adjustment in the area of VI (Bolat et al., 2011; Datta & Talukdar, 2016; Erol & Ergun, 2013), Tuttle and Tuttle (2004) did not portray the adjustment and acceptance of people with VI from a personal tragedy model perspective (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000). That is to say, they did not depict it as simply a process of a person moving along a trajectory from the disrupting and tragic event of the onset of VI towards gradually accepting the changes it brought to who they are and the life they envisaged. Rather, for Tuttle and Tuttle, adjusting is an ongoing process constantly performed by all people – irrespective of any

condition or characteristic – in order to meet the various challenges confronted as they move through differing environments in life, and thus maintain their self-acceptance and positive self-regard. They perceive a person to have self-acceptance when their self-concept – understood in line with prominent psychological theories as the total set of beliefs about themselves as a person (Oyserman, Elmore, & Smith, 2012) – faithfully aligns with their experiences, and they are comfortable with all of their qualities, good and bad. This person recognizes their own shortcomings and detractors, but do not believe these to diminish their value as a person, resulting in positive feelings about themselves; in short, high self-esteem (Oyserman et al., 2012). Challenges are envisaged to thus threaten or actually disorganize a person’s self-concept (Tuttle & Tuttle, 2004).

Tuttle and Tuttle (2004), however, did not discount the impact of VI in this process. While arguing that the process of adjustment with blindness is the same as the adjustment process of sighted people, they theorized that people with VI generally have to adjust to a greater number of challenges as they go through life with VI. Importantly, in line with relational understandings of disability (Shakespeare, 2006; C. Thomas, 2007), these extra challenges – and thus threats to self-acceptance and self-esteem – were produced both by the functional limitations imposed by VI itself and the negative reactions of others to them because of their VI. In other words, they acknowledge both impairment effects and psycho-emotional disablism as factors related to living with VI that may precipitate the need for adjustment in order to preserve one’s positive sense of self (Reeve, 2012; C. Thomas, 2007). Implicit within Tuttle and Tuttle’s (2004) model of adjusting with blindness is an understanding of what it means for people to be living well with VI. Living well entails successfully maintaining self-acceptance and self-esteem through the management of threats presented to the self-concept by everyday challenges –

including both disablism and impairment effects – by constantly adjusting to these challenges through the staged process (Tuttle & Tuttle, 2004).

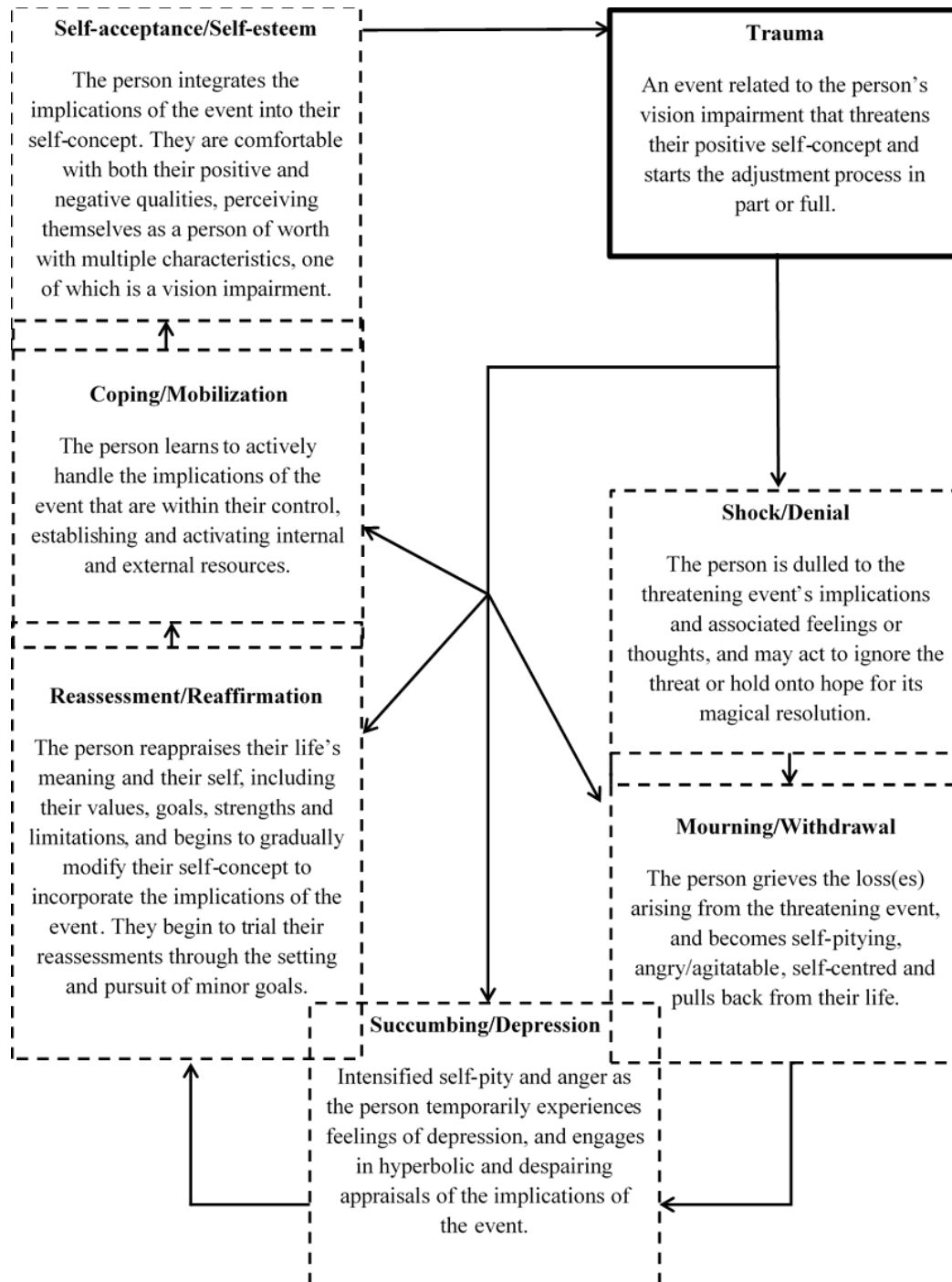


Figure 2.1. A diagram representing the staged model of 'adjusting with blindness' proposed by Tuttle and Tuttle (2004). Multiple arrows extend from the initial trauma stage to indicate that an event that threatens the person's positive self-concept may only precipitate partial readjustment.

This understanding of living well with VI represents a potentially useful alternative working model of wellbeing to guide the provision of VI services to youth, in that it stresses the need for service providers to support these youth in responding to both direct functional limitations of VI and psycho-emotional disablism that they encounter.

However, while theoretically useful, some questions arise when it comes to employing Tuttle and Tuttle's (2004) theorizing to inform the approach of VI services targeting the promotion of wellbeing among youth with VI. Drawing on extant psychological theory regarding self-acceptance and adjustment, Tuttle and Tuttle's (2004) theorizing around adjusting with blindness was informed by "the authors' combined sixty years of work in the fields of education and rehabilitation of individuals who are visually impaired" (p. xii). Therefore, although Tuttle and Tuttle (2004) assert the applicability of the ideas to all people with VI across the lifespan – including youth – to the best of my knowledge no research has been conducted to demonstrate that the model they propose resonates with the experiences of wellbeing of young people with VI. This is salient because – as described earlier in section 2.1 – scholarship regarding people with disabilities more generally has consistently questioned the validity of such staged models of adjustment or adaptation (Elliot & Warren, 2007; Prilleltensky, 2009). Gill (2001), in particular, asserted that, while evidencing the shock that some (not all) people feel at the onset of disability¹⁰ and the value of time for these people in handling this, efforts to evidence the image of adaptation as a common sequence of steps undergone by all people as is presented by staged models have been unsuccessful. Tuttle and Tuttle (2004), themselves, acknowledge these limitations of staged models of adjustment. For this reason – as represented in Figure 2.1 – they qualify their stages by asserting that in response to a

¹⁰ An experience only had by people with adventitious forms of disability, as opposed to genetic or congenital forms (Warren & Manderson, 2013).

threat to their self-concept people may undergo part or all of the stages of adjustment, and – that despite being sequential – the stages are fluid and overlapping in their occurrence.

The need for these qualifications suggests that the lens provided by Tuttle and Tuttle's (2004) work for understanding living well with VI may not sensitively capture the lived experiences of young people, and that further work needs to theoretically develop our understandings of wellbeing for this population. In particular, work drawing on the voices of young people with VI themselves to ensure the relevance of the developed theory to them. It is to this theoretical development to which I seek to contribute with this thesis.

Therefore, in conducting my doctoral research, I aimed to explore wellbeing from the perspectives of youth with VI. To facilitate the achievement of this aim, the research had four specific objectives:

1. To understand how youth with VI conceptualize wellbeing;
2. To outline the indicators of wellbeing considered by youth with VI as the most salient for its measurement;
3. To describe specific factors and their interactions involved in the relationship between their VI and their wellbeing as they conceptualize it; and,
4. To identify resources and strategies they have found useful in dealing with the effects of their VI on their wellbeing.

In achieving these objective, I sought to develop a working theory of what it means for youth with VI to be living well that can inform VI service provision.

Chapter 3

Methodology: Collaboration with comrades

My doctoral research had an emancipatory and practical impetus motivating its performance. Despite my exploratory aim and objectives, and my focus on a concept often discussed from philosophical vantages (Nussbaum, 2005; R. M. Ryan & Deci, 2001), I did not intend to offer a higher-order abstract conceptualization of wellbeing. Rather, this research was conceived as a collaboration between myself and other young people with VI intended to ‘liberate’ our voices and advance our interests with regard to VI services (Berger & Lorenz, 2015; Duckett & Pratt, 2007; M. Oliver, 1997). The act of the youth sharing and exploring their experiences and accounts targeted this empowerment in two ways. First, I hoped that through their collaboration, the youth would become personally empowered (cf. A. J. Petersen, 2011). Second, my research sought to problematize (ideas of) representation (Scott-Hill, 2002): that is, to interrogate how youth with VI represent their own wellbeing and its maintenance, and how this representation then fits with [often implicit] assumptions regarding their wellbeing employed by VI service organizations (outlined in Chapter 2). Their accounts were employed to propose substitutive lenses through which organizations could understand their wellbeing and thus refine their policies, procedures and practices (Goodley & Lawthom, 2005). Given this focus, I drew upon literature regarding participatory research in designing my study (e.g. Cartwright & Allotey, 2006; Foster-Fishman, Law, Lichty, & Aoun, 2010; Greenwood & Levin, 2005).

I also engaged with literature surrounding insider research and autoethnography due to my own position as a young adult with VI (Hayfield & Huxley, 2015; Voloder,

2008, 2013). I am legally blind due to a genetic eye condition (described in section 3.1 below), and I completed my research – with the exception of my thesis write-up – in my early-to-mid 20’s. My personal position unavoidably influenced my research, with my biological VI and my participation in various settings and spaces that surround life with VI inspiring this project. To this project, I brought my own experiences and understandings not only of wellbeing but also of what it means to live with VI. Furthermore, on a social level, I held many pre-existing relationships with other youth with VI – as a brother¹¹, friend, acquaintance, and volunteer peer mentor – as well as with the staff working at the VI service organizations as a client, volunteer, and student researcher (see Anderson, Warren, & Lee, 2014). The effects of this insider status were felt throughout the entire research process (Billo & Hiemstra, 2013).

I commence this chapter by reflecting upon my own VI and describing how these reflections guided me to adopt a critical realist epistemological perspective. I then outline the actual participatory methods and practices that I employed to meet the project’s aim and objectives. In the third section of this chapter, I consider my own ‘insider-ness’ that informed my adoption of a friendship-as-method participatory approach (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003) in order to manage the power dynamics of field relationships. I conclude the chapter by discussing the study limitations and methods employed to ensure its rigour.

3.1 My Impairment and My Critical Realist Participatory Approach

My own experiences of disability informed my epistemological approach to the exploration of wellbeing among youth with VI in the current study. In line with social

¹¹ My youngest brother has the same underlying genetic eye condition as I do and attended various events that I attended as part of my fieldwork.

understandings of disability described in Chapter 2 (Goodley, 2011; Shakespeare, 2006; C. Thomas, 2007), I have encountered many forms of disablism rooted in the structuring of material and institutional environments, or within others' attitudes towards disability. I have encountered difficulty in establishing formal contracts (e.g. for a mobile phone plan) because of the non-equivalent status of a driving license and the forms of personal identification available to me. On many occasions, I have been asked to sit out of class activities because of insufficient accommodations or sat myself out in others to avoid the spectacle and hassle. On rarer occasions, I have been actively denied the provision of alternatively-formatted learning materials. Finally, in various social settings, I have encountered considerable social ridicule and, more rarely, physical aggression as a result of others' attitudes towards or misconceptions of VI. Nonetheless, similar to others who have critiqued the social model of disability despite their acknowledgment of its importance and value (Hughes & Paterson, 1997; Morris, 1996; Paterson & Hughes, 1999; Shakespeare, 2006), I recognize that analysing my experience of these environmental barriers alone would not capture the full relationship between my VI and my wellbeing. My VI has had undeniable impairment effects upon my experiences and, at many points, wellbeing (C. Thomas, 1999).

The primary cause of my VI is Retinitis Pigmentosa, a degenerative eye condition in which certain retinal cells of the eye gradually cease functioning following an 'outwards-in' progression. The cells on the perimeter of the retina (rods) die off first and then this degeneration gradually works inwards towards the retina's centre (cones). This results in a progressive loss of vision – starting with the vision on the periphery and then gradually moving to the centre of the visual field – producing, along the way, what is called “tunnel vision” (Charcón-López, López-Justicia, & Vervloed, 2014, p. 358). That term best describes my current vision. The rate of this degeneration varies between people

and can accelerate or decelerate at different points in time for the same person.

Furthermore, given the important role of rod cells in enabling human vision in lower and variable lighting, a major impact of my Retinitis Pigmentosa has been the phenomena of “night-blindness” (Charcón-López et al., 2014, p. 358). That is, my eyes are unable to function in settings that are of a lighting level below the higher threshold that I require, and I experience a related prolonged disruption to my vision when moving from dim to light settings, or vice versa.

The direct effect of the degenerative nature of my eye condition and the related night-blindness on my wellbeing has been apparent to me at many points in my life, alongside and through interactions with the effects of environmental forces. The gradual deterioration of my sight throughout my teenage years produced many negative emotions and thoughts. I experienced significant frustration at the realization that my family, friends and I were going to have to adapt further as previously performable tasks (e.g. reading school novels, navigating busy environments during daylight) became significantly harder, even with adaptive resources, due to further losses of sight. These realizations also brought with them accompanying anxieties about the future and the losses of even more sight that would likely occur, and the things of value that this future degeneration may cost me: would I be able to drive a car, or see the face of the woman I love on our wedding day? Night-blindness also directly contributed to my inability to fully participate in activities I perceived as life-enriching. Some of these experiences could have been avoided or reduced through the alteration of factors in my institutional or material environment, but not all. For example, the specialness of running around the neighbourhood as a seven- or eight-year-old with my best friend to see Christmas light displays, or the wonder of baby penguins walking up a beach with my family before the sun had risen, would both be lost through social/environmental alteration.

Collectively, these experiences – and many others – highlight the undeniable reality of my VI and its effects upon my lived experience. They indicated to me – as has been asserted by many others (Pols, 2010; Prilleltensky, 2009; Shakespeare, 2006; C. Thomas, 2007) – that fuller understandings of either my own or other young peoples’ experiences required direct attention to the reality of VI and its interactions with multiple other environmental forces: the material constitution of environments; established societal institutions and cultural norms; and the attitudes and resultant behaviours enacted by other people towards us. Thus, I approached my doctoral research from a position of critical realism, similar to that endorsed by others working in the space of disability (Bhaskar & Danermark, 2006; Craig & Bigby, 2015; Shakespeare, 2006) or healthcare service provision (Houston, 2001, 2005, 2010; C. Oliver, 2012; Pilgrim, 2014). Below, I outline critical realism, how it fits with my personal reflections, and how it informed my research.

3.1.1 An overview of critical realism

As a theoretical perspective, critical realism entails an ontological and epistemological position which posits that there is an objective or “intransitive” (Pilgrim, 2014, p. 2) real world which exists regardless of our engagement with and understanding of it (Bhaskar & Danermark, 2006; Danermark, Ekstrom, Jakobsen, & Karlson, 2002; Houston, 2010). In contrast to constructivist approaches, critical realism affirms that this world has real effects in our lives beyond the significance attributed to it by human perception and interpretation, both in terms of ‘natural’ and ‘social’ worlds. In other words, attitudes and social institutions, for instance, are perceived to be just as objectively real as the forces and substances studied in the natural sciences (e.g. physics, chemistry).

At the epistemological level, critical realism upholds the insights of constructionism (Crotty, 1998; Danermark et al., 2002; Houston, 2010) and holds that we can only know and understand the world through the filter of our constructed, or “transitive”, view of reality (Pilgrim, 2014, p. 2). This encompasses any form of human knowledge, both in terms of the way we perceive and the way we talk about the significance and meaning of the world, which is established, perpetuated and altered by people through our interactions and communication with each other (Crotty, 1998; Danermark et al., 2002; Houston, 2010).

Critical realism postulates an objective reality that is more intricately-constituted than occurs in well-established positivistic perspectives, including in psychology (Goodley, 2011; Pilgrim, 2014; Teo, 2009). This objective reality extends beyond that which is readily observable to consider three ontological layers (Bhaskar & Danermark, 2006; Danermark et al., 2002): the “empirical” and “actual” layers recognize that we do not experience all events that occur in the world (Houston, 2010, p. 75). The empirical layer comprises those we do notice, while the actual layer comprises all events which occur irrespective of our awareness (subsuming the empirical layer). Underlying these layers and outside of human perceptual capacities, the “causal” layer comprises the “generative mechanisms” (Houston, 2010, p. 75) that produce these events. Consider, for example, a verbal altercation between a youth with VI and their sighted classmate perceived by a teacher. A teacher may overhear a joke made about the student’s VI: this event falls within the empirical layer. Witnessing this, the teacher may assume that the sighted classmate acted in this way due to a discriminatory attitude. This inference alludes to an underlying mechanism that produces the observed behaviour: this attitude is not itself observable and thus resides in the causal layer. Although this may be a valid inference, other events or factors may also have contributed to this event – through

alternative or additional mechanisms – of which the teacher is not aware (Craig & Bigby, 2015), and such unwitnessed events are no less real. The students may actually have a shared understanding that such humour is acceptable, and the youth with VI may in fact reciprocally mock their sighted classmate¹².

Therefore, by acknowledging our inability to observe all events and the mechanisms that contribute to their occurrence, critical realism upholds a constructed view of knowledge (Bhaskar & Danermark, 2006; Danermark et al., 2002; Houston, 2010). In our efforts to successfully act in the world, we seek to understand it. However, we postulate (rather than observe) causal explanations for phenomena, guided by values and aspirations, and within existing language and knowledge (Bhaskar & Danermark, 2006; Danermark et al., 2002; Houston, 2010); these postulations are refined in response to our interactions with others and shared experiences.

This critical realist approach carries certain implications for my research. First, it prioritizes the incorporation of “everyday knowledge” (Danermark et al., 2002, p. 33) of people in explorations of social phenomena due to, not only the constructed nature of knowledge, but also the fact that social phenomena are often produced by people’s understandings of them (Bhaskar & Danermark, 2006; Houston, 2010). Second, critical realism argues that the social world is too messy and dynamic for basic, predictable rules (which are characteristic of positivism) to exist, due to the unrestricted interplay of many stratified mechanisms, and the non-static nature of social phenomena. Instead, critical realism seeks to develop understandings of given social phenomenon in their specific contexts through reference to these mechanisms (Bhaskar & Danermark, 2006; Danermark et al., 2002; Houston, 2010). Finally, taking a critical realist perspective

¹² I had this very understanding with many of my classmates and found being able to laugh at my VI with friends a helpful strategy for living with my VI. This is not to say, of course, that teachers should not respond to such jokes and inquire into their intent and interpretation by all parties involved, as it is most certainly not the case that all young people with VI would share this experience.

entails an ethical view of the produced knowledge. By acknowledging that knowledge is constructed from particular social positions, which are not equally powerful in society, critical realism holds that social scientific knowledge should be used to drive change (Bhaskar & Danermark, 2006; Danermark et al., 2002; Houston, 2010). It was this particular way of understanding social phenomena that led to my adoption of critical realist perspective in my research.

3.1.2 The critical realist approach of the current research

The critical realist perspective readily aligned with my own reflections upon the relationship between VI and wellbeing, as well as the research project's driving emancipatory purpose. Adopting a critical realist perspective resonated with my recognition of the need to consider the effects of VI and material/social environmental forces, due to its theorization of multiple mechanisms at different strata of reality (Bhaskar & Danermark, 2006; Danermark et al., 2002; Houston, 2010). Furthermore, it demanded the consideration of the biological reality of VI as one factor, while still upholding the constructed and positional view of knowledge central to the emancipatory impetus of this research.

My intention to explore and unpack these interacting forces from the perspectives of the youth with VI themselves also aligned with critical realism's prioritization of the everyday knowledge of people (Danermark et al., 2002). Youth with VI are active social meaning-making agents; what it means for them to 'live well' (a social phenomenon) is perpetuated and changed through their understanding of wellbeing. Thus, critical realism would assert that it is crucial to include the input of young people in developing understandings of wellbeing among youths with VI.

A critical realist perspective also gave me a specific understanding of exactly what I was doing in my research. In exploring the concept of wellbeing from the perspectives of youth with VI, I sought to unpack their varied understandings of the phenomena in their everyday lives to which they attributed a significant positive meaning or value (cf. Pols, 2010): the connected phenomena from which the social phenomenon of their wellbeing emerged. In addition, I also aimed to explore the kinds of factors and their mechanisms (at the causal layer) involved in contributing to the ongoing promotion or diminishment of their wellbeing (experienced at the empirical layer). This included both factors exerting their influence on their wellbeing as participants conceived it, but also those that shaped their actual understandings of the concept and, as such, affected the real state of affairs that they sought to promote.

Understanding my research aims in this light informed my methodological thinking. My focus on the everyday conceptualizations of wellbeing of youth with VI necessitated a methodological approach that prioritized the knowledge and voices of these youth. Furthermore, my interest in unpacking the layered factors and mechanisms that the youth understood as being at play in these experiences meant that data collection needed to occur – at least in part – in-situ, amidst the complex interplay of factors and mechanisms governing these interactions and how they were experienced. At the same time, I wanted a methodological approach that allowed both the young people and I to delve into the deep messiness of the causal layer of reality to theorize the many mechanisms at play. These considerations led to my adoption of a participatory research strategy.

Participatory methodological traditions offer established principles for exploring a social phenomenon from the perspectives of those most affected by or intimately involved in it (Cartwright & Allotey, 2006; Duckett & Pratt, 2007; Foster-Fishman et al., 2010;

Fowles, 2007; McIntyre, 2008). They aim to reduce ingrained research power disparities so that researchers and participants work together as collaborators throughout the research process. These traditions hold that our understanding of the world around us (our ‘knowledge’) is socially manufactured through our interactions with this world and with each other about our experiences of this world – and so aligns with critical realism (Bhaskar & Danermark, 2006; Danermark et al., 2002; Houston, 2010). They also resonate with a critical realist perspective in that – acknowledging its constructed nature – they assert that knowledge should be action-oriented: should be developed and used to destabilize and alter social structures that subjugate the population driving the research (Duckett & Pratt, 2007; Foster-Fishman et al., 2010; Greenwood & Levin, 2005).

Participatory approaches to research seek to empower participants; recognizing the merit of their everyday knowledge and insights, affording them a voice, and supporting their ‘conscientization’ and broader skill development. The concept of conscientization (Freire, 1972) – refers to the promotion of people’s analytical engagement with their circumstances and the factors within which they are situated, as well as their targeted action for the alteration of any oppressive factors or forces (P. Roberts, 2000). These principles facilitate critique of issues significant to the community of focus in order to promote the creation of shared knowledge and inform actions targeting improvement of social systems (in this case, VI services).

Several strategies can be employed to disrupt the traditional power imbalances between the researcher and participants. Participatory research designs often incorporate alternative methods of data collection alongside more traditional qualitative methods of data collection (Gubrium & Harper, 2013; Lopez, Eng, Robinson, & Wang, 2005). ‘Photovoice’ is one such method, in which participants take photographs of objects, locations or situations within their life or community in order to identify issues that are

salient to them (Foster-Fishman et al., 2010; Lopez et al., 2005; Wang & Burris, 1994, 1997). Participants are invited to select particularly significant images and produce a verbal reflection explaining and analysing their meaning. This gives participants greater influence over the portrayal of their perspective than in more commonly used methodological techniques (Lopez et al., 2005). As discussed below, a photovoice approach was adapted for the current study. Participatory methods also help to promote critical thinking among the participants regarding the broader contexts of their lives (Foster-Fishman et al., 2010; Lopez et al., 2005). In doing so, they provide a voice with which participants can express personally-relevant perspectives of their direct experiences, thus empowering them.

3.2 Study Design and Methods

My study design was adapted from the Youth ReACT (Research Actualizing Critical Thought) methodological framework (Foster-Fishman et al., 2010). This engaged adolescents over three phases – ‘problem identification’, ‘data analysis’ and ‘feedback’ – in order to engage these youth in critical consideration of their communities, to gain useful insights for the improvement of youth-based community programs. Because this method simultaneously promoted youth critical interrogation of their lived experiences and developed practical recommendations, it offered a template for the current study. The Youth ReACT method was adapted in various ways for the current study (see Table 3.1 below on page 93).

The Youth REACT method was transformed to ensure accessibility to all youth with VI, irrespective of their level of remaining vision or the recentness of their vision loss. In the first stages of data collection, the photovoice method preferred by Foster-Fishman and colleagues (2010) was replaced by a method in which participants were

invited to audio-record salient sound environments. In doing so, my intention was not to construct photography as an activity beyond people with VI¹³. Rather, this decision was made in recognition of the potential accessibility challenges of photographic methods for some youth with VI – especially those who have recently experienced VI. Furthermore, as the salience of sound to many people with VI (although not all) is heightened in their experience of their world (Downey, 2016, 2017; Thaler, 2013), engagement with this medium offered valuable insights into the lived experiences of the participating youth. Successful use of audio-recorded diary methods among people with VI in previous research further supported this decision (I. Papadopoulos & Scanlon, 2002; Worth, 2009).

Further changes were made to the Youth ReACT method due to practical considerations. Delays in recruitment meant that my original intention to engage study participants in a participatory data analysis process was changed to a member-checking process, in which study participants provided feedback on the thematic structure derived from the researcher-driven thematic analysis described below (discussed further in section 3.2.4).

The study design comprised two phases (described in detail below). First, each young person participated in three one-on-one or group sessions, and an audio-recording task. Phase two entailed an additional member-checking focus group session for each participant. The study design and methods – including all amendments made during fieldwork (described below) – received approval from the Monash University Human Research Ethics Committee. All documentation – including advertising flyers, explanatory statements, consent/assent forms and handouts – were made available in

¹³ I am aware of recent development work to improve the accessibility of photography as an activity – including the sharing of taken photographs – among people with vision impairment (Adams, Gallagher, Ambard, & Kurniawan, 2013; Adams, Kurniawan, Herrera, Kang, & Friedman, 2016; Harada et al., 2013).

normal-print, large-print, electronic and, where possible, Braille formats to facilitate accessibility.

3.2.1 Recruitment and participants

Recruitment for the current project entailed ongoing engagement with several private and government institutions involved in the delivery of services, including educational services, for youth with VI. My research originally focused on the wellbeing of adolescents with VI. Drawing on my personal experiences that had spawned my interest in this topic, which had occurred during my teenage, secondary-school years, I was particularly interested in these secondary-school years and so opted to define ‘adolescence’ in terms of the 12-18 years age-range which aligned with the ages when young people generally attend secondary school in Victoria, Australia (Victorian State Government Department of Education and Training, 2017a). Initial recruitment therefore focused on an eligibility criterion that young people had to be aged 12 to 18 years (inclusive). Information about the study, particular inclusion criteria (detailed below), and my contact details were distributed by the various collaborating organizations to their clients via email, postal mail, social media, and newsletters (see Appendix A for the content of the study advertisements distributed to participants)¹⁴. In addition, I distributed information about the study at community events run by the organizations, and when I was interviewed about the project for radio broadcasts/podcasts run by two organizations. In each study advertisements, I asked interested youth to contact me directly; those under 16 years of age were asked to contact me with a parent/guardian.

¹⁴ The project was initially presented as an exploration of the youths’ conceptualizations of ‘psychological wellbeing’. However, in line with the participatory approach, ‘psychological’ was removed during data collection as participants felt it both necessary and important to discuss a broader range of topics than this reflected.

Table 3.1

Differences Between Original (Foster-Fishman et al. 2010) and Adapted Youth ReACT Method

Method Component	Original Method	Adapted Method
Complementary method of participant-driven data collection	Photography	Audio-recording
Method of capturing personal reflections regarding participant collected data	Written personal reflections	Audio-recorded personal reflections
	No explicit limits placed on the length of these reflections	Recordings kept to “about a minute in length” to ensure the feasibility of facilitated discussion of them in interviews/focus groups
Presentation of data before data analysis	Photography exhibit held before data analysis	No presentation of data before data analysis occurred

Method Component	Original Method	Adapted Method
Level of participatory data analysis	<p>Activity introducing basic process of thematic analysis conducted in an initial data analysis session with participants</p> <p>Small groups of participants performed initial coding and first-order theme derivation in the same initial data analysis session</p> <p>Based on derived themes, all participants as one group contributed recommendations regarding all study objectives</p>	<p>Returning participants took part in an additional member-checking focus group discussion regarding the themes produced by researcher-driven thematic analysis</p>

Note: Youth ReACT = Youth Research Actualizing Critical Thought.

This approach to recruitment yielded very little success and, over two-and-a-half months, I was only contacted by five adolescents. The young people who did contact me were ultimately not interested in participating, were ineligible based upon other criteria, or were not all available at the same time to facilitate the planned focus group study design. This design was reflective of Foster-Fishman et al.'s (2010) original method, in line with their assertion that this promoted the critical thinking of their participants.

As a result of the delays to recruitment, I revised both my study design and recruitment strategy (Billo & Hiemstra, 2013). First, I increased the flexibility of my study design so that youth could participate in either focus groups or interviews depending on their other obligations (e.g. study, work). In addition, in response to community feedback, I expanded my focus from secondary-school-aged adolescents to a broader category of young people ('youth') ranging in age from 12 to 25 years. This shift had an additional benefit to the feasibility of my research, as VI service organizations began emphasizing the value they saw in a collaborative study with 'young adults' – referring to people in their 20's and early 30's. At the same time, when I attended the VI community events, numerous young people aged 18 to 30 years (who were outside my original age range of inclusion) expressed interest in participating in the research. These young people informally shared stories with me both from their secondary school years but also from their current lives, which led me to reconsider the narrowness of my focus on the secondary-school years. Their stories highlighted that the transition from childhood to adulthood stretched well beyond the secondary school years (Ansell, 2016), with many of the same topics and issues relevant to their wellbeing apparent in young people's stories extending through adolescence into early adulthood. Consequently, I increased the study age range. I continued to employ the same recruitment strategies, with the addition

of increased in-person attendance at organization and community events (discussed further in section 3.4).

Inclusion criteria. During recruitment, interested youth were screened based upon their self-report answers to questions based on the four inclusion criteria. Participants were all required to:

- 1) be aged between 12-25 years of age (inclusive);
- 2) perceive their own VI as increasing the difficulty of daily tasks;
- 3) have no other sensory or cognitive impairment which they felt would prevent their full participation; and,
- 4) be comfortable communicating in English.

Following this screening, eligible people were sent an explanatory statement and consent/assent documentation in their preferred format (i.e. standard print, large print, Braille, electronic). Parents/guardians of youth aged under 16 years of age were sent a parent/guardian explanatory statement and consent form, while their adolescent child was sent an age-appropriate explanatory statement and an assent form. Potential participants indicated their willingness to participate through returning the consent form. Those who continued with participation (21 out of 41 potential participants) after reviewing the documentation were allocated to a set of sessions in the first phase; wherever possible, participants were allocated to a group with participants of a similar age. Personal background and vision history information was collected from each participant or their parent/guardian initially over the phone at this time, and additional clarifying information was also sought where relevant. This personal information included demographic and VI-specific information on: age; gender; residence; education (i.e. their own and their parents'); employment; cause of VI; age at onset/diagnosis of VI; degree of VI (e.g. best-

corrected visual acuity, legal-blindness status); and their history with regard to accessing VI services.

Final sample. A final sample of 21 young people (6 females, 15 males) participated in the first phase. Their mean age at the time of recruitment was 18.62 years (SD = 3.12, range = 13-24). The most frequent primary cause of VI among the participants were retinal dystrophies (11 participants, 52.4% of the sample), with other causes including albinism (2 participants, 9.5%), neurological trauma (2 participants, 9.5%), retinoblastoma (2 participants, 9.5%), and other (4 participants, 19.0%). Participants also reported varying levels of remaining vision. Only two were not classified as legally blind which, under Australian legislation, is defined as: a) a visual acuity of <6/60 in both eyes, b) a visual field of <10 degrees in the better eye, or c) an equivalent combination of both (Australian Government Department of Social Services, 2017). The mean age at onset of their VI reported by the participants was 4.59 years of age (SD = 5.15, range = 0-18). Nine participants reported other chronic health conditions or disabilities, including learning disabilities, mental health conditions, and forms of physical impairment. As shown in Table 3.2., a relatively high level of socio-economic advantage characterized the areas in which most participants lived at the time of their recruitment, determined from the Australian Bureau of Statistics' (2013b, 2013c) Socio-Economic Indexes for Areas (SEIFA) formulated from the Australian Census data. The majority of the participants received 'mainstream' schooling, with only one participant having attended a school specialized in the education of those with VI; they later transferred into a mainstream setting. Nine participants had some form of employment, with some employed full-time, while others were working part-time or more casually.

Table 3.2

Descriptive Statistics for Personal Background Information of Participants

Characteristic	Number (Percentage)
<i>Relative socio-economic status</i>	
1 st Decile (lowest)	2 (9.5)
2 nd Decile	0 (0.0)
3 rd Decile	1 (4.8)
4 th Decile	3 (14.3)
5 th Decile	0 (0.0)
6 th Decile	0 (0.0)
7 th Decile	3 (14.3)
8 th Decile	1 (4.8)
9 th Decile	5 (23.8)
10 th Decile (highest)	6 (28.6)
<i>Educational status</i>	
Current - Secondary School	8 (38.1)
Completed Secondary	5 (23.8)
Current - Undergraduate	3 (14.3)
Current – TAFE or Other	3 (14.3)
Completed Tertiary (Any)	2 (9.5)

Note: TAFE = Technical and Further Education.

3.2.2 Materials

Participant audio-recording task handouts and semi-structured facilitation guides were prepared for the first study phase (see Appendix B and C). Academic colleagues in the field of adolescent mental health external to the project and service provider staff were consulted to ensure the age-appropriateness of the language used and accessibility of any of the session tasks respectively. The guide for the first session in this phase covered topics intended to open collaborative conversation and enumerate the practicalities of the tasks involved. As the audio-recording task was intended to drive discussion in the subsequent two sessions in this phase, the guides for these sessions included targeted

questions exploring participant recordings, and general questions resembling the overarching study objectives. Responsive prompting was used during interviews or focus groups to encourage fluid and open conversation.

The participant handouts provided a point of reference between sessions and also summarized the audio-recording task. They included information on: the question/s of focus; practical parameters (i.e. length of recordings); example recording ideas; and, my contact information. Finally, to perform the audio-recording, participants were given the options of using a provided audio-recorder (either an Olympus VN711PC Digital Voice Recorders or an Olympus VN731PC Digital Voice Recorder), or a familiar personal device (e.g. their own smartphone). Both options were readily compatible with computers via a supplied USB cable, which facilitated easier collection of participant recordings during the sessions and allowed participants to connect the recorder to a computer with their preferred accessibility software and thus more easily manage their recorded files when using the device. This latter consideration was important given the concern in participatory research of preserving participants' control of the data that they produced (Cartwright & Allotey, 2006; Duckett & Pratt, 2007; McIntyre, 2008). Use of this method meant that participants could listen to their recordings and keep or delete whichever files they desired prior to attending the session at which the recordings were collected by the session facilitator. Tactile indicators were also added to the devices' button interfaces after consultation with service provider staff.

3.2.3 Procedure

Study phase one. All participants – and their parents/guardians where required – provided written consent or assent. Given feedback from some interested youth, participants were given the option of taking part in the first phase either via interviews or

focus groups (hereafter collectively referred to as ‘discussion sessions’) depending on what best suited their circumstances. One participant took part in all sessions via telephone due to their geographic distance from Melbourne and the challenges this presented for in-person sessions. Each participant took part in a 1-hour training session and two audio-recorded 2-hour discussion sessions. The first two sets of sessions allowed pilot testing of the method, as well as data collection, and thus were co-facilitated by a research assistant who took notes on the reception and success of the questions and prompts used.

Between each session, participants completed the audio-recording task. They recorded sound environments or lone sounds of approximately one minute in length as representations of moments or experiences in their life which they could later share in-session for the purposes of discussion. They were also asked to audio-record – again, for approximately one minute – reflections on these sound environments/sounds, or any reflection on other relevant experiences for which they could not think of a soundscape to record as a representation. Due to time constraints, participants were asked to identify the most salient recordings they took to discuss in-session. In order to preserve the participants’ power and control over this data, only recordings that the participants wished to share were collected from their recording devices in the discussion sessions.

Table 3.3 outlines phase one step-by-step.

Table 3.3

Step-by-step Description of the First Phase

Point in phase	Itinerary
Training Session	<ul style="list-style-type: none"> • Discussed project rationale, aim and objectives • Emphasized project’s interest in the participants’ subjective views of “psychological wellbeing” and their related experiences^a • Ran through audio-recording task, including the first question of focus, the handout and use of each participants’ selected audio-recording device
Between Sessions	<ul style="list-style-type: none"> • Participants recorded soundscapes/reflections to answer the research question “What is going on in your life when you are doing well?”
First Discussion Session	<ul style="list-style-type: none"> • Collected participant recordings • Shared recordings and discussed the same question posed for the audio-recording task • Ran through second audio-recording task questions and handout
Between Sessions	<ul style="list-style-type: none"> • Participants recorded sound environments and reflections based on their answer to “Does your vision impairment affect how well you are doing?” • If yes, they answered “In what ways does your vision impairment get in the way of you doing well?” and “What helps you to deal with your vision impairment when it gets in the way of you doing well?” • If no, they answered “What helps you to stop your vision impairment from getting in the way of how well you are doing?”
Second Discussion Session	<ul style="list-style-type: none"> • Collected participant recordings • Shared recordings and discussed these same questions posed for the audio-recording task

Note: ^a The “psychological” was dropped during data collection to reflect the breadth of topics raised by the participants.

All participants agreed to be contacted with any additional follow-up questions after the discussions sessions. Eight participants raised topics in their original two sessions that were not fully explored due to time constraints, and thus were followed up later either in-person (three participants) or by telephone (four participants). One participant took part in two additional sessions: one in-person and one via telephone. Some of these additional conversations were audio-recorded, while others were documented through written notes. For each study phase in which they collaborated, participants were reimbursed with a \$20 gift card.

3.2.4 Analysis and member-checking

QSR International NVivo 10 and IBM SPSS 23 were used to manage the qualitative and demographic data respectively. Following Braun and Clarke's (2006, 2013) six stages, thematic analysis was performed on the sound environment, reflection and discussion session recordings. First, all recordings were transcribed verbatim by an external transcription company, a VI service organization volunteer, or by myself¹⁵. Once transcribed, to ensure accuracy and facilitate data familiarization, I then read over each transcript whilst keeping detailed notes of ideas or messages arising from the content, along with reviewing any written discussion session notes. This was followed by inductive coding of each transcript line-by-line. Next, the final set of codes and the data excerpts captured within them were reviewed in order to develop a thematic structure of first- and second-order themes. The themes were then defined and relabelled (Braun & Clarke, 2006, 2013).

¹⁵ I encountered ocular fatigue due to my own VI and the highly visual nature and extended hours of screen time of the thematic analysis process (i.e. in transcribing audio-recording, reviewing transcript accuracy, reading transcripts to promote data familiarization). As a result, my supervisors and I introduced several strategies to manage this fatigue, which included the outsourcing of part of the transcription.

Study phase two. Adding to Braun and Clarke's (2006, 2013) model, the presentation of this thematic structure to a subset of the same participants over additional three-hour audio-recorded group discussions served as the last step in data analysis and represented phase two of the study. Eleven of the 21 participants returned for this member-checking phase: eight of fifteen young men and three of six young women. These final sessions were conducted as group sessions with the aim of reaching group consensus on the key messages to be taken to VI service organizations and providers from their experiences. Consequently, the sessions were organized through consultation with interested participants. An unfortunate by-product of this process was that all of these sessions were held in a metropolitan centre, and so all interested participants who lived remotely except one were unable to attend due to travel constraints. Each participant in the member-checking phase took part in one additional audio-recorded group discussion session, with a total of three sessions conducted. Due to limited time availability, two of these sessions were concurrently held by myself or a research assistant: one group was comprised of two younger youth (aged 14 and 15) and one of three older youth (aged 18, 21 and 25).

This member-checking process engaged participants in a conversation about the accuracy with which the identified themes captured and depicted their experiences. To enable their informed consideration of the themes, participants were provided with succinct bullet-point descriptions of the ideas captured within each theme, and this was accompanied by illustrative quotes. Where relevant, the relationship of each theme to the other themes in the structure was highlighted. This information was provided in the accessible format of their preference two-to-three days before the session, as well as in an accessible written format and presented orally by myself to the participants during the session. To avoid overwhelming participants with the oral presentation of information, the presentation and discussion of the themes was staged in two halves of the three-hour

sessions. The recordings of the participants' discussions in-session in this second phase were transcribed and thematically analysed again using Braun and Clarke's (2006, 2013) staged process. Inconsistencies identified between the analysis of the phase one data and that collected during the phase two member-checking discussions were considered and integrated into the thematic structure via discussion with my primary supervisor.

The original thematic structure was well-supported by the participants, with evident discrepancies primarily regarding the language in which particular themes were described. In general, participants felt that the themes that I had identified from their shared experiences and accounts captured the central elements of life that were important and key factors (e.g. barriers, resources) significant in determining the relationship between their VIs and these important life elements. One major amendment was proposed by participants to the thematic hierarchy: the participants felt that the themes originally outlined in the member-checking phase did not sufficiently capture the importance of independence to them, and the significance of their senses of identity – of who they perceived themselves to be – in determining what they considered salient and how they maintained a valuable life. In response to this feedback, I then returned to re-engage with the sections of the transcripts from the first phase that were coded as representing ideas of independence, freedom, choice and identity. I did so to further explore and unravel any significance of these elements to the wellbeing of the youth to which I had not been sensitive in my initial thematic analysis. This further analysis led to the disaggregation and re-labelling of the major thematic life domain originally labelled 'Progress and accomplishment' into three discrete major themes: 'capability'; 'control'; and, finally, 'a sense of identity'. In reporting on the final themes and thematic structure throughout this thesis, all participants are referred to using a unisex pseudonym to protect their identities.

The above study design sought to provide participants with greater control over the topics of focus and a stronger voice in order to drive change in VI service provision (the emancipatory goal) by enabling their critical exploration and exposition of their understanding of wellbeing (the academic aim). To complement this study design, I also utilized my 'insider status'. Below, I outline how my insider status informed my study design throughout my fieldwork.

3.3 An 'Insider', an 'Activist' or a 'Friend'?

Social sciences have varied in their attitude towards insider research – that is, research into a community, or a group of people with a particular status, conducted by a person who is a member of that community or who shares that status (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015; Voloder, 2008, 2013). Disability studies has been a leading social science discipline in championing insider research, with the slogan 'Nothing about us, without us' a driving mantra (Kulick, 2015; Shakespeare, 2006). Proponents of insider research have demonstrated the value of such research across many levels from the practical to the political. Being an insider researcher can facilitate the easier establishment of field relationships as a point of similarity; aid in the unsettling of conventional power biases towards the researcher in the research process; and, offer a different angle from which to approach an issue and thus suggest different lines of exploration than that considered by an outsider researcher (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015; Worth, 2008). However, the recognition of the value of insider research can also be overstated. Worth's (2008) study with disability geographers found that several placed greater value on research that had been conducted by researchers with disability due, in part, to the perception that these researchers would have knowledge of disability as an experience that non-disabled researchers could not. Similarly, some disability scholars

have asserted that the emancipatory undertaking of disability research was a space only for those with a personal connection to impairment and disability (Branfield, 1998; Charlton, 1998). They argued that non-disabled researchers were not able to remove themselves from the oppressive systems and structures imposed upon people with disabilities and, as with other insider social researchers, have argued for the increased (or even inherent) insight into an overarching lived experience of disability provided by their intimate connection to the topic. Despite such assertions, many other scholars have problematized these simplistic and overstated perceptions of the value of being an insider for research (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015; Kulick, 2015; Shakespeare, 2006; Worth, 2008). Such questions of representation – and who is best to represent whose experiences – highlights the complexity and challenges which accompany the potential benefits of insider research, something which I attempted to balance at the outset of and throughout my research as I describe in the next subsection.

3.3.1 An insider within what? Disability culture and challenges of representation

During my research, I recognized the value of my ‘insider’ position in developing a rapport with my participants, in guiding possible lines of inquiry upon which to hear their voices, and in seeking to disrupt traditional power imbalances in the research process. However, my personal experiences around VI – somewhat ironically – raised questions about the assumptions underlying some perceptions of the value of insider research (Branfield, 1998; Charlton, 1998; Shakespeare, 2006; Worth, 2008).

My prior participation in many VI-related events in Victoria, Australia, and long-standing acquaintance with others with VI through such events raised questions regarding how to appropriately use my insider status during my doctoral research. In particular, I grappled with the question of how my status could inform my understanding of – or

potentially could obscure – the experiences of the participating youth. In reflecting on this question, I considered whether I shared a common experience of VI with these others and whether this meant that we shared a particular view of the world around us: what many have discussed as a disability (sub)culture (Hopfe, 2011; Peters, 2000; Riddell & Watson, 2003).

Discussions about the existence of disability cultures and subcultures have often been central in debates regarding representation of the voices of people with disabilities (Shakespeare, 2006). Within the disability movement, as well as in the academic discipline of disability studies, several contributors have appealed to the existence of a shared disability culture developing from a united identity politics, advancing the rights and interests, and fighting the oppression of people with disabilities (Peters, 2000; Swain & French, 2000). Peters (2000), in particular, argued in favour of an overall disability culture. She highlighted – among other things – the common and deliberate (re)definition of terms by people with disabilities to discuss their lives. This broad ‘disability culture’ was evidenced through the existence of many active community groups in which people with disabilities find peers who influence their understanding of their self and their impairments, as well as in the mutual fight of many people with disabilities against oppression to change society (rather than simply gain admittance into its current form) so that it better embraces heterogeneity. Others have refuted that such a disability culture exists, and instead critique the subsuming of many people with varying disabilities by the dominant identity championed by this movement (Shakespeare, 2006). Within the specific context of VI, Downey (2017) highlighted that the existence of a blind subculture, in which a shared way of viewing and understanding the world is shaped by a mutual experience of VI, remains controversial. While this debate continues, Downey (2017) acknowledged the potential for VI subculture formation through the growing

utilization of alternative means of knowing space, such as echolocation, and the possible benefits this may present for the VI community.

It would be presumptuous, arrogant and inappropriate for me to claim a resolution to such debates based on my own personal experience; yet I was aware of the considerable differences among how youth (and people more generally) view their VI and how they relate to the environments and society around them. For example, I presented at a VI skill development program six years ago, with my long-time friend with VI, Joe (pseudonym), who had no remaining light perception. While we both spoke about attending typical undergraduate university social events, it was clear that my strategies would not work for him (and vice versa); instead, he would often use sonic – although not always viable in these loud settings – and olfactory landmarks to locate himself. It struck me, instantaneously, that it would be much more complicated to communicate his strategies to accompanying sighted friends who may not be as aware or even capable of detecting them. Thus, significant differences existed between how Joe and I experienced VI, and thus how we related to our VI and the world.

Other experiences also highlighted to me the differences in whether youth with VI felt they were, or whether they wanted to be, part of a VI community with a particular shared experience of VI and the world. Although I have always felt connected to some type of a VI community – even if I have not always been the most active member – and have maintained contact with friends made through events run as part of this community, I have encountered numerous youth who have denied their affiliation with this same community. They did not attend events run by VI service organizations, VI community organizations (e.g. VI-specialized sports leagues) or by other people with VI themselves. They also kept in minimal contact with others with VI. I vividly recall one evening's conversation with a middle-aged dog-guide-user on the bus. On learning of my VI, he

asked me where I was going and when I informed him that I was heading out to a pub with my friends, he stated that it was good I was venturing into the “sighted world”. He described that he had seen many people get “stuck” in the “vision impaired world” only going to “vision impaired events”, and how he had fought to break out of this world which tries to “suck you in”. This conversation suggests that, in addition to divergent perspectives and experiences of active VI community members, youth with VI may not even want their life and wellbeing to be understood through ideas arising from my participation in this community.

Such variability in perspectives and experiences emphasized to me that my way of thinking about ‘living well with VI’ could in some ways be inapplicable to my study’s participants, and that there were also extant risks to the quality of my research and analysis if I were to uncritically treat my participants and myself as members of an identifiable group. It would not be fair to say that my personal experiences with others with VI and their different points-of-view and experiences compared to my own wholly contradicted the appropriateness and value of exploring my participants’ and my own lived experiences as representatives of the group ‘youth with VI’. This is because my insider status also highlighted the existence of a degree of similarity in our experiences and ways of interacting with the world (Hopfe, 2011). For example, despite our different experiences at and ways of navigating undergraduate social events, Joe and I also had common experiences of discrimination and around our optimal use of mobility aids in more everyday navigation of public space. It would be equally reprehensible to overlook these points of similarity, especially as they would likely offer items of particular importance for service providers to ensure that they address when they do, inevitably, approach the provision of services to youth with VI as a group at some level. Nonetheless, my personal experiences highlighted the need to be more critical and

mindful in approaching my project as research into the lived experiences of ‘youth with VI’. In short, I realized there existed the potential for valuable insights into different ways of living well with VI to be overlooked if I drew too heavily on my own perspective or that of any one participant. Thus, the differing perspectives among youth and people with VI that I had previously encountered drove home to me the inaccuracy of essentializing assumptions that have at times underpinned the represented utility of insider research, including in disability studies research (Branfield, 1998; Worth, 2008). Indeed, Shakespeare (2006, p. 195) argued that “[j]ust because someone is disabled does not mean that they have an automatic insight into the lives of other disabled people. One person’s experience may not be typical and may actively mislead them as to the nature of disability”. I contended that a similar assertion specifically regarding VI rang true.

Coming to this research with my own appreciation of the layered complexity of living with VI highlighted to me the care with which I needed to ensure that my insider status insight did not preclude or overshadow the voices of the youth with which I was collaborating; a potential danger of insider research (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015; Worth, 2008). This was not to say that I should not draw upon my personal experiences of wellbeing and VI and incorporate them into the study; given my aim to explore wellbeing from the perspectives of youth with VI, my personal experiences presented a valuable resource much like those of the other youth. Rather, it highlighted the need to sensitively manage this. In fact, my prior experiences within the VI community stressed to me the value of my insider perspective as a point of reference to utilize throughout the process of critically exploring how different youth experienced and understood living well with VI (Voloder, 2008).

3.3.2 The differences of ‘insider-ness’

As my fieldwork unfolded, I adopted a form of “insider-ness” as a useful point of connection from which to commence and frame a dialogue between myself and study participants. In line with the nature of dialogical relationships (Frank, 2005), I sought to engage in constructive comparison and conversation with the youth from our individual perspectives, rather than overly-focusing on any elements of shared experience produced by VI. I avoided the mindset that, through the project, the participants and I could produce one unifying account that represented all of our experiences in entirety (Frank, 2005; Owton & Allen-Collinson, 2013). Reflecting upon her own experience conducting insider research, Voloder (2008) emphasized that the value of conducting research as an insider is not simply an increased insight into the lives of participants. Instead, it is in the provided opportunity to unpack the complexities of a group’s lived experiences that the true strength of insider research lies. In this vein, I considered my own experiences in my analysis of my participants’ situations and shared my own experiences with participants to prompt deeper analysis of the difference in our experiences. This was evident in my research encounters, such as in the following conversation with one participant:

Alex: [A]s a young woman wanting to look her best, it's been interesting. I wouldn't say it's been a problem, but it's just been something I've had to work with... You know, like having to find sighted people that I can shop with... [It is] just some of those little things that... have been challenging, but also in a really positive way.

Ross: So, you mentioned a couple of things there. You mentioned outfit shopping, which... I don't do a lot of. I get gifted shirts and I wear them... Can you tell me a little bit more [about] shopping for your outfits and when perhaps your vision

presents an obstacle to that? How does it affect you? How does it make you feel?

And what strategies have you used to handle that impact?

Following Voloder (2008), I used my experiences as a youth with VI as “a contrasting tool” (p. 35). In the same way that a researcher may draw on the account of an earlier participant to inquire deeper into later participants’ experiences, I treated my own insights as an alternative perspective to prompt participants for further information. In so doing, I was able to better contextualize our different experiences of living with VI, and gain a sense of the factors and mechanisms involved in shaping them in line with my critical realist approach (Danermark et al., 2002; Houston, 2010).

Despite the benefit of using my own experiences as a contrasting tool, this approach also carried with it particular risks or limitations that would be of less concern for an ‘outsider’ researcher (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015; Worth, 2008). In particular, in employing my own experiences I had to actively monitor the risk of becoming “self-absorbed” (P. A. Atkinson, 2005, p. 403). In other words, I actively sought to avoid (unintentionally) focusing on my own experiences and taking for granted my own understanding of living well with VI and, thus, overlooking or failing to critically unpack particular elements of the youths’ experiences (Voloder, 2008). I engaged in active reflexivity throughout my research, keeping a fieldwork diary to the best of my capacity (discussed below). Constant conversation with my supervision team also assisted in the negotiation of these multiple perspectives. I also sought to consider and manage power dynamics in my relationships with the youth during my enactment of this dialogical approach.

The potential risks of using my insider status that accompanied the valuable use of my own experiences as a counterpoint, therefore, placed greater importance on the principles of participatory research described above (Cartwright & Allotey, 2006; Duckett

& Pratt, 2007; Foster-Fishman et al., 2010). In giving participants greater control over the topics of focus, some of this power was removed from myself in our collaboration. The youth were then able to bring elements of lived experience and wellbeing for them into our critical gaze. Furthermore, by working to disrupt the traditional power relationship of the research process, this approach also encouraged the youth to challenge any interpretations of their experience that I expressed. Again, this meant that they could highlight any elements of importance that I overlooked.

Commencing my fieldwork, it became quickly apparent to me that participatory methods alone were insufficient. How I actively positioned myself, and then how participants positioned me in relation to themselves and the VI community during fieldwork was also central. Although it provided an initial point of similarity with other youth, my status as a youth with VI alone was not sufficient grounds upon which to sustain a dialogue about the lived experience of VI as a peer-collaborator rather than a ‘researcher in control of the study who happened to have VI’. Instead, driving this dialogue involved deliberate commitment to my relationships with the youth, some of which were friendships that pre-dated this study. Thus, in informing my research practice, I drew upon literature around the unitization of friendship-as-method (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003).

Proponents of friendship-as-method highlight the utility of approaching research from “a stance of friendship” (Owton & Allen-Collinson, 2013, p. 287) in disrupting the traditional power dynamics of the research process. Friendship is understood as a strong connection between two people who – over an extended period of time – come to know each other by moving through and sharing their experience of the world together (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003). Translating this into a research approach, Tillmann-Healy (2003) describes that adopting friendship-as-method generally

entails conducting research via the actions and in the time-period and spaces of friendship. This demands time both in terms of intensity over a given period and with regard to the total duration of fieldwork and moves the research beyond the interview room to more informal social settings, including parties, casual social ‘hang-out’ sessions, coffee shops and so on. Research is practiced through standard data collection methods (e.g. interviewing, note-taking), but important data is also understood to arise spontaneously during regular informal communication, swapping stories, and participation in activities of mutual interest (e.g. playing a particular sport). Although the feasibility of such time commitments and wide-reaching forms of participation depends upon several factors outside of the researcher’s intentions (e.g. institutional requirements), Tillmann-Healy (2003) indicated that the most important element of employing the friendship-as-method approach is conducting research with the spirit or qualities characteristic of friendship. In friends, we seek qualities of: trustworthiness; truthfulness; a welcoming non-judgmental nature; dedication; dependability; respect; magnanimity; empathy; and, reciprocity (Matheson, Olsen, & Weisner, 2007). Employing the friendship-as-method approach, therefore, involves engaging in relationships with participants drawing on these same qualities. As a result, adopting a stance of friendship is about engaging in field relationships with sincere respect, openness and care toward the participants which may in fact lead to decisions that hinder project objectives but protect the interests of participants (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003).

Below, I describe how I practically applied this stance of friendship within my collaboration with the youth with VI, the various challenges I encountered during this process (including some missteps on my own part at the outset of my recruitment and fieldwork), and some key complexities inevitably entailed in its adoption.

3.4 Power and Positioning in Practice

My fuller adoption of this stance of friendship in my research was not instantaneous. Many of the reflections and considerations outlined above developed throughout my fieldwork, especially in the first few months. In particular, my ideas about the optimal means of practically instigating and then maintaining collaboration with participants were reappraised over these initial months (Billo & Hiemstra, 2013). This process involved consideration of my extant relationships with people within the ‘field’ and their power balances, including their implications for the ethics of different avenues of engaging youth. I describe these considerations below, before elaborating my resultant enactment of friendship-as-method (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003).

3.4.1 Mixing pre-existing and new (power) relationships

Given my insider status (described above), the balances of power between myself and many participants were not as clear-cut as in traditional social science research.

Participatory research aims to challenge and disrupt conventional power imbalances in which the researcher holds a majority (if not all) of the power in their relationships with each participant throughout the research (Cartwright & Allotey, 2006; Duckett & Pratt, 2007; McIntyre, 2008). In contrast, on commencing my fieldwork, I sought to maintain my awareness of and work to manage different levels of power imbalance with different participants.

My relationships with several participants existed as (close) friendships prior to my doctoral research. Consequently, throughout my research, these relationships were characterized by a more even balance of power. This is not to say that I saw the management of the power balance in these relationships as unrequired. The considerable effort required of both parties in a pre-existing relationship to manage their multiple

identities when the roles of ‘researcher’ and ‘participant’ are added has been previously described (Garton & Copland, 2010; Owton & Allen-Collinson, 2013), and, thus, I was aware that changes in these friendships would need to be monitored. Nonetheless, it was easier to attain the minimization of traditional research power imbalances and establishment of a collaborative friendship dialogue. However, as my pre-research encounters with several others were fleeting or non-existent, more traditional researcher-participant relationships were generated, regardless of our shared status as youth with VI, with a power imbalance biased towards myself. I felt this was particularly true of the younger participants (i.e. 12-15 years of age) who may have perceived me as in a position of power due to my age (i.e. early 20’s), a pattern which has been identified by other scholars regarding field relationships with young people (Fattore et al., 2009; Spyrou, 2011).

3.4.2 Reflections on initial recruitment

My recruitment strategies (described above) were informed through my ongoing and active engagement with VI service organizations. Staff from the various organizations were consulted regarding available resources to aid recruitment and the most effective methods of dissemination to their clients. These staff indicated that methods of mass-advertisement represented the optimal channels for reaching both active young clients, and those not currently receiving services. This ensured my inclusion of interested youth who did not necessarily wish to affiliate or participate in the VI community.

My recruitment also entailed consideration of the ethical implications related to my pre-existing friendships and envisaged new field relationships. I was particularly sensitive to concerns about the potential for unintended coercion in face-to-face recruitment, and sought to ensure that youth – particularly, younger participants – did not

feel pressured to participate. Even within my pre-existing friendships, I was wary of different forms of coercion and often stressed to these friends not to participate from a sense of obligation as a friend. Given these considerations, I felt it appropriate to favour recruitment methods that did not entail these (perceived) risks in order to respect participant autonomy.

This ethical concern with free and informed consent notwithstanding, it became apparent that these recruitment strategies were neither the ideal strategy for engaging the interest of youth with VI (given the delays to recruitment described earlier), nor the optimal means of positioning myself as a ‘friend’ with whom the youth could collaborate. In contrast, the most successful method for sparking interest from other young people with VI was through an in-person presence in the VI community. Consequently, I adapted my approach to recruitment and fieldwork.

3.4.3 Being a ‘friend’

Following initial delays in recruitment, I changed my approach to my fieldwork to one of comradery and companionship (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003). In consultation with my supervisors – including around conducting face-to-face interaction without imposing unintended pressure upon interested youth¹⁶ – I returned to more active VI community involvement: youth activity groups; sporting leagues/programs; and, informal social gatherings (e.g. parties). This allowed me to develop new relationships with potential participants; my deliberate effort in getting to know them (and allowing them to know me) extended beyond the focus of the research.

¹⁶ I managed this by often giving one group announcement on my first time attending an event and then only discussing my research, again, when approached. Where this was not possible, on approaching a young person I would include an explicit statement about the voluntariness of participation and provide them with information to take away so they could contact me if interested. Several youth – after asking questions about the research – quite comfortably expressed their disinterest in participation and continued to happily talk and hang out with me.

In addition, despite the added researcher-participant dynamic, I made concerted efforts to maintain personal communications and interactions with pre-existing friends.

Furthermore, this friendships-as-method approach extended my dialogue about ‘living well with VI’ with young people beyond formal research settings to these more informal interactions (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003). I used a number of specific strategies to enact this approach.

First, I increased my attendance of VI community events particularly those run by and for youth with VI, which are quite well-attended by this population. This included youth activity group programs and camps run by organizations, and several ‘blind sports’ competitions primarily run by volunteer members of the VI community themselves, their family, or through particular VI-related organizations. Thus, I spent several weeknights and many weekends at these events. I did not just attend, rather embedded myself in the proceedings of these events. I won and lost games to many new and old friends at a ten-pin bowling bar on youth activity nights and accrued several bruises and a sprained ankle from my ineptitude in VI-specialized sports. Most notably, I joined and played for a team in one sports league over multiple seasons – a team for which I continued to play beyond my fieldwork – experiencing the collective pride of our cohesive team-play and chagrin of our embarrassing team losses. I went to grab coffees, lunch or a beer after the formal proceedings were finished, and – outside of these regular community events – attended other one-time functions: for instance, a trivia night and one participant’s birthday party.

This active community involvement brought new decisions about my behaviours at these events, which I navigated both through documenting my thoughts in my fieldnotes, and through regular consultation with my primary supervisor. One such decision surrounded my consumption of alcohol during fieldwork, a decision which was almost thrust upon me. Having a few social drinks was a common part of the informal

social activities that occurred around many of the VI community events. At the social gathering at the end of the first event I attended, another community member returned from the bar with a beer for himself and for me. I graciously accepted this beer and – aware of the norm of returning a ‘shouted’ round of drinks – also bought another two beers (one for myself and one for my companion). This issue regarding my participation in alcohol consumption highlighted the tension between my dual roles as researcher and friend: I did not want to look unprofessional but felt that to decline the offer to share a drink with community members could create distance between myself and the community members. It would have re-positioned myself as a researcher who could not drink because I was working, rather than a peer. In the end, I decided to balance these competing concerns and engage in a limited amount of social drinking: no more than two or three beers over a whole event, depending on the length of the event.

Increased participation in the VI community was not the only means by which I took a stance of friendship in my collaboration with the youth with VI. Several participants did not attend the events that I was able to regularly attend. For some, this was due to a lack of interest, while others faced travel and logistical difficulties. My own active participation in these events meant nothing to my relationships with these participants, and thus my efforts to sustain personal connections and more equal balances of power with these youth took other forms. I kept in regular contact with all participants via telephone, and these regular conversations supported my participatory and friendship approach in two main ways. First, these conversations served, in part, formal research purposes: I updated participants on project progress, future steps and my own work efforts, which kept me accountable to participants as collaborators. They also kept the participants engaged in the research process. Such frequent contact with participants also facilitated my friendships with participants. Following the more formal update, these

conversations were frequently prolonged – some lasting for approximately an hour – and covered many topics beyond the project. This included discussion around my attendance of certain VI community events, other recent social outings, anecdotes about my partner or family members, my own or their current/changing living arrangements, and my understanding of changes to Australian Federal Government funding schemes for disability services occurring at the time of my project (Whitburn, Moss, & O'Mara, 2017). The value of these regular personal catch-ups with participants in fostering a personal friendship was exemplified in my relationship with Caelan. As Caelan lived quite remotely, regular in-person communication with him was not possible. However, through multiple phone calls, we developed a strong personal connection over Australian Rules Football. Caelan always raised football whenever I rang; evaluating the performance of my team – the Essendon Bombers – or his team, and often engaged me in good-natured football-supporter banter which spilled over into our interview sessions:

Ross: It is recording now.

Caelan: Essendon [football club] sucks.

Ross: And he was waiting to do that.

Through active participation and my deliberate commitment to maintain a personal connection with the participants, I made and sustained new and existing friendships respectively. In conducting this research from a sincere position of comradery alongside a participatory methodological approach, the balances of power between myself and the participants became more equalized; at the same time, the youth themselves became empowered within the research relationship. This approach brought a sense of active contribution to their collaboration, as was evident in how participants such as Max spoke about the project:

Doing this program, I just told my parents, “I’m going to do it, I’m going to help this... guy called Ross, I met him at [this event and] he’s vision impaired like me, and he wants to hear my input... to help [the VI service organizations] grow as... organizations and through this project I’m going to help him achieve that”.

Thus, approaching my fieldwork from a position of friendship aligned with and supported the emancipatory goals driving this research (Berger & Lorenz, 2015; Duckett & Pratt, 2007; M. Oliver, 1997). However, this value and benefit of this approach did not come without costs or challenges.

3.4.4 The challenges and costs of friendship-as-method

Forming and maintaining friendships with my participants produced several challenges and costs. In particular, the ethical complexities of data collection in my research practice and impacts upon my own emotional status both required consideration.

My use of a friendship-as-method (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003) approach to fieldwork had implications for the collected data. These manifested in the content that participants perceived they could discuss during the project sessions, and upon what information that I felt it was acceptable to collect as data. With regard to the former, it became apparent to me through in-session interactions with some participants that their awareness of my dual position was actively leading them to perceive certain discussion topics as off-limits:

Elliot: I'd say the majority of the time I spend with friends that they're from [my volunteering] or a couple from vision-impaired-related events **pauses** ...

Ross: *Such as myself.*

Elliot: Such as yourself **laughs** I'm not sure what...

Ross: *You can mention that.*

Elliot: Can I mention that we're friends, **changes voice to a joking whisper** they won't find out **laughs again**

Elliot and I have been friends for a considerable time, and as he began to raise this topic he overtly expressed his uncertainty around whether he was allowed to mention our pre-existing friendship. This uncertainty was not a factor for all participants, many of whom showed no hesitation in explicitly weaving mention of our friendship into their accounts. Nonetheless, having this interaction with Elliot made me wonder whether other participants' considerations on what to share in the project had been impacted in the same way. Armed with this thought, I endeavoured to explicitly indicate to all participants, where it was appropriate and not jarring or presumptions, that they could discuss their relationship with me if relevant.

Alongside participants' own potential filtering, being both researcher and friend also raised the issue of what observations/communication was it fair to consider or follow-up as data (Ellis, 2007; Owton & Allen-Collinson, 2013; Seal, Bloom, & Somlai, 2000). Maintaining friendships with the participants, and thus engaging with them in various social settings, meant that they often shared stories with me not raised in their interviews/focus groups. These stories were told more frankly, and participants visibly engaged in less in-moment consideration upon our conversation in informal interactions. For example, over coffee following our first interview, one participant shared with me the highly political and negative undercurrents at play within a particular VI community group, naming (in quite unflattering terms) multiple offenders. This contrasted their glowing description of this group's importance to their wellbeing in our formal session. Immediately following this coffee, I wrote out notes capturing the details of this particular conversation. This process prompted my own reflection on the situation that led the participant to this revelation and whether I ought to include the specific details as data. I

considered that approaching my research from a position of friendship was not about enacting a deceptive ruse to better infiltrate the participants' lives, but required an equal commitment to my dual roles as researcher and friend (Owton & Allen-Collinson, 2013; Tillmann-Healy, 2003), enacting real care for the participants – if necessary putting them above the project. In this vein, I felt that including the particularities of the participant's revelations may expose them to social ramifications (Ellis, 1995; Stein, 2010), and so I opted to make note of only the general theme(s) raised by participants when sharing these accounts.

My emotional investment in my participant friendships also had costs in my personal life. Being or becoming friends with participants meant that I increasingly cared about how they perceived me (Owton & Allen-Collinson, 2013). At points, I found myself emotionally burdened by my field relationships during my downtime, concerned about mistakes in expression that I felt I had committed. One such mistake occurred in the last of several early-to-mid evening telephone conversations during the data analysis period, when I was feeling particularly exhausted (as discussed below). I was confirming Harper's background information and, despite knowing from focus group sessions that he had withdrawn from a university degree, insensitively asked about his highest level of completed education. I started the question in a way that immediately felt jarring: "I know that you *attempted to go to university...*". Harper gave no indication of offense, and thus, despite instant anxiety, I decided in-moment not to stop to apologize for my phrasing. However, my concern about potentially having offended Harper and my frustration at myself lingered for the remainder of that evening and the next day. Similar social concerns, and related feelings of guilt, arose when I was unable to attend VI community events at which I was expected, or even when I had to inform participants of delays to the project timeline. The significant impact of these social concerns and emotional reactions

led me to develop particular strategies to take a step back from the project when they arose in order to maintain work-life balance (as recommended by Rager, 2005), including exercising and reading audio-books.

Despite the associated challenges, such as the additional ethical considerations and emotional costs, this personal involvement in the VI community was worthwhile. It was through this approach that the power dynamics between myself and the participants became more balanced, and participants were motivated to actively and critically contribute to our collaborative exploration of our wellbeing as peers. This approach enabled me to ensure the quality of my research, as I discuss in the final section of this chapter.

3.5 Evaluating the Quality of the Project

During my research, I engaged in mindful reflection and deliberate efforts to ensure its quality. The current project occurred within the disorderliness of the real world (Billo & Hiemstra, 2013). Factors both beyond and within my control impacted upon and restricted its conduct, and the output that was yielded. These project limitations are acknowledged.

First, a gender bias was present within the study sample: female participants comprised less than a third of the sample (6 out of 21 participants). This bias reflected cultural/institutional gender biases in the attendees of regular and well-attended VI community events that were available for me to attend: in other words, the VI-specialized sporting programs and service provider youth programs were predominantly attended by young men. In some instances, this was explicit: one youth program was a social inclusion initiative targeting boys and adolescent men with VI. Young women were not permitted to attend, as it was gender-specific¹⁷. Similarly, although the VI-specialized

¹⁷ This program has since been expanded and is no longer gender-specific.

sports were not exclusively for young men with VI, their members and participants still predominantly comprised males (at all ages). As a consequence of the underrepresentation of women in the study sample, the themes and ideas raised by the participants in this project may be gendered. While gender was raised by a few of the participating young men and women, given the sample composition, issues affected by gender may not have been examined fully (if at all) in this study. Related to this, some participants raised themes regarding the role of their ethnic backgrounds and religious beliefs in their wellbeing and their management of difficulties associated with their VI. However, as I did not collect this type of background information from participants, these important intersections could not be more fully examined. Future research continuing the exploration of the lived experiences and wellbeing of youth with VI should seek to do so with samples containing more equal gender and ethnic representation.

Second, given the use of both interviews and focus groups in data collection, some variations may have also arisen in the ideas and experiences participants expressed, or how deeply they explored them. Variation also existed across the participants in the amount of time between their discussion sessions in the project's first phase: those who had longer interceding periods of time may have engaged in greater reflection on the research questions. Alternatively, they may have forgotten the details of the project or become bored. Despite these differences, qualitative review of the transcripts indicated no readily apparent discrepancies in the ideas raised or depth of discussion across the sessions.

A further limitation related to the selected participant-driven audio-recording task. Many participants found this audio-recording task easy and consequently returned to the discussion sessions with novel insights into their own lives. Nonetheless, some found the task difficult, particularly in finding sounds to record to represent their experiences.

While all participants discussed the practicalities and scope of this task – including the presentation of a few simple examples – I deliberately emphasized the openness of the scope in order to avoid restricting participant voices. Future participatory research with youth with VI using participant-driven data collection tasks (e.g. similar audio-recording tasks, participant diaries) should engage the young people in detailed but well-managed discussions around the topics and focus of the task. Part of treating participants as equals involves recognizing that they possess sufficient autonomy to engage in an open conversation without being immediately led to some action. Greater engagement of the participants in the analysis phase of the current research beyond member-checking, as originally planned, would also build upon this work in future similar research (Foster-Fishman et al., 2010).

One final limitation affecting the conduct of this research arose as an interaction between my own VI and many of the highly visual tasks – at least with my current set of personal adaptations – involved in data collection and analysis (i.e. field and reflexive journal note-taking, transcription, transcript review, coding). Throughout this phase of my research, I experienced ocular strain and fatigue. I proactively managed this, devising a set of strategies with my supervisors: external transcription support; use of rest breaks; and, restricting my hours of work in a day. Nonetheless, at points, this fatigue and these management strategies impacted my ability to maintain these records. Following fieldwork, I was sometimes too tired to write out my notes or a reflexive entry in the evening. As many field events and interviews/focus groups occurred over consecutive days, I encountered a backlog in some instances. Despite these challenges, keeping fieldnotes and a reflexive diary was a valuable process, and I thus sought to combat these challenges. On public transport journeys home from events, I utilized the in-built note-taking feature on my smartphone to bullet-point – in my own shorthand – the timeline of

the event and any accompanying reflections (Schensul, Schensul, & LeCompte, 1999). This meant that when I was able to write a fuller entry I had all the information in short-form to prompt my recollection (Schensul et al., 1999).

Although important to acknowledge and consider, the presence of these limitations did not undermine the quality of this research, which in its design and conduct satisfied established criteria for qualitative research quality (Lincoln & Guba, 1986; S. L. Morrow, 2005). Lincoln and Guba (1986) assert that the quality – or “trustworthiness” (p. 76) – of qualitative research should be evaluated by four criteria: credibility; dependability; confirmability; and, transferability. Credibility captures the extent to which qualitative research, from commencement to the reporting of the researchers’ interpretations of the collected data, achieves what it claims to achieve. In my research, I made deliberate effort to maintain a truthful representation of the voices of participants. Many of the methods utilized in the current study have been explicitly detailed to ensure satisfaction of this criteria: extended participant engagement, data-source triangulation – in this case, participant sound-recordings, personal reflections and in-session discussions – and member-checking (Lincoln & Guba, 1986; S. L. Morrow, 2005). In addition, my efforts to empower participants to act as (or as close to) equal collaborators with me throughout the research process, through the use of participatory data collection methods (e.g. participant-driven audio-recording data collection task) and my adoption of a friendship-as-method approach have also worked to preserve the participants’ voices and promote the project’s credibility.

My research also satisfied the criteria of dependability – that a uniform approach must be taken in conducting a qualitative research project across the different time periods, investigators and situations involved. Dependability was promoted in this study through both regular consultation with my supervisor and the action of working to keep

regular fieldnotes, including regarding research decisions and their justifications (Lincoln & Guba, 1986; S. L. Morrow, 2005). Extending this, confirmability – the notion that reported findings from a qualitative research project are grounded in participants’ voices (Lincoln & Guba, 1986; S. L. Morrow, 2005). The confirmability of my findings is demonstrated throughout this thesis by presenting clear evidentiary quotes in support of my assertions.

Finally, transferability refers to the extent at which individuals who engage with a particular piece of research are able to determine whether the concepts and findings it reports, from within its particular context, are salient and useful to them in a different context (Lincoln & Guba, 1986; S. L. Morrow, 2005). Detailed description of the context of the research – including the researchers’ particular perspective, participants’ circumstances and the relationships between the participants and researchers – should be provided to promote this transferability. It is for this reason that I engaged in the detailed reflection of the research process in this chapter. I have also provided as much contextual information around participant accounts in order to illustrate the conditions under which participants’ experiences and reflections were produced. This effort, of course, was balanced with the priority of protecting the participants’ confidentiality and anonymity.

To further promote the transferability of participants’ ideas of ‘living well with VI’, and their implications for VI service provision, in the next chapter I provide an overview of the Victorian VI services context, before subsequently presenting my research findings over the remainder of the thesis.

Chapter 4

Vision impairment services in Victoria, Australia

Acknowledgement of the context in which this work was conducted is necessary to fully understand how the participating youth with VI regarded their wellbeing. In particular, an outline of the service provision context is important. The participatory research approach I adopted for this research holds that all human knowledge of the world– for example, of what contributes to and threatens our wellbeing – is socially constructed by people (Cartwright & Allotey, 2006; Foster-Fishman et al., 2010; McIntyre, 2008). As such, this knowledge is rooted in the particular social context in which people exist (Bhaskar & Danermark, 2006; Danermark et al., 2002). The participants were well-aware of the action-oriented impetus of our collaboration and actively reflected upon their experiences with existing services all throughout. Thus, providing an overview of the services available in Victoria, Australia – the geographic location of this research – will contextualize the participants’ accounts and the knowledge produced through our collaboration.

This chapter commences in the first section by describing the landscape of services available to young people with VI in Victoria, Australia. I also present the participants’ self-reported use of different kinds of service provision. In presenting this overview and the participants’ history of service utilization, this chapter also demonstrates the relevance of my larger critique of VI services as being underpinned by an understanding of ‘living well with VI’ grounded in the personal tragedy model of disability that I espoused in Chapter 2 (M. Oliver, 1990; Prilleltensky, 2009; Swain &

French, 2000). In the second section of the chapter, I argue that – while there has been clear movement beyond the personal tragedy model of disability in the Victorian VI services context in the wake of the disability activism of the 1970s, 1980s and 1990s in Australia (Soldatic & Pini, 2012) – the strong influence of this personal tragedy model remains.

4.1 An Overview of the Victorian Services Context

Victorian youth with VI and their families can utilize services from various educational or rehabilitative organizations as they transition from their early teenage years into adulthood. Services, resources and supports are available both within the Victorian State Government Department of Education and Training (DET) and the public healthcare and welfare systems. Not-for-profit, faith-based and independent institutions, and privately-owned specialist practices can also be utilized (Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015).

As youth with VI can access services and supports for and as part of their education, the DET represents a key provider of services in Victoria. These services are provided through itinerant visits by professionals to schools and periodic attendance by students of specialized government-run programs, due to the Victorian Government's general political shift towards the inclusive education of students with disabilities (Subban & Mahlo, 2017; Victorian State Government Department of Education and Training, 2016). Instead of separate specialized government schools for students with VI, the Statewide Vision Resource Centre provides a key hub for these itinerant and periodic services within 'mainstream' education settings (Statewide Vision Resource Centre, n.d.-c; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). It provides professional development and informational

newsletters regarding the education of students with VI, production of alternatively formatted learning materials, and skill development programs targeting the ECC introduced in Chapter 1 (Hatlen, 1996; Sapp & Hatlen, 2010). In addition to the Statewide Vision Resource Centre, students with VI can also receive support from a visiting teacher employed by the DET to work in their region of the state. Finally, the DET also offers various funding initiatives or programs for schools implementing particular educational services or inclusive strategies for the student (Victorian State Government Department of Education and Training, 2017b).

To be eligible for state-based support, students are required to meet certain criteria. The DET primarily supports students within government schools, although some avenues of support are available to those in the catholic or independent education system (Statewide Vision Resource Centre, n.d.-a; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Second, students also must be deemed to have VI by the criteria set out by the DET (described earlier on page 15): a best-corrected visual acuity of $<6/18$, or a visual field of <20 degrees. Thus, students' visual function and functional vision capacities are assessed by the Education Vision Assessment Clinic within the Statewide Vision Resource Centre (n.d.-b; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). This assessment has implications for the funding available to a student and their school. Funding is available through the DET's *Program for Students with Disabilities* for students who meet Australian legal blindness criteria: a) a best-corrected visual acuity $<6/60$ in both eyes, b) a remaining visual field of <10 degrees in the better eye, or c) combined acuity and field loss resulting in comparable impairment (Australian Government Department of Social Services, 2017). Nineteen of the 21 participants in my research met these criteria. This funding is for any supports, programs or technologies

deemed necessary by their Student Support Group – comprising their parent/guardian, teachers, principal/nominee and, if appropriate, the student themselves (Victorian State Government Department of Education and Training, 2017b). Meanwhile, students assessed as having VI but not legal blindness are ineligible for this funding scheme. Instead, these students can apply for specific equipment grants from the DET for crucial specialized technology or equipment (Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Apart from these financial resources, all other DET supports (e.g. production of alternatively formatted learning materials, visiting teachers) are equally available to students with VI irrespective of whether they meet criteria for legal blindness.

These DET services, systems and resources are accompanied by other organizations providing similar education-focused support to youth with VI. Both the Victorian Catholic Education system and Independent Schools Victoria provide visiting teacher services for students with disabilities enrolled in their schools, including students who meet the aforementioned criteria for VI (Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Specialists from non-government VI services organizations (discussed below) also support the education of youth with VI by informing schools about the accommodations required in order to support the participation and achievement of the youth with whom they work (Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). This may include strategies, such as environmental accommodations to promote the independent mobility of the youth around the school environment, and the suggestion of certain technologies or equipment for the school to implement.

Youth can also receive educational VI support through the Insight Education Centre for the Blind and Vision Impaired (2016d; Victorian State Government

Department of Education and Training & Statewide Vision Resource Centre, 2015). This centre opened in 2013, following a six-year process of support- and resource-building that commenced in 2007 in response to the announced upcoming closure of Vision Australia's Burwood specialized school for students with VI¹⁸ (Insight Education Centre for the Blind and Vision Impaired, 2016a). This initiative was led by parents of children with VI because of their concerns about the public education system's capacity to meet the education needs of students with VI following this announcement. Both an independent primary school – the only specialized school for the education of students with VI in Victoria – and a broader vision resource centre, it supports young people either through full or partial enrolment (in combination with a 'mainstream' school) in the primary school, or through the attendance of periodic life skill day programs run by the centre aimed at all levels of education (Insight Education Centre for the Blind and Vision Impaired, 2016b; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Both the primary school and day programs provide tailored services, resources and supports targeting skill development in line with the ECC (Hatlen, 1996; Sapp & Hatlen, 2010), while the former also provides education within the general core curriculum. The centre is specifically built for accessibility and specialization both in the general design of the learning environments (e.g. room acoustics and lighting) and in the specialist facilities (e.g. a completely equipped independent living skills room; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Finally, the Insight Education Centre (2016c) also runs a mobile classroom service in which three vehicles – fully equipped and specifically designed to be portable and accessible functioning classrooms – travel to students in the 'mainstream' education system who experience difficulties in

¹⁸ Vision Australia's specialized school was closed in 2009.

attending the centre, including those who live in regional locations who receive limited services.

In addition to educational services, other resources and programs are provided to youth with VI from other organizations. This includes two major not-for-profit organizations, Vision Australia and Guide Dogs Victoria, who together represent the major providers of multidisciplinary team-based vision rehabilitation services in the state (Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Both provide a wide range of VI services, resources and programs: eye specialist assessments; O&M training; occupational therapy; assistive technology provision and instruction; dog guides; recreation support; counselling; self-advocacy resources; and, formal and informal connection with peer support and larger communities (Guide Dogs Victoria, 2017a, 2017c, 2017d; Vision Australia, n.d.-a, n.d.-c). As they transition from their early teenage years to young adulthood, youth can also utilize services or initiatives of these organizations that are targeted at specific age groups. This includes children's and teenage camp programs targeting the development of certain skills (Guide Dogs Victoria, 2017a), tertiary education bursaries (Vision Australia, n.d.-e), and employment programs (Vision Australia, n.d.-d). In addition, Vision Australia provides advocacy support regarding individual-level access and discrimination issues, and both Vision Australia and Guide Dogs Victoria are involved in forms of larger advocacy to inform legislation, policy and community attitudes/beliefs regarding VI (e.g. Vision Australia, n.d.-b).

Beyond both the education sector and these two not-for-profit organizations, youth with VI and their families living in Victoria can also utilize services and programs offered by community-based and volunteer-supported organizations. Several programs or community leagues exist for different 'blind sports' for youth with VI to participate in

(Blind Sports & Recreation Victoria, 2015). Meanwhile, other organizations, like Blind Citizens Australia (2017), also provides advocacy services similar to those provided by Vision Australia and Guide Dogs Victoria.

Many services provided across multiple sectors are available to Victorian youth with VI. This includes group programs and one-on-one specialist training targeting the development of certain skillsets among these young people (e.g. O&M skills, the use of assistive technology), funding for both technologies and the modification of environments with which youth regularly interact (e.g. school environments), and both individual and systemic advocacy. Other programs or community initiatives are aimed at supporting youth – and adults more generally – with VI in their recreation and, after their departure from secondary education, their employment. Unsurprisingly, given my recruitment of participants with the assistance of service organizations in Victoria, this variety of services was also reflected in the lived experiences of my participants as represented in their self-reported receipt or use of different types of services (Table 4.1). Furthermore, 20 participants of 21 (95.24%) explicitly reported receiving services through multiple organizations or providers.

However, despite this variety of VI services and the multiple service providers in Victoria, overall these services approached addressing the wellbeing of Victorian youth with VI by targeting two types of change. I conclude this chapter in the next section by highlighting these points of focus of the Victorian VI services and identifying their significance in framing the participants' discussions regarding their wellbeing.

Table 4.1

Frequencies at which Participants Reported the Receipt of Different Services

Type of Service	N (%)
Assistive technology	21 (100.0)
Education support (e.g. visiting teachers, accessible learning material)	21 (100.0)
Camp programs	19 (90.5)
Orientation and mobility training	19 (90.5)
Skills development day programs	17 (81.0)
Non-sport recreational services (e.g. accessible library services)	16 (76.2)
Occupational therapy	13 (61.9)
VI-specialized sports	13 (61.9)
Instruction in Braille	10 (47.6)
Counselling/Psychological services	7 (33.3)
Employment services	6 (28.6)

Note: VI = Vision Impairment.

4.2 The Focus of Victorian Vision Impairment Services

Most of the VI services available to youth in Victoria were focused on addressing the difficulties encountered by these young people either through developing their skills or by changing their behaviour. One-on-one instruction from visiting teachers provided by the DET, and programs run by the Statewide Vision Resource Centre and the Insight Education Centre are explicitly built around the ECC and thus are focused on promoting the skillsets it outlines as impacted by growing up with VI (Hatlen, 1996; Sapp & Hatlen, 2010). For students within the government education system, such skill development is complemented by the funding of assistive technologies and other supports intended to reduce the impact of any functional limitations associated with their VI. Furthermore, a direct link is presumed between VI severity and the level of difficulty that a young person

encounters at school in the allocation of this funding. This is evident in the set eligibility criteria that allocates only restricted technology/equipment grants for students with clinically less severe VI compared to the broader funding for students who are legally blind (Victorian State Government Department of Education and Training & Statewide Vision Resource Centre, 2015). Similarly, much of the multidisciplinary rehabilitation services offered by Vision Australia and Guide Dogs Victoria are centred on providing young clients specialist instruction to develop their O&M, technology use and independent living skills. This provision of assistive technologies and these various services targeting the development of skills presumed to be diminished by VI were those most frequently received by the participants in this research (Table 4.1). This predominant focus on such individual-level services indicates the sustained influence of the personal tragedy model of disability in locating the cause of the difficulties faced by the youth in their VI and thus seeking to bring about individual change to address this cause (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000).

However, it would be inaccurate and unfair to suggest that all of the Victorian VI services described in the preceding section solely targeted such individual change. The impacts of disability activism are immediately represented in Victoria's political shift towards the inclusive education of students with disabilities (Subban & Mahlo, 2017; Victorian State Government Department of Education and Training, 2016). Furthermore, the greater recognition of institutional and material environments in producing the difficulties associated with disability championed by disability activism is also evident in the Victorian VI services surrounding youth. The need to address such barriers is evident in the Statewide Vision Resource Centre's provision of professional development resources for teachers (Statewide Vision Resource Centre, n.d.-c; Victorian State Government Department of Education and Training & Statewide Vision Resource Centre,

2015). Advocacy-related supports offered by Vision Australia, Guide Dogs Victoria and Blind Citizens Australia also seek to bring about change in or the removal of these barriers. This includes both instruction and resources seeking to promote the self-advocacy skills of youth with VI (Guide Dogs Victoria, 2017b), as well as service providers (e.g. visiting teachers, O&M specialists) engaging in both direct individual-level and systemic advocacy. Although, it is important to note that under several conservative Australian federal governments in recent decades funding for more systemic forms of advocacy around disability – such as that provided by Blind Citizens Australia – has been significantly reduced (Soldatic & Pini, 2012)¹⁹. Such funding decisions reposition the difficulties of disability at the individual-level and in line with the personal tragedy model (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000).

Nonetheless, individual-level advocacy support is most certainly available to youth with VI in Victoria, and it is this advocacy work that represents the second point of focus of Victorian VI services. To complement the upskilling of youth with VI themselves, this advocacy is primarily focused on asserting the access rights of people – including youth with VI – to environments and to information. An O&M specialist, for example, providing advice to schools about how they should amend their physical environment in order to support a young person’s mobility, or a visiting teacher advocating to the school for the right of the young person to receive study materials in the electronic format accessible to them.

It is important to recognize this focus within Victorian youth VI services upon individual-level skill development and behaviour change, and upon addressing issues regarding material access through advocacy, as it makes a striking juxtaposition with the

¹⁹ The funding of disability services in Australia is currently undergoing a process of major change with the introduction of the National Disability Insurance Scheme (Whitburn et al., 2017).

participants' accounts shared in my research. Participants most certainly reported the significance of both direct effects of their VI and issues of material access to environments or information, and identified services addressing these issues as invaluable in maintaining and promoting their idea of a good life (discussed in Chapter 9). However, I argue over the subsequent chapters that the negative attitudes and reactions of others (e.g. parents, friends, peers, teachers) regarding their VI had an equally (if not more) important impact upon the wellbeing of participants. These negative social interactions represented a powerful form of direct psycho-emotional disablism encountered by the participants (Reeve, 2012).

Chapter 5

The refraction of wellbeing by youth with vision impairment

Through our collaboration both in formal research encounters and more informally, the participants articulated the many elements that they valued and that filled their lives when they felt well. This included, for example, success in achieving their own goals at school or in a hobby; having close friendships and family relationships characterized by mutual care, similar interests and mirth; having the capacity to rely on their own skills and thus make decisions free of reliance on others; and, having opportunities to be both physically active and restful. Through thematic analysis, these life elements were clustered within four key domains that contributed to the participants' experiences of wellbeing: the four themes of *physical health, social connection, capability* and *control*. Furthermore, participants also discussed numerous factors related to living with their VI that influenced the positiveness of their lived experiences. This included many impacts of living with VI on their ability to participate in certain activities and settings or perform certain tasks (e.g. driving as discussed in Chapter 8), and negative social reactions to their VI from family, friends, teachers and broader communities, that were not directly produced by their actual VI. A range of strategies and resources were also utilized by participants to handle these encounters with these impacts of living with VI, such as informal and official supports or services, different adaptive technologies or equipment, advocacy, and both distracting and cathartic activities (discussed in Chapter 9). Finally, the influences of several personal or contextual factors were apparent in how participants understood and appraised the quality of their lived experiences: age, an urban or non-urban residence, family history, socio-economic status, other health conditions and religious beliefs. From this data, I developed

a conceptual understanding of wellbeing as perceived by the young people with VI, which I elaborate in detail over the next five results chapters – including the publication constituting the current chapter – before discussing the model’s theoretical and practical significance (Chapter 10).

Chapter 5 commences my elaboration of this conceptual model by presenting an overview of the major themes identified within the participants’ discussions. It comprises a manuscript accepted for review by the journal ‘Applied Research in Quality of Life’ on the 07/12/2017. After briefly introducing the four thematic life domains into which the participants’ important life elements were grouped, this article explores three overarching themes that ran through the participants’ discussions of what it meant for them to be well. *A personal sense of life in balance* captured the importance to the participants of ensuring that they pursued and attained – to personally-set levels – all of the different life elements that they considered valuable, as the maintenance of each individual element would also then facilitate the attainment of other elements of life that they valued. This cycle allowed the participants to experience a general sense of balance across their life and which therefore supported the positiveness of their lived experience (i.e. afforded them a sense of wellbeing), even in the face of momentary difficulties. Meanwhile, in line with theories of self-concept (Oyserman et al., 2012; Stets & Burke, 2000), the theme of *a sense of identity* captured the participants’ consistent references to who they perceived themselves to be, what they felt they were capable of and where they felt they belonged. The young people drew upon these ideas about ‘self’ throughout our discussions in describing why they found a particular element of their life (e.g. their friendships) to be valuable, and the impact of their VI in pursuing and experiencing these elements. Finally, *situated sameness* referred to the participants’ explicit emphasis on the similarity of the elements that they identified as valuable with those that they perceived were valued by most

people, while concurrently articulating differences in their experience of these elements related to their VI and other life circumstances (e.g. their family history, their location of residence). These three overarching themes offer a valuable lens through which to view and understand the construct of wellbeing for the current participants and other youth with VI. I discuss further significant contributions of this paper to my thesis in the concluding remarks immediately following this article (section 5.2).

**5.1 Paper 1: Exploring wellbeing in youth with vision impairment: Insights for
vision rehabilitation**

Exploring wellbeing in youth with vision impairment: Insights for vision rehabilitation

Abstract

This article explores the discussions of 21 young Australians (aged 12-25) with vision impairment regarding their lived experiences and what it meant for them to be well. It follows calls for the development of the theoretical underpinnings for vision rehabilitation services. The youth participated in interviews or focus groups and collected complementary soundscapes and reflections during participatory audio-recording tasks. Participants identified multiple valuable elements of their life contributing to the positive quality of their experiences: for example, success in their pursuits; caring, like-minded and jocular relationships; independence and freedom; and, their healthy body and associated feelings of vitality. These elements fit within four thematic domains: social connection; physical health; capability; and, control. Thematic analysis also identified three larger themes present in how participants discussed their quality of lived experience. First, they emphasized the maintenance of balance between the life elements that they considered important, with each element supporting the attainment of others. Second, their understandings of the elements in each domain and what constituted balance between them was determined by their contextually-situated sense of identity to which they explicitly and implicitly referred. Finally, the young people's notions of a good life were seen to sit within a conceptual space of 'situated sameness': they perceived the elements that they valued as also valuable to the general population, but uniquely shaped by their own vision impairment and other life circumstances. These findings suggest that vision rehabilitation providers need to adopt a more relational approach to wellbeing among youth.

Childhood causes of vision impairment (VI) often contribute to a life of disadvantage (J. E. Brown, 2009; Gilbert & Foster, 2001). As they transition into adulthood, youth with VI encounter barriers to employment and in establishing social networks (J. E. Brown, 2009). Vision rehabilitation services seek to address these lifelong difficulties, through the promotion of functioning and wellbeing irrespective of a person's VI (Binns et al., 2012). They include a broad array of services: specialized instruction around accessing information in alternative formats (e.g. Braille); support in the use of adaptive equipment (e.g. magnifiers, white canes); provision of skills and training to enhance independent completion of daily living tasks; and, the design of strategies for orienting and moving around in different environments with one's remaining vision.

Vision rehabilitation services complement medical, surgical and optometric treatments, as well as prevention-focused initiatives implemented to address the impacts of childhood and youth VI. They are essential in promoting the wellbeing of young people with VI from non-preventable and non-treatable causes (Rahi & Solebo, 2012). However, recent reviews have demonstrated their inconsistent effectiveness in promoting positive psychological and quality of life (QoL) outcomes in adults (Binns et al., 2012; Rees et al., 2010). Findings on the effectiveness of vision rehabilitation services in promoting such outcomes among children and youth are both limited and inconsistent. Binns et al. (2012) concluded from their review of research evaluating vision rehabilitation trials published between 1950 and 2010 that no well-controlled research around service provision to children had yet been conducted, with the studies they did find focusing on the level of uptake of assistive devices by children or their performance of functional tasks like reading rather than their QoL. Meanwhile, although some more recent studies indicate that recreational programs and activities can improve aspects of social relationships and self-perceptions among young people with VI (Goodwin et al.,

2011; Qasim et al., 2014), others have found poorer social and self-perception outcomes following some recreational programs (Dursun et al., 2015). Rees and colleagues (2010) stressed the need for greater clarity around the outcomes used as wellbeing indicators, and deeper understandings of which service elements act as active mechanisms promoting wellbeing, in order to optimize these services. Similar conceptual clarity and development is necessary to inform services for younger populations as well (Haegele & Porretta, 2015), and the *United Nations Convention on the Rights of the Child* (1990) holds that youth with VI should be considered possessors of valuable knowledge regarding their wellbeing and thus should contribute to such dialogues (Ben-Arieh, 2005; Llewellyn & Leonard, 2010).

In general, a person's *wellbeing* encapsulates the extent to which their life entails positive experiences and enriched quality: it is not just the absence of detracting factors (Ben-Arieh et al., 2014; Manderson, 2005; R. M. Ryan & Deci, 2001; Wallander & Koot, 2016). However, the specific image of a life that meets this criterion varies across contexts and people. As such, recent efforts to incorporate the voices of youth with VI themselves into our conceptualizations of wellbeing for them as a population have increased. This has included capturing the thoughts and feelings of youth with VI regarding their lived experiences and values, in particular as part of the effort to develop psychometric measures of VI-specific QoL in order to facilitate more sensitive service evaluation (Tadic et al., 2013). Experiences of independence, self-worth, and positive social relationships have been identified as important to youth with VI, and as negatively impacted by practical (e.g. transportation) and social (e.g. stigma, bullying) VI-related factors (Chang & Schaller, 2000; Khadka et al., 2012; Rosenblum, 2000; Tadic et al., 2014). Despite these preliminary insights, in their recent review of the QoL measures developed for younger populations with VI, Tadic et al. (2013) reported that several QoL

measures did not define this construct they were intended to measure, and often comprised content that predominantly focused on a youth's functional performance of daily visual tasks. Such conceptual ambiguity and reduction raises questions around the validity, accurate interpretation, and utility of these measures, and indicates the need for ongoing refinement of the construct of wellbeing used to inform services to this population (Tadic et al., 2013). The current article aims to contribute to this refinement and examine the discussions of youth with VI around their lived experiences and what it means to them to be well, particularly in terms of how living with VI shapes their experiences, in order to inform vision rehabilitation services.

Methods

The study employed a two-phase participatory qualitative design based on the Youth ReACT method, which seeks to actively engage adolescents to explore issues in their communities (Foster-Fishman et al., 2010). The participatory research approach was enhanced by the first author's own status as a young person with VI. It enabled the first author to more easily adopt the position of a peer-collaborator with the participants to disrupt traditional researcher-participant power imbalances and allowed the exploration of the differences between the participants' and the first author's own experiences to guide inquiry (Tillmann-Healy, 2003; Voloder, 2008; Worth, 2008). Phase one data collection took place in late 2014 to early 2015, before a second analysis phase that occurred five months later in 2015.

Participants

Twenty-one youth with VI were recruited through southern Australian vision-related service organizations, who distributed study information to their members. Interested youth with VI were invited to contact the first author, who screened them for eligibility;

where potential participants were aged under 16 years, this occurred in consultation with a parent or guardian. Participants had to: 1) be aged 12 to 25 years; 2) perceive their VI as increasing the difficulty of daily tasks; 3) have no other sensory or cognitive impairment which they felt would prevent their full participation; and 4) be fluent in English.

Demographics (e.g. age, education) and a VI history (e.g. cause, age at onset/diagnosis, severity) were also collected (see Table 5.1). Those eligible were sent an explanatory statement and consent documentation in their preferred accessible format. Participants were reimbursed with a \$20 gift-card per study phase.

Fifteen young men and six young women participated, with a mean age of 18.62 years ($SD = 3.12$). Most (67%) were undertaking formal secondary or tertiary education; all participants received 'mainstream' schooling. Participants reported varied causes of their VI and levels of remaining vision. Only two were not classified as legally blind. Legal blindness in Australia requires a) a visual acuity of $<6/60$ in both eyes, b) a visual field of <10 degrees in the better eye, or c) an equivalent combination of both (Australian Government Department of Social Services, 2017). The mean age at onset of VI was 4.59 years ($SD = 5.15$). Nine participants reported additional conditions, including learning disabilities and mental health conditions.

Table 5.1

Causes of Vision Impairment and Education Levels of Participants

Characteristic	N (%)
<i>Cause of Vision Impairment</i>	
Retinal dystrophy	11 (52.4)
Albinism	2 (9.5)
Neurological trauma	2 (9.5)
Retinoblastoma	2 (9.5)
Other	4 (19.0)
<i>Education Level</i>	
Secondary (current)	8 (38.1)
Secondary (completed)	5 (23.8)
Undergraduate (current)	3 (14.3)
TAFE or other (current)	3 (14.3)
Tertiary (completed)	2 (9.5)

Note: TAFE = Technical and Further Education.

Procedure and materials

This study was reviewed and approved by the Monash University human research ethics committee. All participants provided written informed consent; for four aged under 16 years, both parent or guardian consent and their own assent were obtained. Seven took part in individual interviews (including one telephone interviewee, due to geographic distance), while fourteen took part in small focus groups of two or three people. This flexibility of participation in either interviews or focus groups was offered both to afford the youth with a range of commitments and thus diverse experiences the chance to share them in the project, and in recognition of all participants as equal collaborators in line with our participatory research approach (Tillmann-Healy, 2003). During phase one, each

young person took part in three sequential research encounters, ‘discussion sessions’, over a two-to-three-week period. First, a one-hour training session re-introduced the project’s aim, emphasized their status as active collaborators and ran through the practicalities of data collection. Training sessions commenced by emphasizing the project’s focus on participants’ subjective understandings of wellbeing, including what they associated with the term ‘psychological wellbeing’. Given our participatory approach, ‘psychological’ was dropped during data collection as participants felt it was insufficient for the breadth of topics they raised. Next, a deliberately broad definition of wellbeing as “how good a person is feeling or doing” was provided – based on the general definition of wellbeing identified in previous literature (Ben-Arieh et al., 2014; Wallander & Koot, 2016) – and participants were invited to share any experiences that they felt were related to this, including feelings, thoughts, plans, goals, activities, people and places. The audio-recording task was then discussed and the young people were given opportunities to practice using their chosen audio-recorder.

The second research encounter, a two-hour discussion session, collected information on the participants’ lived experiences that they felt were related to their wellbeing, while the third discussion session (of two hours’ duration) collecting information about any effects of their VI on these experiences and how these effects were handled. Between discussion sessions, the youth completed an audio-recording task, either using their own smartphone or an accessible audio-recorder, in response to a series of questions reflecting the study aim and objectives. This task was devised as an audio-based version of the photovoice method (Wang & Burris, 1997), in order to be more accessible for youth with VI. Although VI does not preclude a young person’s ability to take and share photography, some people with VI may not feel confident about taking photographs that represent an intended meaning, including those who have experienced

recent vision loss and may still be functionally adapting to this change. Furthermore, audio-recordings offered potentially unique insight into the youths' lives, as sound holds a more complex significance in the experiences of some people with VI (Downey, 2017). Participants recorded sounds and their own reflections (approximately one minute in length) to represent experiences they wanted to share in the subsequent session.

Each discussion session commenced with the sharing of participant audio-recordings; the meanings of these recordings were then explored via responsive prompting to encourage fluid and open conversation. Such questions asked the youth to elaborate on what each recording meant to them (e.g. "Can you tell me a little bit more about that?"), before prompting questions about particular aspects of the experience were asked (e.g. "How did that help?"). Semi-structured facilitation guides, developed in consultation with academic colleagues in the field of adolescent mental health regarding age-appropriate wording of questions, were used for all sessions. They contained supplementary questions (e.g. "What activities do you spend time on when you are doing well?") that were used, as required, at points when participants did not want to share a recording or could not choose which recording to share. All sessions were facilitated by the first author; the first two sessions were co-facilitated by a research assistant for piloting purposes.

Following the completion of phase one data collection, a number of participants were contacted regarding topics they raised in their sessions that, because of situational constraints, were not satisfactorily explored. Eight participants were contacted, either in person (three), by telephone (four), or both (one). All discussion sessions were audio-recorded and transcribed verbatim by the combination of the first author, an external transcription company, and a VI service organization volunteer.

Analysis and study phase two

Braun and Clarke's (2006) six-stage thematic analysis process was employed to analyze the transcripts of the recorded sounds, reflections and discussion sessions. For data familiarization (stage 1), the first author read over each transcript whilst keeping detailed notes of ideas arising from the content. Written discussion session notes were also reviewed. Transcripts were then inductively coded on a line-by-line basis (stage 2). Examination of the final codes and coded data excerpts facilitated the development of themes (stage 3), which were reviewed with other members of the research team, enabling the creation of a thematic structure of first- and second-order themes (stage 4). These were then defined and relabeled (stage 5).

Phase two was the member-checking of themes identified in the data collected in phase one, five months after phase one data collection was completed. The finalized thematic structure was presented to eleven of the 21 study participants, with an accompanying description of the major themes and illustrative quotes. Although sixteen participants initially expressed interest in this phase, logistical difficulties (scheduling and transportation) prevented five participants from taking part: four being from regional areas, with only one regional participant returning. In one of three audio-recorded group discussions, participants were invited to comment on the fit of the themes with their lived experiences (Lincoln & Guba, 1986). Member-checking sessions were transcribed and thematically analyzed following the above process. Participants supported the developed themes, and the few discrepancies between the phases of analysis were resolved through discussion between the first and second author. This process mainly involved refining the language used to describe certain themes; however, the participants did highlight some aspects of their notions of a good life not adequately reflected among the initial themes. Participants highlighted the unique contribution that they felt their independence and

freedom made to the quality of their lived experiences that was not captured, and the specific role of their unique sense of self in determining what they valued, how they evaluated their experiences and how they responded to difficulties they faced. Following this feedback, the first author returned to re-analyze the participants' discussions around these themes in the initial dataset to more fully capture and understand their significance to the youth. As a result of this feedback and analysis, one original thematic valuable domain of life ('Progress and fulfilment') was separated into three stand-alone themes ('Capability', 'Control' and 'A sense of identity'). QSR International NVivo 10 was used for qualitative data management throughout the study. Pseudonyms were utilized in the reporting (stage 6 of analysis) to protect participants' privacy. Due to privacy concerns, exact age is not reported; instead, an indication of the participant's age group is provided.

Results

Participants provided detailed descriptions of the elements that occupied their lives when they felt they were doing well, and that were in turn threatened or diminished when they felt they were not. We conceptualize these elements as fitting within four key thematic life domains that contributed to the positiveness of the participants' lived experience: *social connection, physical health, capability, and control*. Organized within these four thematic life domains identified through our thematic analysis, we begin this Results section by providing a brief summary of the elements of life that the participants consistently identified as valuable.

Social connection

Participants valued the connections they shared with other people – in both close one-on-one bonds and in communities – and identified several elements of desirable social

relationships that they felt contributed to the positivity of their lived experience. First, they placed importance on having a point of similarity with their counterparts, which they felt afforded them a shared understanding of the world. Max (aged 19-25) explained this similarity and understanding when he described his first friendship with another young person with VI: “For them, it’s the same. They’re going through the similar things that you’re going through”.

In addition, participants desired trustworthy, caring and supportive relationships with others:

Caelan (aged 19-25): I think about friends as like they give me confidence. These are the friends that I made when I was going blind, and they were just like extra pillars to keep me up and... I’ve named my canes, and they started that thing.

Interviewer: Named your canes?

Caelan: Naming my canes, yeah. Like the one I’ve got here is called [Beryl] and my one before that was... it’s either [Horatio] or something like that.

Caelan’s friendships that he established within a local youth group during his vision loss were valuable to him as important supports that helped him manage the many difficulties and adjustments he faced in this time. In particular, Caelan prized them for their light-hearted and humorous approach to living with VI, which made “the despair of being blind less spikey [or] intense” and gave him a feeling of confidence. As such, the value that Caelan found in these friendships also highlighted another element important to the participants in their social relationships. Participants valued humor in their relationships, often describing the happiness and enjoyment that shared jokes produced, as well as the sense of closeness to another that humor often fostered.

Finally, it was important to the participants that they felt included and accepted as they were. For example, Lee’s (aged 19-25) relationship with his housemates and their

larger group of friends was a positive relationship, in which he was welcomed and also comfortable to express himself:

It's really important when you live with people to be able to be honest with them. [It makes] it such a more comfortable place to live... We do a lot of group things. Like one of my friends had a few mates around and, all of a sudden, his mates become my mates.

Physical health

The thematic life domain of physical health captured the importance the participants placed upon maintaining the functioning and fitness of their biological body, as well as the related subjective feeling of health. The participants wanted to meet their body's base needs (e.g. nutrition, sleep), manage their weight, and avoid injury, illness or pain.

Meanwhile, participants prominently described the valuable subjective feeling of health in terms of a feeling of vitality: having the energy to take part in activities or events: for example, energy to go see their friends, to complete their homework, or to tackle the next day. This feeling of energy was reflected in the boost Jamie (aged 19-25) felt after her regular exercise class: "[I'm] excited, ready to go. I can probably climb Mt Everest after doing it".

For participants, their bodily health and subjective vitality were interwoven. For example, sleep – an identified basic bodily need – was recognized as central to such feelings of subjective energy. Frankie (aged 19-25) explained: "A good night's sleep... helps you to function the next day [and without it] you're just gonna feel like crap". Similarly, Harper's (aged 19-25) enjoyment of lap swimming was tied to both bodily health, insofar as he avoided pain and it encouraged him to eat healthily, and its positive subjective effects:

I feel good in my body [after swimming]. That's a really important thing having had a lot of pain but also there is a sense of self-satisfaction.

Participants maintained their bodily health and subjective energy levels by ensuring that they both engaged in physical activity and relaxation. Regular physical activity (e.g. exercise, sports) promoted participants' subjective vitality (described by Jamie and Harper above), as well as their physical fitness. Taylor (aged 12-18) explained this: "If you're not active, how are you going to lose weight?". For several, weight management was additionally important due to their awareness of high rates of inactivity among the VI population, and because they felt that they encountered enough judgement from others regarding their VI without also being overweight. Participants also described many valuable forms of relaxation, including listening to or producing music, craftwork, meditation, sleeping, and reading. Relaxation enabled both their recovery from injury or pain – "resting or listening to music... are still always good... often in addition to painkillers" (Harper) – and energy replenishment. Val (aged 19-25) described the importance of "putt[ing his] feet up": "The next day I feel refreshed... and then you come back [to everything with] more energy to go back into [my study and sport]".

Capability and control

The final two thematic life domains – *capability* and *control* – were highly interconnected. Capability captured the value to the participants of success and demonstrating their competence to themselves and others in many occupations and activities (e.g. education, employment, pastimes). For example, Jay (aged 19-25) stressed the significance he placed on succeeding in his hobby of wrestling in order to prove his doubters wrong: "There are critics that have told me, 'Oh you can't wrestle, you're blind.' If I could succeed... it would just prove to them that I can". Being able to do what others

have said they cannot – and to succeed in these endeavors – was important to all participants. Also central was making progress towards shorter-term goals identified within higher-order aspirations. Such progress invoked a subjective sense of accomplishment that the participants found immensely valuable:

School will let me get to the university course I want ... I guess [that would give] a sense of achievement. It's like, well, I've always wanted to do a math[ematics] or a physics course and... to get a job as a mathematician. (Morgan, aged 12-18)

Morgan wanted to obtain good grades and thus obtain success at school, but this was also a short-term goal on the path to achieving his career aspirations.

Participants stressed the importance of being in charge in the pursuit of their own goals. They wanted to feel, and have others recognize, that they made the decisions behind what happened in their life. Independence and freedom were raised as pivotal ideas discussed by participants within this thematic domain of control, and were understood as interrelated yet distinct factors:

You have the freedom to go wherever you want at night time, but if it's somewhere new to you, somewhere that's poorly lit, somewhere that's got a dodgy [uneven] footpath or is very busy, you might not feel you have the independence to go there. (Lee)

As Lee illustrated, participants understood freedom to mean that minimal restrictions existed upon them from external forces, typically other people. This was evident in Shannon's (aged 19-25) description of the freedom that his father gave him: "He's happy for me to be [returning] home any time... but he'd want me to do it in a safe manner". Independence, in contrast, referred to participants' abilities to rely on their own capacities and resources to pursue endeavors they desired. Alex (aged 19-25), like others, emphasized that she "hate[d] the feeling of having to rely on someone else", especially

because such reliance entailed losses of freedom. This was clearly explained by Val, who described the challenges for young people with VI who relied on parents for transportation: "I meet other people and say 'Why don't you come up and play [sport] on the weekend?' and it's 'Oh my parents work so they can't drive me'". Understanding independence as the ability to rely on one's own capacities and resources demonstrated the close interrelation of the domains of capability and control. Being successful in progressing towards goals or meeting certain standards (capability) enabled one to have independence and freedom: "If you didn't have something you were good at... you wouldn't be able to do anything in life [and] you'd be relying on other people" (Jesse, aged 12-18). At the same time, being independent and thus having greater freedom (control) was perceived as foundational to being successful, and thus acquiring greater independence was viewed as an accomplishment in itself: "When you get that sense of independence, you get that sense of accomplishment as well" (Frankie).

Beyond the four domains: larger themes of wellbeing

Participants identified three reasons that they found the elements, captured within these four thematic life domains, valuable. First, attaining or maintaining these elements produced a range of positive feelings (e.g. self-satisfaction, confidence, happiness, comfort). Second, many of these valuable elements also offered resources or strategies for handling any negative events and associated feelings. For example, Caelan's new friendships within the local youth group provided him with emotional support and a reason to smile during the difficult period of his vision loss. Others developed greater self-belief through their experiences of accomplishment that enabled them to push past difficulties: "I just... take the challenge and do it" (Peyton, aged 12-18). Finally, the pursuit of these elements led to the development, or the affirmation, of a positive sense of

identity. Morgan, for example, explained that his academic achievement represented the realization of his self-perception as “smart”, and was thus important to how he felt about how he was going:

I think that I'm meant to be clever... and so when I fall short of that benchmark I've found for myself... I think I've let myself down.

Meanwhile, for Jules (aged 19-25), a sense of belonging and social connection was important to his sense of self: “Community in itself... contributes to our belonging and who we are, and so I think it's important for that reason: because we have a social identity as well as a personal identity”.

Given the value of their individual elements, when presented to them in the member-checking phase of the project, participants perceived the four thematic life domains identified in the thematic analysis as “a summary of wellbeing” that provided “a fairly good, broad view” (Alex). They stressed the importance, however, of “communicat[ing the domains] in such a way that [they are] not seen as reductive: so, we’re not trying to reduce wellbeing to this, but we are trying to highlight these as key parts of wellbeing” (Harper). The valuable elements clustered in the four thematic domains were not to be taken to represent the life and wellbeing of all youth with VI, nor to capture all that needed to be understood about what enriched the quality of the participants’ lives. The many desirable elements across the four thematic domains were not mutually exclusive but were instead overlapping and interconnected (discussed below). For instance, feeling energized, while inextricably tied to their bodily health, physical activity and relaxation, also influenced and was influenced by the extent to which participants were able to independently pursue and achieve success in their goals and engage in their social life. In analyzing the participants’ discussions around the multiple valuable elements of their lives, three overarching themes emerged that framed

the participants' experiences: *a personal sense of life in balance, a sense of identity, and situated sameness.*

A personal sense of life in balance

Extending discussions of balancing independence with the receipt of support by youth with VI from previous research (Tadic et al., 2014), balance was crucial to the participants' understandings of what it meant for them to be well:

What are the kinds of things that are going on in your life when you're doing well?

Frankie: When I did the recordings, I sort of thought about the different components, so being physically healthy and... normally I'd have some good friends in my life, you know, family's generally there. I'm generally on top of my uni[versity] work... I saw it as very much of a balance.

As concisely articulated by Frankie, participants sought to maintain a subjective sense of balance between the many elements of their life (across the thematic domains) that they considered important. For example, Taylor described the importance of engaging in regular physical activity in order to balance out more sedentary time spent on either homework which he considered important for his achievement at school, or engaging in more restful activities:

I quite often find myself inside for long periods of time, just sitting there either playing video games or doing homework, so... it's just good to get outside every now and then.

Importantly, the precise level of each of the valuable elements necessary for the participants to experience a sense of balance was personal. Participants all pursued similar valuable life elements – such as trustworthy and supportive friends, success in their work or education, and physical fitness – but did so to distinct and individually-

valued levels. Lee, for example, saw the attainment of his goals as a clear priority, which meant that at times in his life he prioritized his career over his social life; however, when he felt he needed to see his friends, he would then go and seek out time with them:

I'm more of a progress person... the other parts of [life] don't bother me too much... I'll usually notice, let's say, if it's been a couple of weeks and I haven't caught up with any friends... And so [then] I will, so I guess that is a way of keeping it in balance.

Although on the surface the special priority that Lee placed upon progress in his career appeared to be antithetical to the notion of balance, this was not the case for Lee as he experienced this arrangement as his subjective view of his own life in balance.

The importance of this balance to the participants was rooted in their perceptions that the various desirable elements of life were interconnected:

Can you tell me what you mean by 'balance'? Because... you said it was important.

Frankie: So, by "balance", I kind of mean that... the whole conversation one thing sort of led into another, but by balance, they're all connected. You've sort of got a bit of everything [and] I suppose balance is sort of being in that stable state. So, if you don't have enough sleep, then... you can't process information mentally or whatever. So, I see balance as everything being all connected but they sort of need to be equal and sort of in a stable sort of state as well.

To Frankie, feeling as though she had a good balance among the elements she considered important to the quality of her life – that is, success in her study, time with her family and friends, time for sleep and rest – was important as each of these elements in turn supported the maintenance of the other desirable elements. In short, the valuable elements in the participants' lives were mutually-supportive: participants perceived these elements as "go[ing] around in a circle" (Ash, aged 12-18). For example, Drew (aged 19-25)

asserted that “if you're not [physically] healthy, then you're not going to... be able to learn or... enjoy what you normally do”. Other participants, such as Jordan below, similarly described how their independence and control in their own life was supported by having friends with whom they shared an understanding of each other. Echoing previous descriptions of health and wellbeing as recursive (Manderson & Warren, 2016), balancing the different valuable elements of life as central to a self-sustaining cycle of wellbeing for the youth.

If you're understood [by others] then... you can do the things that you want to do... because they understand what you need and want. (Jordan, aged 12-18)

Given this, the participants actively maintained this personal sense of balance. This occurred through a deliberate process involving both their motivated effort, and the establishment of structure and “routine because it's... something to guide when I do this, when I do that and it really helps that balance” (Frankie). While searching for employment, Lee deliberately stuck to a daily routine to simultaneously pursue success in his goal of obtaining a job and still maintain the elements important to his social connection and physical health:

I'd usually [work on applications] until about lunch [then], so I didn't just fall into the trap of just being lazy, [I would] catch up with people... go for a walk, go to the gym.

Such deliberate effort to maintain routine was necessitated by the threat to a personal sense of balance presented by varying VI-related obstacles encountered by participants. These difficulties could reduce their motivation to stick to their plans by making objectives feel “just too hard” so the participants “didn't want to do anything” (Pat, aged 12-18). They also directly disrupted routines or plans. For example, receiving

(often unsolicited) help from others with limited understanding of VI – who often relied on negative assumptions about their incapability – was described as a threat to their day’s structure:

[Say I was going from] A to B and I drop in “I’m vision impaired, could you help me out?”, [the person] would then spend their time and slow me down... I know how to [find my way], and they don’t know what works for me, so they’d try different things and, of course, that just eats into time. (Shannon)

Because of the disruptive nature of such uninformed assistance, Shannon (and other participants) determinedly avoided such assistance when not absolutely necessary.

The personal sense of balance that the participants actively sought to maintain was influenced by how they understood themselves. This sense of identity was the second overarching theme framing the participants’ discussions.

A sense of identity

Participants frequently raised their sense of who they were, where they came from and belonged, and where they were going – their “different operating systems” (Morgan) – in discussing their lives and what they valued within them. Coherent with general theories of self-concept (Oyserman et al., 2012; Stets & Burke, 2000), this sense of identity represented their own beliefs about their multiple personal characteristics: their values, personality traits, competencies, social roles and community memberships. All participants explicitly or implicitly drew upon their own view of their particular characteristics – sense of identity – in describing their understanding of, and weighting given to, the different elements they considered it important to have (Oyserman et al., 2012; Stets & Burke, 2000). For instance – as indicated earlier on page 165 – progress towards his goals was paramount for Lee as “a very capable person” with “many other

things I want to achieve”. Meanwhile, Elliot (aged 19-25) – who was of a similar age and position in life to Lee – admitted that he was “not an overly competitive person” but was “more comfortable going with the flow”. These self-perceived identities became explicit during the member-checking phase, when several participants highlighted that the understanding of wellbeing “var[ied] between different people, [with] what they value and how they value it” (Pat).

Participants’ discussions also illustrated that their sense of identity was a product of their unique circumstances, again echoing theories of self and identity (S. Atkinson, 2013; Stets & Burke, 2000). How they experienced and understood the social world, and their relationship to the wider community, was influenced by various intersecting factors. Although this included their VI, it was not the sole factor shaping participants’ perceptions (as has been identified by Kaplan-Myrth, 2000). Other influential factors included age, religious beliefs, urban or rural residence or upbringing, and family history:

Like, my dad’s a farmer and all the people around are like mostly farmers and so I grew up on the farm, I thought I’d be a farmer – [that’s] no longer the case... But I know that my life already, or before [my vision loss], wasn’t normal either because like my brother [is] blind, and I also have an uncle who’s got a mental [disability]... and like I’m also like a Christian, and that’s really rare for down my way. (Caelan)

As Caelan illustrated, multiple social factors intersected to shape participants’ experiences over time. From this, they produced unique histories of themselves in the world, including their sense of who they were. Furthermore, given that participants were constantly encountering new experiences, their identities and the influence of these identities on what they considered important in their lives changed over time (S. Atkinson, 2013). Caelan originally understood his life in terms of his self-perception as a

farmer and what this meant based on his family history and the cultural norms of the community in which he grew up. However, his sense of identity was altered by his vision loss, and associated experiences; themselves influenced by aspects of his family history, as well as his feeling of being different due to his religious beliefs.

Caelan's references to feelings of normalcy illustrated the significance of the concept of 'situated sameness', which was the final overarching theme identified as framing the participants' accounts. In this, participants discussions of the elements of life that they valued were characterized by simultaneous references to their similarity to and evident difference from an imagined 'normative' or general population.

Situated sameness

Success in one's goals, bodily health, feelings of energy, independence, and supportive family and friends are not things uniquely valuable to our participants. Similar ideas of agency, competence, good relationships, and physical health have not only been highlighted in previous qualitative research with other youth with VI (Cochrane et al., 2008; Tadic et al., 2014), but also with sighted children, adolescents and young adults with or without other disabilities (Fattore et al., 2009; Foley et al., 2012). In the current study, participants engaged directly with their similarity to an envisaged (sighted) general population, while also through their discussions they elaborated the uniqueness of their perspectives due to their VI-related experiences and other factors.

For the participants, living with VI did not mean that a different set of standards was required to evaluate how their life was going. Participants frequently indicated both implicitly and explicitly that what they considered important were the kinds of elements that everyone considered important. References to this 'sameness' was evident in

Peyton's description of the valuable emotional connectedness he felt when listening to music:

The reason why people love music and it's very famous is because it gives you... the emotions, just [makes] you cry and that. (Peyton)

Similarly, Jamie felt that "everyone needs to be able to feel like they can accomplish anything." Both Peyton and Jamie emphasized that these aspects of life were prized by most people regardless of their level of vision.

Our participants' discussions, however, also demonstrated that living with VI influenced how they experienced many of these elements that they felt were valuable to most (if not all) people. Although emphasizing this sameness, living with VI – as one factor that made participants feel different from "normal" people (Elliot) – simultaneously introduced 'difference' into the participants' accounts. This difference was evident in two main ways. First, VI-related experiences shaped the reasons underlying the value that participants found in these elements. For example, drawing on experiences related to their VI, participants outlined distinct reasons for the importance of their independence, and for the success they experienced in their pursuits. Drew – like many participants – placed greater importance on her independence because she had witnessed others having restrictions placed on their freedom due to their VI: "I love to be independent... It's very important because some parents of children with disabilities, they don't really give their children much independence." Meanwhile, although recognizing it as a valuable experience for anyone, achieving his personal goals (e.g. reaching his money-saving milestones) held special value for Lee as this proved wrong those who doubted his prospects due to his VI:

I don't see how it would be different from any other person... I just love the feeling of being able to say "Yes, I did it" ... maybe the one time I do get

competitive is when I meet [people who] talk down to me [to show] those people that... it doesn't matter that I can't see. (Lee)

Second, the participants' discussions also revealed nuances in what it meant for them to have or fulfil these valuable elements, again, arising from VI-related experiences. For instance, what it meant for them to be relaxing, to have positive friendships or to have a thriving social life was evidently different compared to a sighted person. Harper's definition of 'relaxing' was tied to his VI and the ocular strain from his interactions with the (highly visual) world around him: "I love watching TV and movies... but it was always much more enjoyable listening to music because I could just switch the vision off and relax." Meanwhile, a shared sense of humor held distinct importance for many participants in their understandings of friendship: "Well, if something [you can't see] happens and you joke about your sight with your [sighted] friends and they laugh and you laugh... you feel like you can relate to them" (Jesse). As Jesse explained, such shared humor held distinct significance in participants' friendships with sighted others as it enabled them to turn awkward social interactions around their VI (e.g. a missed social cue) into positive points of connection. In addition, several participants reported how others with VI represented their predominant means of social connection, frequently due to the bullying and exclusion they faced in sighted society. Throwing themselves into this VI community, in turn, shaped their social lives; it influenced both where and how they connected with friends. These participants and their friends with VI "all like going places that are easy to get to... quiet and have plenty of lighting, so that means they might always go to the same place" (Lee). Moreover, Frankie recorded the sound of herself typing on her keyboard to highlight that, due to the low incidence and geographic spread of youth with VI, she largely connected with friends via the internet:

The sound of clicking you can hear is me touch-typing [which has] become the main means of communication for me [with] many of my friends [who] live all over the state.

This difference introduced by their experiences of living with VI into the participants' accounts regarding these important elements of their lives – that they emphasized were valued by all people – was not uniform. Although participants shared many common experiences related to their VI – such as restrictions upon their freedom by over-protective parents – considerable variance (which we term 'difference') was apparent due to the diversity of VI causes and ages at onset. Such difference was especially evident among those with deteriorating eye conditions compared to those whose VIs were stable. Those whose vision loss was degenerative described how the importance of certain elements of life stemmed from “when [they] found out [their] sight had deteriorated [and they] started taking more notice” (Jamie). Jamie, for example, placed high value on relaxing among natural scenery, which was especially important for her given future vision loss may take her ability to appreciate such scenery away. In contrast, those with more static VI could not share such experiences. Furthermore, the 'differences' evident in the participants' accounts were often further complexified by the influences of various non-vision-related factors. As discussed above, non-vision-related characteristics and circumstances (e.g. religion, interests, family history) were important contributors to participants' senses of identity and played their part in informing their unique perspectives around why they prized and how they understood the particular elements that they perceived as widely valued in society. The influences of such non-vision-related characteristics and circumstances interacted with the participants' experiences of living with VI, so that the 'difference' in how each participant experienced the valuable elements of life was, in itself, diverse. For instance, both Caelan and Max

experienced similar restrictions on their prospective careers as a result of their VIs, which in turn influenced the criteria by which they defined their future success, but this influence varied because of their divergent backgrounds.

Growing up on his family farm in a broader farming community as described earlier, Caelan had initially envisaged his successful future as involving himself taking over from his father in running the farm. This was a role for which he felt he possessed the necessary skills: “[Driving on the farm] gave me a sense of who I was on the land... I was the farmer with the big four-wheel motorbike able to stop sheep from getting out”. The sudden onset of Caelan’s vision loss and the barriers it presented to this career, however, led him to adopt novel life experiences as his criterion of success: “I went ‘Money’s not everything’ and [my brother] was like ‘Well, then why are you moving out?’ And I’m like ‘Experience.’” In short, Caelan’s definition of a successful future was disrupted and displaced. Max’s experience of these career restrictions had a different flavor. Unlike Caelan, Max’s sense of his own competencies – irrespective of his VI – had directed him away from practical professions (e.g. engineering), despite his parents’ desires. Furthermore, Max had no interest in science – “if Einstein discovered this, I don’t care because I just don’t want to learn about it” – and, instead, was drawn to business, viewing a job in the corporate world as definitive of his success:

My parents always wanted me to do engineering, because my dad’s an engineer and mum’s an engineer as well... And I always knew that I wasn’t going to get into that kind of subject because I didn’t understand science at all... and finding out that [business] was there I was a bit more happier because I knew that I was okay with the math[ematics.] I had the patience to put reports together [and] there’s nothing that’s going to stop me from doing that [as] like vision impairment does play a major factor.

Max's personal interests and self-recognized competencies meant that his relationship with the career restrictions of VI contrasted Caelan's, as even though "in the truth... I can't just go to any course... I did what I wanted to do" (Max). If anything, Max felt these restrictions strengthened the importance of his future career in business. This comparison of Caelan's and Max's definitions of success demonstrates that participants' experiences of the elements they considered important in their lives were situated by the intersection of their experiences of living with VI and other influential personal factors.

Taken together, these ideas highlighted that the participants' senses of who they were (identity) and consequent understanding of what was important to them, thus, thematically occupied a space of *situated sameness*. That is, the participants emphasized that they found the same elements of life important to them (as youth with VI) as are valued by all people, while elaborating how their understandings and experiences of these elements were somewhat different due to (or situated by) their experiences of life with VI and other intersecting personal factors. A frequent tension existed in their lived experiences between their self-perceived sameness to and difference from their perception of the (sighted) 'normal' population. For example, Pat highlighted the sameness of his altered class participation:

If everyone else was getting ten questions and I'd get like seven or something. So, it'd take me more time to do the one question but I'd get less of them and still know how to do what [the teacher] want[ed us to learn].

This situated sameness of the participants' accounts suggests that a simultaneous acknowledgement of both sameness and difference in the lives of youth with VI is required to sensitively understand and support their wellbeing. This tension had often been poorly managed by others in the participants' lives. Alex recounted negative experiences in which – because of her VI – the staff at her high school pigeonholed her

and failed to recognize that her preferred social connections were with peers of her own age like any other young person:

As an eighteen-year-old in year 12, [I] didn't want to be hanging out with year sevens just because there was another one who was blind. (Alex)

In contrast to Alex's experience, participants commended service providers who conducted "several consultation sessions [in which] they asked about... a long list of stuff", and then "actually started putting together a personalised plan" in which "they'd suggest [something, but] it was just an option" (Val). Participants wanted and needed others to acknowledge the impact of their VI, but to do so in a way that was not ignorant of them as a person like any other whose lived experiences were situated at the center of many complexities.

Discussion

The current article examined key themes arising from the discussions of 21 youth with VI regarding their lives when they are doing well in order to shed light on their conceptualizations and lived experiences of wellbeing. Four thematic life domains in *social connection*, *physical health*, *capability*, and *control* were identified as capturing the elements that they consistently identified as important. However, they stressed that their wellbeing should not be reductively understood as the individual maintenance of these domains statically defined and valued. This resonated with similar criticisms of "the dominance of a 'components approach'" to wellbeing by S. Atkinson (2013, p. 137); that is, the approach to discussing and examining wellbeing that is predominantly focused on the determination of the specific sub-domains that combine to make up the construct of wellbeing. Participants emphasized the importance of maintaining balance between the many elements that they valued in their life due to the mutually-supportive nature of these

elements. Furthermore, this balance was personally-defined, grounded in their senses of identity that arose from, and changed with the intersecting influences of their VI and many other factors upon their lived experiences. Finally, the participants' discussion of the elements of their life that they valued appeared to be located in a conceptual space of situated sameness. In short, the participants felt that the important elements of their lives were the same as those valued and pursued by most people, but concurrently elaborated in their discussions how they valued, performed and experienced these elements differently due to their VI and other factors.

These overarching themes framing the participants discussions align with more situated and relational theorizations of wellbeing (S. Atkinson, 2013; White, 2017). S. Atkinson (2013) asserted that an individuals' sense of self, and their experiences of wellbeing that it informs, should be conceptualized as products of an ongoing and situated interaction between the individual and their specific social context. This relationality was evident in the current participants' accounts. Not only did they weight similar elements of their lives differently (their personal balance), but they also described their own situated experience of these elements (situated sameness) due to their identities that were continuously shaped by their life circumstances, including their VI. The salience of these ideas in the current participants' discussions also holds significant implications for the practices of service providers – not only those employed in rehabilitation and healthcare settings, but also specialist educators – and family members seeking to promote the wellbeing of youth with VI, as we now turn to discuss (Warren & Manderson, 2013).

Implications for practice

Our participants' discussions of situated sameness and balance offer guidance for services promoting the wellbeing of youth with VI. Echoing calls for nuanced strategies for

inclusive education (Tadic et al., 2014; Whitburn, 2014a), this emphasis on simultaneous sameness and difference suggests the need for service delivery that more sensitively responds to their situated experiences. This resonates with extant ideas of client-centered policy and practice (Leplège et al., 2007). However, while many service providers commonly self-perceive such policy as upheld in their practice, it has been repeatedly recognized that the operationalization of these policies is vague and often restricted by business-minded healthcare structures despite individual best intentions (Bright, Boland, Rutherford, Kayes, & McPherson, 2012; Gupta & Taff, 2015; Leplège et al., 2007; Levack, Dean, Siegert, & McPherson, 2011). The context-dependence of the participants' senses of identity that informed what elements of their life they considered important – and their sense of balance between these elements – stressed the importance that service providers should incorporate other influential factors beyond VI into service provision. They should also mindfully engage with the client's expertise regarding their own lived experience during the assessment and planning process of service provision (Bright et al., 2012). Providers must be careful to present professional recommendations as options to be considered by the client, rather than definitive solutions applicable to a current client (in one context) because of its success with a previous client (in another context). Vision rehabilitation organizations providing services to youth should also allow service providers the necessary timeframe to fully implement this more active but time-consuming collaboration (Bright et al., 2012). Furthermore, service providers should support parents, teachers and other relevant stakeholders to similarly adopt a person-centered approach; for example, by encouraging the young person's opportunity-taking, rather than perceiving and acting on only vision-related concerns.

The process of balancing multiple valuable life elements, as described by current study participants, can also serve as a key point of traction for such sensitive and flexible

service provision. Personal balance was central to their maintenance of wellbeing, and thus targeting its promotion will help produce lifestyles that support this goal. Service providers should seek to promote similar life domains for all participants (e.g. physical health, social connection), but ensure that the extent to which they focus on each aligns with the value ascribed to them by each individual youth with VI. For example, a service provider working with Lee – in line with his definition of personal balance on page 165 – would focus on affording him strategies or resources to support him in overcoming barriers to success in his career, and then to a lesser extent connect him with social groups. Moreover, running or endorsing a range of regular recreation programs would be an important element of a service delivery model targeting the promotion of this personal balance; in addition to the social and self-esteem benefits identified in some previous research of such recreation programs (Goodwin et al., 2011; Qasim et al., 2014). These regular programs will aid the youth with VI to establish the routine and structure in their week identified as helpful in promoting balance by the current participants, and thus facilitate their fulfilment and ongoing maintenance of the various important life elements that contribute to their wellbeing. Our findings also suggest that vision rehabilitation organizations should employ service providers who are qualified, capable and willing to engage with their young clients more holistically, beyond their designated specialty. Taking this holistic focus would allow service providers to support each client's personal sense of balance by working to promote multiple elements of their life contributing to their wellbeing in response to their particular preferences and circumstances.

Directions for future research and conclusion

Future research should build upon the current study by addressing certain limitations. Some of the current participants found the audio-recording task difficult, especially in

finding sounds to represent their experiences. While all participants were engaged in discussions around the practicalities and scope of this task, instructions were deliberately kept broad in order to avoid restricting the voices of the participants. Future research in this population using participant-driven data collection should engage participants in detailed but well-managed discussions around their topics and foci. Furthermore, due to time constraints of both participants and researchers, we employed an adapted Youth ReACT method (Foster-Fishman et al., 2010) limiting the analysis phase of this method to member-checking of the coded themes and their relationships. Future research should also include more detailed and participatory methods of data analysis. Such methods would involve a continued collaboration with youth and would provide further insights regarding the conception of wellbeing that vision rehabilitation should target (Rees et al., 2010), as demonstrated in the current study.

In conclusion, our participants' contributions advocated a broader vision rehabilitation focus that supports the ongoing balancing of the important elements of a young person's life that contribute to their life quality and fall across four key life domains: social connection; physical health; capability; and, control. Service providers should offer a breadth of programs and services, and work in active collaboration with youth with VI in order to ensure they support each youth's personal balance between these elements in their specific social context.

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5.2 Concluding Remarks on Paper 1

In explicating the major themes in my participants' discussions, this paper presents a conception of their wellbeing as related to their history and senses of identity, as existing in a tension between their self-perceived normativity and difference due to their VI and other factors, and as a process of balancing the important elements of their lives across four key life domains: *physical health*, *social connection*, *capability* and *control*. This conceptualization holds three specific implications for understanding wellbeing among youth with VI.

First, the importance of maintaining a personal balance between the important elements in their lives captured by the overarching theme of *a personal sense of life in balance* – and informed by their *sense of identity* (a second overarching theme) – indicates that the degree to which the participants were experiencing a sense of balance across the life elements represented an important indicator of wellbeing. Other sighted youth have similarly described their experiences of QoL as the sense that their life is well-balanced (Helseth & Misvær, 2010). Second, this also highlighted the importance of their deliberate maintenance of routine and structure in their life in order to maintain this personal balance. Thus, this intentional maintenance of routine represented one strategy the participants found helpful in maintaining their wellbeing. Finally, in describing their senses of identity, and their similarities and differences as compared to their perception of 'normal' (sighted) society – the overarching theme of *situated sameness* – the participants also identified several interacting VI-related and non-vision-related factors that shaped their understandings and experiences of wellbeing. These are depicted in Figure 5.1.

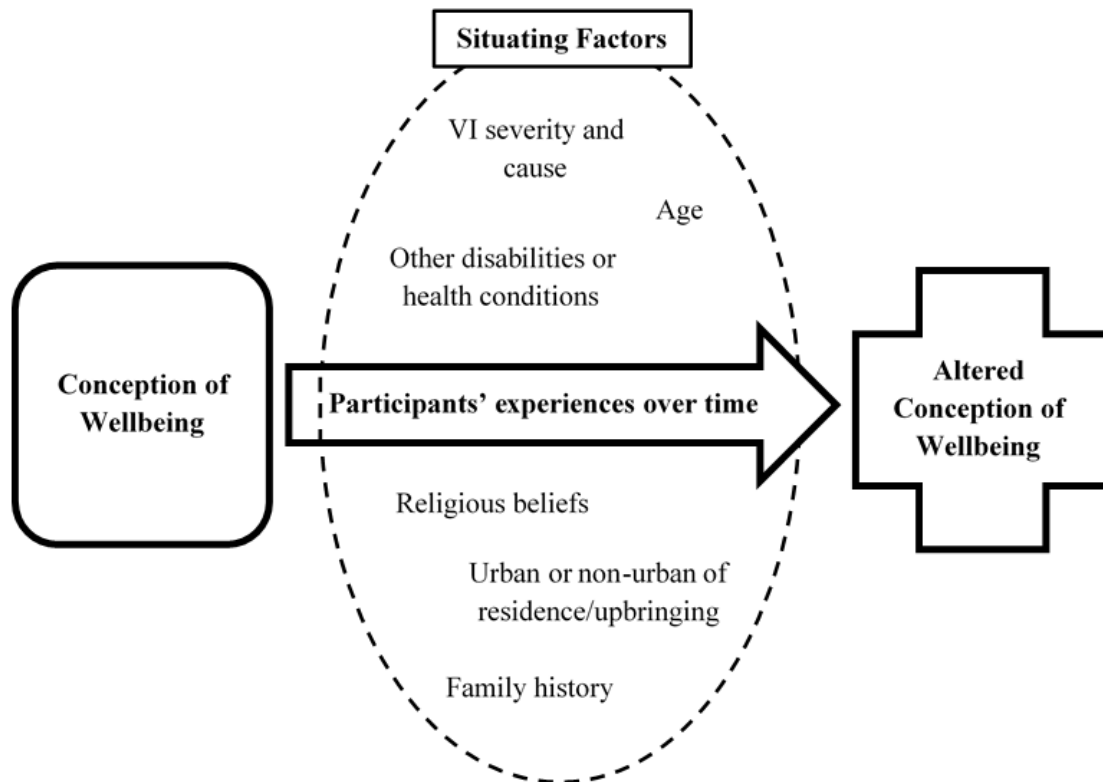


Figure 5.1. A diagram illustrating the shaping effect over time of the various situating factors at play in the participants' lives on their conceptions of wellbeing. *Note:* VI = Vision Impairment.

These insights offered by this paper into the key indicators, influential factors, and useful strategies and resources identified within the participants' discussions of living well with their VI are preliminary. Over the subsequent three results chapters (Chapters 6, 7 and 8), I elaborate in turn on my brief description of the four thematic life domains evident as key contributors to and thus indicators of wellbeing in the participants' discussions. Chapter 8 is centred on the two particularly interrelated domains of capability and control. In so doing, I present how the participants defined, understood and valued each of these domains with respect to important life elements they captured, and delineate the barriers and difficulties participants confronted to each domain's fulfilment related to their VI. In Chapter 9, I then discuss how the participants went about

maintaining what they considered important in their lives despite these barriers,
including highlighting the particular strategies and resources that they found useful.

Chapter 6

Both body and energy: An expansion of physical health

Chapter 6 comprises a publication manuscript accepted for review by the ‘Journal of Adolescent Health’ on the 05/12/2017. In this article, I present the participants’ discussions that revolved around the theme of their physical health in order to contribute to the ongoing development of knowledge regarding how best to promote physical health among youth with VI. This is in light of the greater physical inactivity and poorer physical fitness found in this population compared to sighted youth (Augestad & Jiang, 2015; Haegele & Porretta, 2015). In particular, given the consistent finding that the personal motivation of youth with VI strongly predicts their participation in physical activity (Augestad & Jiang, 2015), my young participants’ understandings of their physical health are delineated in order to guide development of programs that more directly fit with the conceptions of physical health of youth with VI. The paper also offers insights into the barriers and supports the participants experienced in relation to their physical health that should be considered in the development of services.

This paper is included as a chapter in my thesis as it elaborates the various elements of life that participants felt contributed to the quality of their lived experience that were clustered through thematic analysis within the thematic domain of physical health. *Physical health* represented one of the four thematic domains of life identified in the participants’ accounts around what was important to them feeling as though they were living well; the other domains being their social connection (discussed in Chapter 7), capability and control (discussed in combination in Chapter 8). Four major subthemes

were especially salient in the experiences shared by the participants around the larger theme of their physical health: two that captured important outcomes within the domain ‘physical health’, and two that reflected important processual components of maintaining their physical health. With regard to the former, participants wanted to maintain their material *bodily health and fitness* – i.e. meet their basic bodily needs, avoid harm, and promote their fitness – as well as their subjectively-experienced levels of *energy*. Furthermore, to maintain these two outcomes, the participants felt that it was important to engage in both regular *physical activity* and *relaxation*. In the following paper, I elucidate the participants’ discussions captured within these subthemes in greater detail. I discuss further contributions of this paper to my thesis, with regard to the barriers and factors at play in the participants’ experiences of physical health, in my concluding remarks following the paper (section 6.2).

6.1 Paper 2: “You need the more relaxed side, but you also need the adrenaline”:

Promoting physical health as perceived by youth with vision impairment

“You need the more relaxed side, but you also need the adrenaline”:

Promoting physical health as perceived by youth with vision impairment

Purpose: Within a larger investigation of their conceptualizations of wellbeing, this article explores elements of physical health discussed by youth with vision impairment to inform physical health programs, with youths’ personal motivation to be physically active previously identified as key to participation.

Methods: Twenty-one youth (aged 12-25) participated. The qualitative data discussed was collected for each participant across three interviews/focus groups and audio-recording tasks in a project regarding their conceptualizations of wellbeing.

Results: Thematic analysis identified an understanding of physical health characterized by four subthemes. First, participants’ *bodily health and fitness* produced positive self-perceptions, but also held greater importance given the increased physical risks of living with vision impairment. Second, *energy* – a positive, motivating feeling – held additional salience given extra demands upon participants related to their vision impairments. Thus, *relaxation* strategies (e.g. reading) were essential to meet these demands and recover from injury/pain (bodily health). Meanwhile, *physical activity* promoted fitness and vitality. Specific activities also entailed freedom of movement, contrasting heightened environmental risks in other settings.

Conclusions: To better align with possible participation motivators, participants’ discussions suggested that programs should target relaxation and energy in youth with vision impairment – alongside physical activity – and offer free and safe movement in space.

Keywords: young people; participatory methods; physical activity; relaxation; recreation; vision rehabilitation.

Introduction

Youth with vision impairment (VI) show significantly lower fitness levels and elevated obesity rates compared to sighted youth (Augestad & Jiang, 2015; Haegele & Porretta, 2015), and engage less in official and leisure-time physical activities (Engel-Yeger & Hamed-Daher, 2013; Sacks & Wolffe, 1998). Research among youth with VI and other disabilities has identified limited knowledge or training among parents, educators or program organizers around engaging these populations, and a lack of accessible opportunities as major barriers to their physical activity (Augestad & Jiang, 2015; Haegele & Porretta, 2015; Shields et al., 2012). Transportation difficulties, financial costs, poor physical skills, and social obstacles further increase this inaccessibility (Augestad & Jiang, 2015; Haegele & Porretta, 2015).

These findings are significant as physical activity and health are valuable themselves and intertwine with other salient wellbeing outcomes (Biddle & Asare, 2011; Eime et al., 2013; Kristjansson, Sigfusdottir, & Allegrante, 2010). For example, maintaining physical health and fitness can both provide a resource to aid one's endeavors and support self-esteem in line with one's desired physical appearance or competencies, while physical activity enables both stress release and skill development for broader success (Allender, Cowburn, & Foster, 2006; Columna, Fernández-Vivó, Lieberman, & Arndt, 2015; Haugen, Ommundsen, & Seiler, 2013; Holt, Kingsley, Tink, & Scherer, 2011; Perkins, Columna, Lieberman, & Bailey, 2013; Williamson & Carr, 2009). Thus, deepening our understandings of physical activity and health among youth with VI, including their promotion, is crucial.

Research evaluating physical activity interventions for youth with VI has increased (Furtado et al., 2015; Haegele & Porretta, 2015). Some structured or leisure-time initiatives have been found to promote physical activity among youth with VI

(Furtado et al., 2015), with personal motivation drawn from enjoyment or a desire to be fit and healthy serving as important facilitators (Augestad & Jiang, 2015; Shields et al., 2012). For example, Cervantes and Porretta (2013) found that lessons focused on promoting facilitative social cognitions around physical activity among four adolescents with VI, including positive outcomes expectancies, were associated with a short-term increase in their after school leisure-time physical activity as measured by an accelerometer worn by the participants. Nonetheless, such studies are sparse and difficult to compare for best practice due to their various interventions, small samples, non-validated outcome measures and lack of theoretical foundations (Furtado et al., 2015; Haegele & Porretta, 2015).

Clearer guidelines for promoting physical activity and health in youth with VI are required given their significance to a young person's wellbeing (Biddle & Asare, 2011; Eime et al., 2013; Kristjansson et al., 2010). Actively incorporating the voices of the youth, themselves, will be beneficial. Given the significance of personal motivations to their physical activity (Augestad & Jiang, 2015; Furtado et al., 2015; Shields et al., 2012), understanding how young people with VI consider and participate in their physical health and activity will offer insights for more sensitive program development. Furthermore, their perspectives on managing their VI's interactions with their physical health and activity will highlight potential threats to and useful strategies for programs. Therefore, this paper presents the discussions of 21 youth with VI around the major theme of physical health identified in the experiences and stories they shared during their collaboration in a doctoral research project exploring their conceptualizations of wellbeing.

Methods

This study adopted a 12-month two-phase participatory qualitative design, modified from the Youth ReACT method (Foster-Fishman et al., 2010) to ensure the study was accessible for all types of VI.

Participants

Purposive recruitment was conducted for youth with VI. Several vision-related service organizations advertised the study to their clients, instructing those interested to contact the first author (with their parent/guardian if aged <16). Potential participants who contacted the first author by phone were then screened for their eligibility based on their self-report answers regarding four criteria. They had to 1) be aged 12-25 years; 2) have vision impairment of a level self-perceived as hindering everyday tasks; 3) have no other cognitive/sensory impairment self-perceived as impeding participation; and, 4) be comfortable speaking English. If eligible, potential participants were then sent accessible explanatory and consent/assent documentation. If they remained interested, an appropriate session time was determined and personal information (e.g. age, education, a VI history) was collected.

In designing this study, a maximum target of 30 participants was set by the authors: it was agreed through discussion that a sample of this size would allow collection of a sufficiently diverse experience-set to explore wellbeing in this population, while remaining realistically manageable within doctoral research time constraints. In the end, 21 participants (six young women) of mean age 18.62 years (SD = 3.12) participated. Most were currently studying (Table 6.1), and nine (42.9%) reported additional conditions (e.g. learning/physical disabilities). The participants had a mean age of VI onset of 4.59 years (SD = 5.15), and three participants (14.3%) were totally blind (i.e. had

no light perception) while an additional 16 (76.2%) satisfied Australian criteria for legal blindness: a) best-corrected visual acuity of <math><6/60</math> in each eye, b) a visual field of <math><10^\circ</math> in the stronger eye, or c) a comparable amalgam of acuity and field losses (Australian Government Department of Social Services, 2017). Table 6.1 provides further information regarding the participants' causes of VI and prior VI-related service use. Due to the time investment required, participants were reimbursed for each project phase with \$20 shopping center vouchers.

Procedure and materials

Monash University human research ethics committee approved this study. Written consent was obtained for each participant, and additional written parental/guardian consent for four adolescents younger than 16 years of age. In the initial phase, each participant took part in three study sessions conducted as focus groups or interviews – one 1-hour training session and two 2-hour data collection sessions with different objectives (see Figure 6.1) – over approximately a fortnight; in one case via telephone.

Table 6.1

Descriptive Statistics for Participants' Education Levels, Causes of VI and Use of VI-related Services

Characteristic	N (%)
<i>Education Level^a</i>	
Secondary education (current)	8 (38.1)
Secondary education (complete)	5 (23.8)
Tertiary - Undergraduate (current)	3 (14.3)
Tertiary – TAFE or other (current)	3 (14.3)
Tertiary – Any (complete)	2 (9.5)
<i>Cause of VI</i>	
Retinal dystrophy	11 (52.4)
Albinism	2 (9.5)
Neurological trauma	2 (9.5)
Retinoblastoma	2 (9.5)
Other	4 (19.0)
<i>Utilized Service</i>	
Orientation and mobility training	19 (90.5)
Non-sport recreational programs (e.g. accessible library)	16 (76.2)
Specialized sport programs/leagues	13 (61.9)

Note: VI = Vision Impairment; TAFE = Technical and Further Education;
^a All participants attended 'mainstream' education settings; one participant commenced their education in a vision-impairment-specialized setting and then transferred.

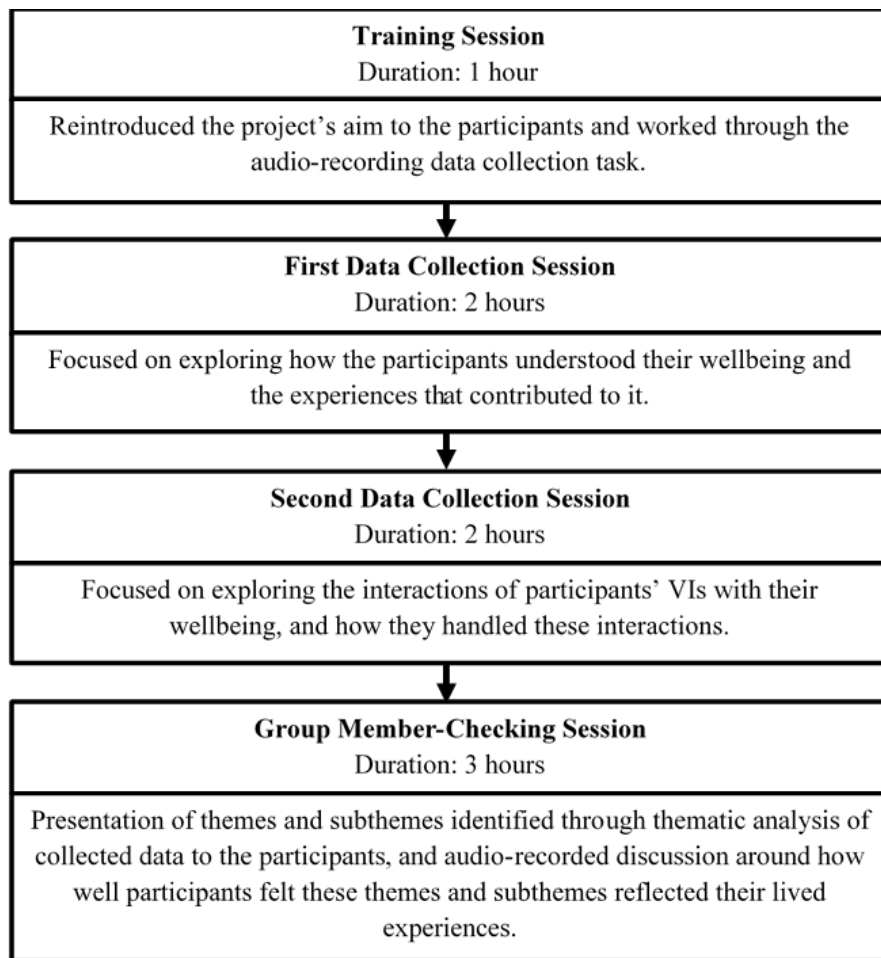


Figure 6.1. A flowchart depicting the four sessions participated in by the participants across the data collection and member-checking phases. *Note:* VI = Vision Impairment.

In the training session, participants' perceptions and experiences of wellbeing were highlighted as the project's focus. The first author emphasized the participants' freedom to raise any topics related to their perception of 'psychological wellbeing' (amended to 'wellbeing' in line with the data shared by the participants as sessions progressed). The participants were then introduced to the audio-recording task designed to complement the study sessions as a variant of the photovoice method (Wang & Burris, 1997) accessible to all participants, including those functionally adapting to recent vision loss. In photovoice studies, participants take photographs (visual data) and often produce

accompanying reflections to identify significant issues in their lives (Foster-Fishman et al., 2010; Wang & Burris, 1997). Similarly, the current audio-recording task asked participants, in their own time, to record sound environments and/or reflections of approximately one minute in length on their smartphones or a provided device that represented or helped explain their experiences regarding the research questions (see Table 6.2 for task prompts). Recorded reflections accompanied sound environments or captured experiences not representable through sound. Across the first phase of the project, the participants captured and provided to the first author a mean of 3.57 sound recordings (Range: 0-17) and 1.76 personal reflection recordings (Range: 0-12).

Table 6.2

Prompting Questions for the Audio-Recording Task Provided to Participants Between Sessions

Timing	Prompting Question(s)
Between Training and First Data Collection Session	What is going on in your life when you are doing well?
Between First and Second Data Collection Session	Does your VI affect how well you are doing? If Yes: In what ways does your VI get in the way of you doing well? And, what helps you deal with your VI when it gets in the way of you doing well? If No: What helps you to stop your VI from getting in the way of how well you are doing?

Note: VI = Vision Impairment.

Participants' audio-recordings were collected from them at each data collection session, and some were played and explored further during audio-recorded discussion regarding the relevant research questions in session. The first author facilitated all sessions in accordance with semi-structured facilitation guides which explored shared audio-recordings through responsive prompting, but also contained reserve questions (see Table 6.3). A co-facilitator attended the first two sets of sessions to enable piloting. Time or conversational restrictions meant that eight participants raised topics in their initial data collection sessions whose examination had been left incomplete, and so they consented to be further consulted via additional in-person sessions or telephone.

Analysis

All recordings were transcribed verbatim and thematically analyzed following Braun and Clarke's (2006, 2013) staged model. This commenced with data familiarization (stage 1) through transcription and transcript review, followed by line-by-line inductive coding of the transcripts (stage 2), and then derivation of larger themes from the content of the codes (stage 3). These themes were examined and situated in a hierarchy (stage 4), and then defined and relabeled (stage 5).

Table 6.3

Prompting and Reserve Questions for the Data Collection Sessions

Data Collection Session	Prompting in Response to Participant Recordings	Reserve Questions
First	<p>What does this recording mean to you?</p> <p>Why is this important to you?</p> <p>How important is it to you?</p> <p>Is this also important to you?^a</p> <p>What did hearing this recording make you think about?^a</p>	<p>What activities do you spend time on when you are doing well?</p> <p>Other than things you do, what other things do you have in your life when you are doing well?</p> <p>What kinds of thoughts do you have when you are doing well?</p> <p>What is your mood like when you are doing?</p>
Second	<p>What does this recording mean to you?</p> <p>Does this happen because of your VI? If so, why?</p> <p>How does this effect how well you are doing?</p> <p>What effect of your VI does this help you handle?</p> <p>How does this help you handle this effect of your VI?</p> <p>Is this also important to you?^a</p> <p>What did hearing this recording make you think about?^a</p>	<p>How does your VI get in the way of how well you are doing?</p> <p>How does your VI affect your mood and your thoughts?</p> <p>What do you find helps you handle your VI when it gets in the way?</p> <p>What do you find helps you when your VI affects your mood and your thoughts?</p>

Note: VI = Vision Impairment; ^a Questions specifically asked of the other participants in a focus group session who did not share the particular recording being discussed.

The second member-checking phase then entailed the discussion of the thematic hierarchy including evidentiary quotes with 11 returning participants in one additional focus group per participant – three sessions in total – for feedback and verification of its validity and applicability regarding their experiences. Logistical difficulties meant that four interested non-metropolitan participants were unable to return. These audio-recorded focus groups were subsequently transcribed verbatim and thematically analyzed via the above procedure. Discrepancies between the first and second phase codes were discussed by the first two authors. Overall, participants endorsed how their lived experiences were represented through the themes and subthemes identified through the initial thematic analysis. Minor amendments regarding theme and subtheme labels proposed by the participants were adopted. Participants also provided the feedback that the importance of their independence and sense of identity to them needed to be more explicitly emphasized. This insight prompted the first author to re-examine the data from the first project phase captured under the codes of ‘independence’, ‘identity’ and related codes (e.g. ‘freedom’, ‘control’) to more fully understand the salience of these themes to the participants. Data management was conducted using QSR International NVivo 10. Pseudonyms and age ranges, demarcating the younger or older half of the age inclusion criteria, are utilized below to protect the participants’ identities.

Results

Participants’ discussions around the theme of physical health centered on four key facets: *bodily health and fitness; energy; relaxation; and, physical activity*. In this section, how each facet was discussed, valued, and maintained is described (for a summary see Table 6.4). The interactions of the participants’ VIs with each are also discussed.

Table 6.4

The Four Elements Discussed by Participants within the Theme of 'Physical health'

Subtheme	Key Ideas Discussed by Participants
Bodily health and fitness	<ul style="list-style-type: none"> • Meeting base bodily needs was important (e.g. food, water). • Avoiding injury and pain was important. • Greater bodily risk was experienced due to VI's interaction with physical and social environment: e.g. ergonomic issues, navigational difficulties and social threats.
Energy	<ul style="list-style-type: none"> • Feeling that they had the necessary fuel and motivation (i.e. a subjective feeling of energy) for their pursuits was important. • Living with VI entailed ocular strain and required greater effort to manage social barriers (e.g. others' ignorance), and so subjective feelings of energy held distinct value.
Relaxation	<ul style="list-style-type: none"> • Taking time for activities or in settings that gave them a break from the pressures and stress of life was important: e.g. reading, listening to music and meditation/mindfulness. • Rest helped them manage pain and replenish their energy levels. • Non-visual and sensorially pleasant activities and settings were important due to prevalence of over- and under-stimulating experiences in their everyday lives.
Physical activity	<ul style="list-style-type: none"> • Engaging in regular exercise and active recreational activities was important, including individual (e.g. running) and group-based activities (e.g. team sports). • These activities helped them keep fit and manage their subjective energy levels, among other benefits (e.g. connection with others). • Activities in which they felt free and safe to move in space provided an invaluable contrast to their mobility in other settings. • Several barriers affected this physical activity: e.g. limited adapted activities, reduced activity skills for sighted sport participation due to VI, concern about others' reactions, and travel distances. • VI-specialized sports were a key avenue of physical activity for many in responding to these barriers but were under-resourced and harder to find.

Note: VI = Vision Impairment.

Bodily health and fitness

Participants valued the health and functioning of their material body: that is, their actual corporeal and biological body with its limbs, systems and organs. Some emphasized satisfaction of “basic [needs] like water, food [and] shelter” (Caelan, aged 19-25), while avoiding pain and physical harm was centrally important. They wanted to live “relatively pain free” (Harper, aged 19-25), and elaborated multiple pain and harm management strategies: foregoing activities sometimes by “identifying as a vision impaired person” (Shannon, aged 19-25); “rely[ing] on [their] parents or... medication” (Alex, aged 19-25); and, relaxation (discussed below).

Living with VI increased the actual and self-perceived physical harms that the participants experienced or risked. Harper’s VI directly contributed to his chronic musculoskeletal pain: “I had... to kind of contort my body to get close enough to the [school computer] screen to see [my school work]”. Similarly, several participants described how, when moving through environments, they often “run into a pole” (Peyton, aged 12-18) or other obstacles despite most having received mobility training (see Table 6.1). Meanwhile, others felt “exposed” (Alex) to physical harm due to negative social responses to their VI. Alex’s experiences of bullying at school left her feeling physically threatened both during these actual encounters, and on encountering the involved students in other scenarios. This greater exposure increased the participants’ awareness of their bodily health and safety:

Walking around in an ever-changing environment... if it’s not making a noise [then] you’re not going...to pick it up [so you] become a little wary. (Val, aged 19-25)

This increased awareness was not constant across participants. Different VI causes and histories, and other factors, uniquely shaped participants’ considerations of physical

safety. For example, Drew (aged 19-25) recorded and shared the sound of a car driving past to highlight her concern about crossing roads: “I have difficulty with roads and... always worry that I’m going to misjudge where the car is”. However, in the following discussion, it was evident that her concern was not shared by other participants, which Charlie (aged 12-18) and Jesse (aged 12-18) attributed to their longer-term mobility training: “Jesse and I started the group [of local young people receiving mobility training] off... so between [Drew’s] four and [our] 11 years is a big difference” (Charlie). Meanwhile, although his vision contributed, Harper explained: “I had [another condition] growing up, so... had a lot of musculoskeletal pain... not related to the vision”. These experiences also shaped his perceptions of bodily health.

Physical fitness was also prized by the participants and was achieved through regular physical activity (discussed below): “It’s good to be fit” (Caelan). They listed multiple reasons for its value; for instance, one benefit was “self-esteem” and feeling like they were “good-looking for once” (Jay, aged 12-18). These reasons were again distinctly forged by VI-related experiences. For example, Alex recorded herself on an exercise bike, reflecting that the importance of her fitness stemmed from her knowledge of the inactivity of people with VI:

The statistic of inactive vision impaired people is I believe quite high, so I have always made it a point to keep active... I don’t want to become overweight.

Alongside these bodily elements, participants’ discussions often identified the valuable, subjective experience of physical health: a feeling of energy.

Energy

Participants frequently made implicit and explicit reference to their subjective energy levels in discussing what contributed to the quality of their lived experience and its

interaction with their VIs. They described valuable moments in their life in which they felt “lively” or “energized” (Val), or they spoke of a valuable “enthusiasm” (Shannon) for their pursuits. At other points, participants outlined undesirable experiences in which they felt “lethargic” or “sluggish” (Elliot, aged 19-25). In short, the participants made reference to their subjective level of energy: a positive but fluctuating motivational feeling. This energy was not only inherently pleasurable, but participants also valued it for the impact it had on their capacity to take part in other activities they considered important: you need “time to re-energize... to go out and do things” (Jules, aged 19-25).

As with their bodily health, several VI-related factors affected the participants’ energy levels. Living with VI demanded “a lot more effort” (Val) for everyday tasks, such as the greater effort Val expended in navigating environments: “It’s physically draining staring at stuff when you haven’t got much to stare with”. Meanwhile, in a larger sense, the participants’ pursuit of key aspirations also required greater effort due to barriers related to their VI, as reflected below in Lee’s advice to younger adolescents regarding career ambitions. Thus, living with VI gave the participants a distinct appreciation for feelings of energy.

Think about your [desired] career... maybe there’s other vision impaired people you might know who already do that job, or alternatively if you really love that job... either start asking people to find out if there is anyone [with VI who does] or be prepared to reinvent the wheel. (Lee)

Entailing fighting for support and understanding from others, this reinvention described by Lee exemplifies energy’s special value to the participants. Such advocacy and social navigation was ongoing, and was influenced and complicated by their specific vision histories due to limited community understandings of VI:

I'd love to be able to... clearly communicate to someone the depth and complexity of my vision [then] I would choose to be different [but] it's easier to try and be the same [which is] why I end up feeling tired. (Harper)

As a result, the participants asserted that "sometimes [they] don't have the energy to fight" (Frankie, aged 19-25). To combat these moments, participants balanced two key strategies to promote their energy levels as well as their bodily health: relaxation and physical activity.

Relaxation

The subtheme of relaxation captured the importance that the participants placed on finding time for themselves, to engage in activities that they found restful and enjoyable. Participants perceived such time as clearly valuable to all people: "Who doesn't like spare time?" (Val). Having this personal time was important for facilitating participants' recuperation, especially due to the additional demands of living with VI. Both activities (e.g. reading, craftwork) and places (e.g. parks, gyms) facilitated relaxation. These activities and places were comfortable: free from concern, judgement and imposition. The participants valued the respite from "pressure of school [or] home [found] in [their] own zone" (Jesse).

[Listening] to music... it's not distracting... impinging or painful. It's just floating there... I so rarely encounter rooms with sufficient and not-over-bright lighting [so that experience] is very relaxing. (Morgan, aged 12-18)

Many participants also portrayed these activities or spaces of relaxation as meditative, and as time to be present in the moment and separate from mental states. Jamie (aged 19-25) "meditate[d] every morning before [getting] up [because] it's a really good way to keep [her] brain in check". She prized moments offering the "surreal"

feeling of being “completely relaxed but... enjoying all of the surroundings”. Similarly, further reflecting on his audio-recording of a favorite song, Morgan elaborated that when listening to music his “head just sort of clears out”. Such detachment and calmness provided a particularly welcome contrast for the participants to the excessively or insufficiently stimulating environments that they encountered in navigating society that unpleasantly interacted with their VI.

Some forms of exercise and sport also enabled relaxation for many participants: it is “a quiet... reflection time, because I don't listen to... anything while I'm at the gym” (Elliot). Thus, their strategy of relaxation overlapped with that of physical activity.

Physical activity

Regular physical activity – including individual activities, such as “time at the gym [or] going for a run” (Elliot), and group activities (e.g. team sports) – was important to the participants for multiple reasons. Such activity facilitated dynamic energy management, serving as “refreshing” (Ash, aged 12-18) or providing “a surge of energy” (Peyton), while also offering at other times an “outlet” for the “inner animal” (Lee). They also promoted physical fitness, as well as the participants’ progress towards larger goals through developing transferable skills: “We learn how to work as a team; that [is something] you can use in every aspect of your life” (Frankie). Playing drums contributed to Jules’ feelings of competence and self-fulfillment, as well as his enjoyment and social connection:

[Playing drums] gives me enjoyment. It's something that I'm good at [and] I can do in community... Drums [are] a small part of who I am [so] being able to be good at it... contributes to how I feel about who I am. (Jules)

Their increased awareness of bodily health and safety also directly shaped participants' valuations of certain physical activities. Several reported extra appreciation of activities where they could move freely and safely in space without concern for environmental hazards. Alex relished the rush she got when she was supported in going roller-skating:

[One aide] would take me skating on a weekly basis [and] being quite a good skater, she could skate around in front of me and I would follow the sound... and I could skate to a good speed without hurting myself and... got a real kick out of that. (Alex)

Val echoed this experience, finding that sport he could participate in out in open spaces afforded him room to run in contrast to his everyday environment:

I could never really run with confidence around [my local area] because there's just all these deviations and depressions and inclines that I don't see... But, when you get out into the middle of [the sporting field] there's nothing to run into... and you have that freedom to just chase

Several barriers often impeded these benefits of physical activity. In addition to physical safety considerations, all participants described their inability to perform skills required for varied sports due to their VI or other conditions: "It's more my physical impairment that makes [footy] hard" (Pat, aged 12-18). Ash felt that she "was just a bad player" in ball sports as her "vision impairment... warps the whole thing". Such difficulty produced further motivational barriers because "it puts [the participants] off" (Ash). Social barriers included being "scared of looking an idiot" (Alex) while participating, and the limited choice of accessible activities. Lee elaborated that "because you don't have as much choice there might not be something that's right for you... so you could be less likely again to be staying as active as the average person".

Nonetheless, the participants were still physically active. Several were active with family and friends who were more understanding and accommodating: playing “with my brothers is just something I love to do [because] we play with [a vision impaired] ball [and] a tennis ball” (Pat). Meanwhile, others with greater remaining vision adapted in their participation in sighted sports: “Basketball [has] a ring with a string [which] goes swish [so] I know I get it in” (Peyton). For the majority, however, their physical activity came through VI-specialized sports (Table 6.1): “Having... a blind sport there just [made being active] a lot easier” (Taylor, aged 12-18). While invaluable initiatives, these programs did not remove all barriers. For example, Val explained how “it is genuinely harder to find [these sports] close to you [so] if you're not prepared to go that far then automatically that's out the window” (Val); a barrier accentuated by other obligations (e.g. study). Furthermore, some participants and their parents/guardians described these programs as under-resourced and under-advertised.

Discussion

This paper presented and explored several elements identified as valuable by 21 youth with VI that were related to their physical health. The participants spoke about maintaining their subjective energy levels alongside their material body's basic needs, physical integrity and fitness, through both being physically active and taking time to rest and escape the pressures of life. Furthermore, participants' experiences living with VI shaped their valuations and undertaking of these elements. In addition to reaffirming previously identified barriers to physical activity (Augestad & Jiang, 2015; Furtado et al., 2015; Haegele & Porretta, 2015; Shields et al., 2012), their insights offer directions for future work targeting the physical health of youth with VI.

The participants indicated potential avenues for promoting their physical activity. Their distinct awareness of physical safety due to their VI and others' response to it, and associated appreciation of physical activities entailing their free and safe movement in space are salient given consistent findings that personal motivations are a physical activity facilitator (Augestad & Jiang, 2015; Furtado et al., 2015; Shields et al., 2012). Offering programs involving this freedom may represent one way to increase the participation of youth with VI in physical activity due to the special salience of such experiences of movement to the current participants, and thus may help to address obesity and fitness concerns in this population (Augestad & Jiang, 2015; Furtado et al., 2015). Such programs should seek to center on sports that involve this free and safe movement – such as those played on larger, open fields (e.g. VI-specialized cricket) – or incorporate greater co-participation by sighted family, friends or program staff to assist the participant's freer movement in an activity, as was enjoyed by Alex when roller-skating. In addition, the activity of their family and friends supported the participants' own leisure-time physical activity, echoing previous studies (Augestad & Jiang, 2015; Furtado et al., 2015; Shields et al., 2012). Positive correlations have been found between the physical activity of youth with VI and their families, and peer guidance has been associated with elevated physical education participation (Ayvazoglu, Oh, & Kozub, 2006; Wiskochil, Lieberman, Houston-Wilson, & Petersen, 2007). These findings suggest that future research should examine how to optimally incorporate family and friends into the physical activity of youth with VI.

However, the current participants' discussions suggested a broader view of physical health, underscoring valuable subjective feelings of energy maintained by balancing physical activity with activities of relaxation. The value of subjective feelings of energy in people's everyday experiences is not novel (e.g. R. M. Ryan & Frederick,

1997), but the participants positioned their subjective energy levels as especially important due to the draining nature of living with VI; also noted elsewhere (Lieberman, 2002). Thus, the feeling of being free from restrictions and pressures – definitive of the current participants’ relaxation – and of having energy represent potential motivators for participation that should also be targeted by physical health programs for youth with VI. However, little consideration of these subjective outcomes has occurred in intervention trials to date (Furtado et al., 2015).

Further evaluation and development of programs targeting relaxation – including mindfulness which was prized by several participants (cf. Marquès-Brocksopp, 2014) – in youth with VI is needed. Lieberman (2002) proposed yoga as one such program; limited extant research (Mohanty, Murty, Pradhan, & Hankey, 2015; Mohanty, Pradhan, & Nagathna, 2014) only offers preliminary support (e.g. reduced physiological arousal; Telles & Srinivas, 1998). The current participants conveyed several relaxation strategies (e.g. reading, music, art), suggesting that multiple recreation programs incorporating these activities, meditation or mindfulness should be available alongside physical activities, such as sports. This range will also meet the different considerations of youth with VI around their body and physical health due to their specific VI and other factors found in this and other research (Kaplan-Myrth, 2000), and in turn promote their motivation to participate in programs.

Strengths and limitations

A number of strengths and limitations of the current study are important to note. A major strength of the current research was that it enabled in-depth exploration of several elements important to youth with VI related to their physical health. To the best of the authors’ knowledge, no previous research has provided youth with VI a voice around

their understanding of physical health. The specific study design and methods were the root of this strength. The ongoing collaboration with the participants over multiple sessions – including a member-checking process – encouraged the participants to consider and critically engage with the research questions regarding their experiences of wellbeing over a longer period of time and away from the confined research interview room (Foster-Fishman et al., 2010; Lopez et al., 2005). This led participants to reflect on more everyday but no less important elements of their life. This ongoing collaboration was further supported through the deliberate inclusion of the participant audio-recording task. This audio-recording task not only gave participants greater control over the data collected by the study as they captured the recordings and thus empowered their own voices, but also encouraged participants to more directly engage with each other's lived experiences as participants shared recordings in their focus groups (Foster-Fishman et al., 2010; Lopez et al., 2005).

Future research can extend on this exploration of the concept of physical health among youth with VI, however, by addressing some limitations of the current study. First, the participants' discussions around the theme of physical health occurred in a study exploring their larger conceptualizations and experiences of wellbeing. This presents a possible limitation as their focus in their considerations was not explicitly on their physical health. Future collaborative qualitative research specifically exploring physical health may provide additional insights. Furthermore, this future work should build on this study by promoting the youths' perspectives through greater participant-driven data analysis (e.g. in coding) as utilized in participatory research among adolescents more generally (e.g. Foster-Fishman et al., 2010), and providing clearer guidance for participant-driven data collection. All current participants were provided instructions around the audio-recording task; however, these instructions were deliberately broad to

avoid restricting participants' voices. Although many participants found this task engaging and thought-provoking – as suggested by the means and ranges provided in the Methods section – some participants found it overwhelming. Future research employing this or similar data collection methods must balance the risk of over-prescription, with that of providing insufficient guidance to enable the full engagement of all participants. Finally, the recruitment strategies employed in the current study likely introduced some selection biases into the sample of participating youth. Recruiting through the specific VI sporting and service-provider-run groups meant both that fewer young women took part in the project due to the cultural and institutional contexts of these programs, and that participants were both more likely to utilize VI-specialized sporting programs rather than adapting their participation in sighted sporting or activity settings. Future research should thus seek to better represent the voices of young people with VI of all genders, as well as further explore the physical health and activity of those that do not take part in VI-specialized sporting groups.

Conclusion

The current participants outlined a broader understanding of physical health than is represented in extant work (Augestad & Jiang, 2015; Furtado et al., 2015). They expounded ideas of bodily integrity and functioning, subjective energy and engagement in both relaxation and physical activity. In addition, participants also described physical activity facilitators (e.g. familial activity) and motivators including those stemming from their VI-related lived experiences (e.g. free and safe movement in space). These insights are critical for ensuring the relevance and traction of physical health programs for youth with VI and thus motivating their participation.

Declaration of Interests

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6.2 Concluding Remarks on Paper 2

This paper outlined four central elements that participants considered crucial in determining how well they were travelling which arose in their discussions around the major thematic life domain of *physical health*. Participants found value in the sustenance of both the physiological and material integrity of their body (their *bodily health and fitness*) and subjective feelings of *energy*, which they achieved through both *physical activity* and *relaxation*. This paper also provided considerable insight into the various factors that influenced the participants' experiences of physical health. In particular, participants confronted several difficulties in their pursuit and experience of the four elements of physical health that resonated with the relational models of disability introduced in Chapter 2, highlighting the significant role of environmental and social impacts alongside the effects arising from their VIs themselves (Shakespeare, 2006; C. Thomas, 2007). These operated both as direct threats to their bodily health and fitness, and subjective energy levels, as well as barriers to their performance of their physical activity. First, with regard to direct impacts upon their bodily health and fitness, participants outlined how the interaction of their reduced vision with features of material and institutional environments (e.g. obstacles, lack of accessibility software on school computers) exposed them to greater threats of physical injury and pain. These threats were compounded by social forces as well, with several participants being the targets of physical victimization from their peers at school. Importantly, this physical victimization impacted upon the participants' experiences of bodily health as both a form of structural and psycho-emotional disablism (Reeve, 2012; C. Thomas, 2007). Being physically bullied not only led to actual physical harm for the participants, but also made them feel constantly wary for their physical safety in a variety of social settings, and thus psycho-

emotionally decreased their experiences of physical safety (and thus bodily health) even in situations free of their attackers. Similar direct and indirect forms of psycho-emotional disablism also threatened the participants' subjectively-experienced levels of energy given the extra effort participants had to put into navigating these material, institutional and social forces. This then compounded upon the ocular fatigue many participants with remaining sight experienced from straining to use their sight to aid these efforts – an impairment effect (C. Thomas, 1999, 2007).

Material, institutional, social and psycho-emotional barriers also produced difficulties to the participants' physical activity – activity which supported both their bodily health and fitness, and feelings of energy – in conjunction with the physical limitations arising from their VI that made it difficult for them to participate in sighted sports. This included their own feelings of embarrassment, the lack of accessible physical activity options, and considerable travel requirements to get to those options that were accessible; consistent with those identified in previous research (Augestad & Jiang, 2015; Haegele & Porretta, 2015). One particular institutional barrier to their physical activity was that, while adapted sporting programs existed and represented key avenues for physical activity for the youth, many participants were not made aware of their existence by service providers; instead, eventually coming across them by happenstance.

Many of these same barriers – such as their victimization at the hands of their peers – also presented difficulties in the participants' social lives. In the next chapter, I turn to outline the participants' descriptions of what they considered positive social connection, and how such difficulties impacted upon their ability to attain it.

Chapter 7

Social connection: Closeness, community and capital

Connection with other people was important to all participants and was identified as something that is valuable to all “humans [who] just generally are social by nature” (Lee). For some participants, their friends, families and wider communities were the elements of their life that they considered most valuable; while even those who prioritized their independent and successful participation in their activities and endeavours in evaluating the quality of their life (Chapter 8) still acknowledged the value of this connectedness.

The value of their relationships with family, friends and larger communities frequently extended beyond the relationships themselves, and it was not uncommon for participants to describe sharing positive experiences with others around the pursuit or attainment of other life elements that they considered important, such as hobbies, sports, their education or work. In fact, these experiences of social connection did not simply co-occur with these other valuable life elements; rather, they further enriched the value of or facilitated the participant’s success in these pursuits. Alex, for example, preferred engaging in physical activity with her friends; another element that she felt enriched the quality of her life (as discussed in Chapter 6):

I probably wouldn’t feel as good about [my social life] if we spent all of our time just going to the movies and eating popcorn [rather than playing sport]. We’ve all done something good [for our health] together.

In this chapter, I explore the participants’ discussions of their social interactions and connections with others as a group of life elements that the participants highlighted as valuable. I commence this chapter by outlining the key qualities defining participants’

positive social connections and indicate the participants' particular emphasis on the valuable resources provided by positive connections with others, engaging with the concept of social capital (Kawachi, Kim, & Subramanian, 2008; V. Morrow, 1999). In the second section, however, I argue that participants' experiences of such positive social connections were impeded by the stigmatizing and oppressive responses of others to their VI, and interactions of their VI with physical and social barriers to their social participation. in line with scholarship underscoring the social basis of disability (Goodley, 2014; C. Thomas, 2007).

7.1 The Valuable Capital of Close Bonds and Communities

Participants discussed social connection and its value at two levels: one-on-one relationships and participation in communities. In this first section of this chapter, after providing an overview of the participants' diverse social lives, I present common qualities of their positive social connections at both levels, as well as the reasons they valued such connections. I then highlight similarities between the participants' accounts of valuable social relationships and those obtained among other young populations and outlined in prominent theories regarding the benefits of being socially connected to others (Cohen, 2004; Feeney & Collins, 2015). In particular, I demonstrate the utility of the concept of social capital as a theoretical lens through which to understand why the participants placed importance on their one-on-one relationships and community participation (Kawachi et al., 2008; V. Morrow, 1999).

7.1.1 Complexities of connection

Participants engaged in considerable discussion around one-on-one personal relationships. Their friendships received the greatest attention as the participants' closest

relationships – in line with the increased importance of friends and peers in adolescence (Gross-Manos, 2014; Huurre, Komulainen, & Aro, 1999; Kef & Deković, 2004; Reitz, Zimmermann, Hutteman, Specht, & Neyer, 2014) – followed by parents. However, echoing the recognized need to examine the breadth of youths’ social networks (Belle & Benenson, 2014; Flynn, Felmlee, & Conger, 2017; Furman & Shomaker, 2008), siblings, other family, professionals and romantic partners were also discussed, and were the most salient connections for some.

Participants’ social lives and networks were diverse. They preferred social networks of different sizes, especially in the case of friendships. For example, while Jamie had “lots of friendship groups”, Elliot’s network was narrower: “I don’t like a lot of people, but I do like the people I like”. Participants also desired differing levels of personal freedom in relationships. Some had extremely close friendships, describing daily contact: “I’ll usually chat to [my closest friends] almost every night over Facebook or text-messaging” (Val). Others needed and desired more personal space: “As much as I am a very social person, I like to have my own time, so I struggle around friends who are quite clingy” (Frankie). Frankie perceived this balance between contact and space as a personal one, aligning with the theme of ‘a personal sense of life in balance’ described in Chapter 5.

This diversity represented participants’ different personal characteristics or circumstances. Age, religious beliefs, familial stability and history, and rurality of upbringing/residence were all implicated by participants. For example, these contextualizing factors influenced the participants’ contrasting experiences of the same types of relationship:

Jesse: I can always trust my parents.

Ross: *Yep.*

Charlie: My [situation is] a bit different because when I was [younger], my parents [couldn't look after me anymore]. I had a lot of support from my [grandparents].

Due to family breakdown, Charlie's parental relationships were not the close and trustworthy centres of his social network as they were for Jesse, echoing previous findings of the negative impact of familial disruptions upon parent-child connections (Bradford, Vaughan, & Barber, 2008; Erel & Burman, 1995; Kouros & Goeke-Morey, 2014). Instead, other family stepped up to support Charlie; a potential mitigating factor to the negative effect of family disruption discussed in previous literature (Lee & McLanahan, 2015; V. Morrow, 1999; Reed, Lucier-Greer, & Parker, 2016).

Participants also discussed how their relationships with others occurred within larger communities of various purposes, sizes and levels of formal instantiation: the line between one-on-one relationships and social groups blurred for several participants. Participation in sports competitions or surrounding events were key avenues for social activity and the formation of relationships for the participants. Many described "sport as [their] social life" due to their participation in "the team social kind of thing" (Harper). Music-related social ties were also identified, such as through Drew's choir or via "a couple of school bands" for Jules. Meanwhile, other participants also felt connected to more diffuse and less tangible collectives. Lee's paid employment enabled him to feel connected to the larger Australian society: "If I spend a day at work and go home, I know that today I haven't been a drain on society... I've done my bit to help out Australia".

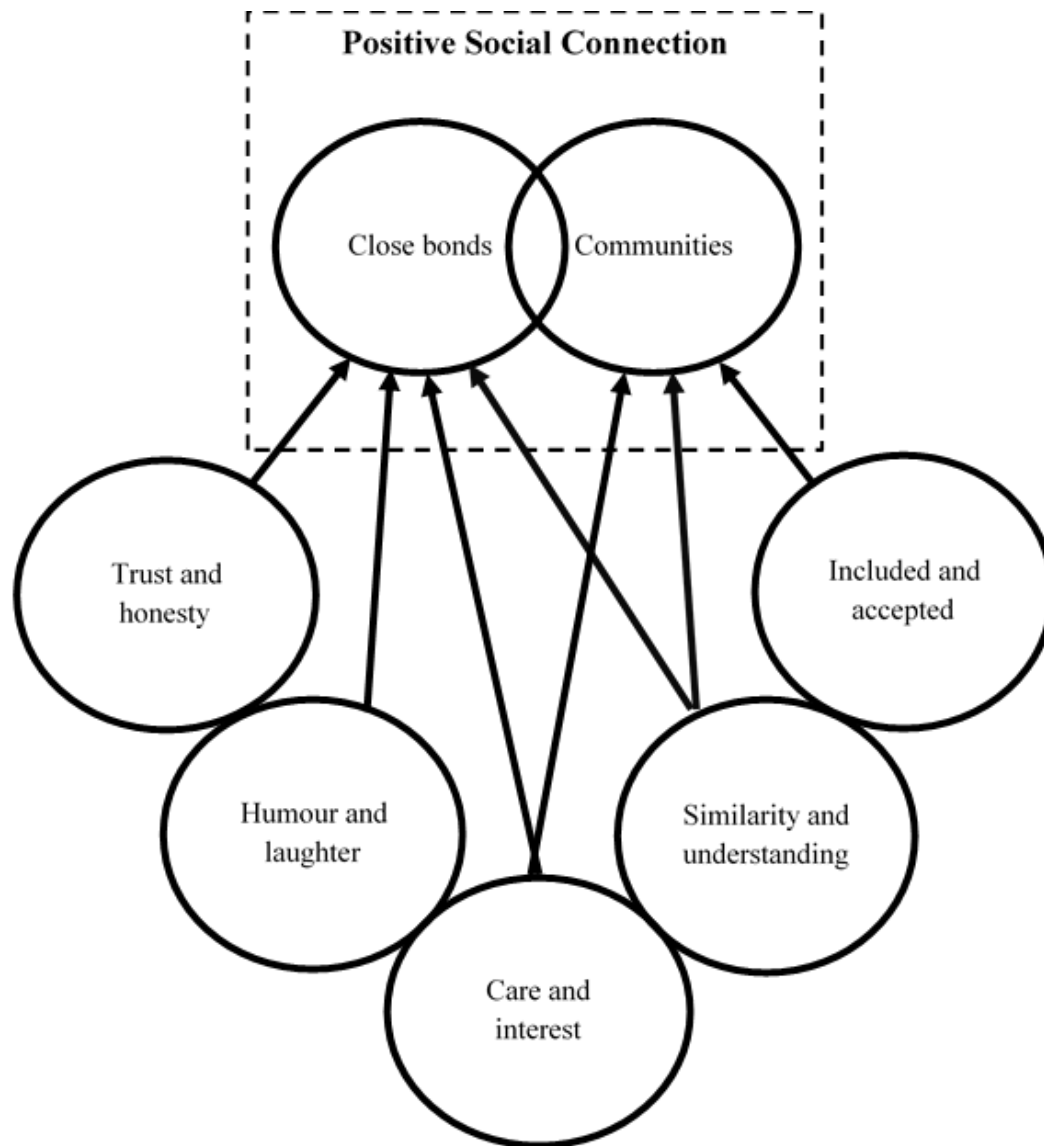


Figure 7.1. A diagram depicting the key qualities (subthemes) that the participants identified as contributing to the value they found in their social connections. The arrows indicate which subthemes were consistently raised by the participants in their discussions of their close one-on-one bonds and their participation in larger communities. For example, the participants generally discussed notions of trust and honesty only in relation to their close one-on-one relationships.

Participants’ personal characteristics or circumstances diversified their community participation as well. Jamie explained that her family had always participated in active outdoor hobbies in the community due to their cultural significance in the regional town of her upbringing: “From kinder[garten] we all had motorbikes... because, you know,

country town, everyone has motorbikes when they're a kid". Whereas, Taylor's age had affected his participation in VI-related communities: "[For a long time], I was too young to participate in most blind sports".

Such diversity notwithstanding, all participants perceived positive social connections as elements that enriched the quality of their lives, and several common qualities of positive one-on-one and community connections were identified in the participants' discussions (see Figure 7.1 above for a list of these qualities). I now outline these qualities.

7.1.2 Close bonds

Sharing close bonds with friends, parents and others was important to participants, and several characteristics contributed to their understandings of such positive close relationships.

Similarity and understanding. These close bonds were commonly grounded in feelings of *similarity*. Several possible points of similarity were identified by participants: a shared ethnicity or culture; "common interests" (Frankie) such as a sport or musical style; or, shared values, such as those of Jamie and her closest friends: "We all have that similar kind of want and drive to be positive and... to help [others]". Thus, the traits, interests, values and group memberships of the participants' closest friends and family overlapped to some extent with their own self-perceived characteristics (i.e. their 'senses of identity' outlined in Chapter 5). For example, Harper emphasized the importance of finding people who shared his interests (i.e. musical and literary preferences) to enable him to form close one-on-one relationships:

People [that I have connected with were the] people who, you know vision aside, have things in common with me... I struggle to get along with people, because... I think in quite an unusual way, and I'm drawn to the alternative aspects of all kinds of culture, whether it be music, whether it be literature.

Harper's quote above also highlighted the defining experience of this similarity. Similarity facilitated greater *understanding* between participants and their counterparts. Harper's belief that he thinks in "quite an unusual way" meant that he sought others who also occupied the cultural fringe because he felt they would share his worldview. Meanwhile, Ash enjoyed spending time with her similarly-aged friends because they had a good understanding of her current life, unlike her parents or her younger brother:

[Spending time with friends is] fun because you get to talk to people that's like your age... so like you can relate to stuff, unlike with... your parents who like have already experienced [growing up], or your brother who is like too young.

Humour and laughter. Humour was central to participants' positive close relationships and the value these relationships contributed to their lived experience. "Joking around" (Jesse) with others – most commonly friends – and sharing "lots of laughs" (Jamie) were invaluable social experiences. First, in line with the intuitive association between laughter and positive emotions (Kurtz & Algos, 2017), sharing humour and laughter with friends or family was inherently pleasurable. Participants loved "spending time with people who can make me laugh [because it] is just a really positive and happy feeling that you can't get any other way" (Lee).

Shared humour, however, represented more than a positive experience. Jokes and funny stories aided participants in forming and strengthening relationships. Shannon found that humour "breaks the ice and it just opens up the lines of communication...

because [the other person knows] I can have a laugh”. He described, in particular, an encounter with a young woman undertaking the same degree as himself:

There was one incident where... I came into the courtyard area and the whole group were there at the one table, and then there was another girl... I'd say, oh, 200 metres away from the table and she said to me “Hi Shannon, Hi Shannon”, and I actually walked past her... because I didn't actually see her. And she came up to me at the table and I'm like, “Oh my God! I'm so sorry” and that's something we've got together to laugh at, you know... and I mean she calls me every now and again so I'm obviously doing something right.

Shannon felt that it was because he had shared the funny side of this incident with this young woman that they had become quite close friends – and from Shannon's point-of-view (hopefully) future romantic partners.

Care and interest. *Care* also characterized participants' close bonds. In the context of disability, care is prominently conceptualized as a non-disabled person's provision of involved support to directly address the special needs of the person with disability, motivated by affection and responsibility (Barrett, Hale, & Butler, 2014; C. Thomas, 2007; Watson, McKie, Hughes, Hopkins, & Gregory, 2004). This care is perceived as one-directional and as having two distinct components: the actual instrumental enactment of practical assistance ('caring for' the care-recipient), and the socio-emotional investment by the caregiver ('caring about' the care-recipient; Barrett et al., 2014; Manderson & Warren, 2013; C. Thomas, 2007). Some participants described care from certain close social ties in such unproblematic terms, such as that received by Drew from her parents: “Just the love and... that they're there for you when you need them, like when you're upset”.

Most participants, however, conceived of caring and supportive relationships in a way conflicting with such narrow conceptions, consistent with previous literature among people with disabilities (Barrett et al., 2014; Manderson & Warren, 2013; C. Thomas, 2007). While all acknowledged that care was expressed through overt support, several participants elaborated subtler and valuable forms of caring about them unrelated to their VI performed by friends and family. Others simply showing *interest* in them as a person, as in Val's relationship with certain members of his local community, was described as care: "It feels like they care... they know you by name... and they talk with you about how things are going and they take an interest in you". Similarly, Frankie desired this same genuine interest from her close friends with VI, to whom she provided assistance herself: "I want to be there because you want to hang out with me... and not because you want me to do something for you". Therefore, the participants' close, caring bonds entailed mutuality – the presence of genuine and equivalent positive feelings held by both members (Matheson et al., 2007).

Reciprocity was also central to care, and thus participants' conception of valuable close bonds. Most participants emphasized and prized "give-and-take" (Matheson et al., 2007, p. 320) in their supportive close relationships. This was exemplified in Frankie's quote above. Due to her greater remaining sight, Frankie provided practical assistance to her friends with less remaining vision but did so on the understanding that these friends genuinely cared about her. Similarly, Pat identified care and support as key to positive close friendships, and highlighted how it ran both ways:

[The value of having friends] is just having like three or four friends that you can just rely on to be there when you want them to be there and... you'll be there for them if something happens to them.

Echoing feminist disability studies scholarship (C. Thomas, 2007) and subsequent research evidence showing that people with disabilities both provide and receive care (Manderson & Warren, 2013; Meltzer, 2017; Shandra & Penner, 2017), the participants' close relationships challenged the perceived unidirectionality of caring relationships that include people with disabilities.

Trust and honesty. Closely related to these ideas of reciprocity, trust also characterized participants' close bonds. Jay labelled his close relationships as “full-on trust relationship[s]” and emphasized trust's importance: “Trust with my friends... I wouldn't trade it for the world”. Trust is a positive expectation that one party will act in a certain way, that is held by another party which leaves them vulnerable to the former's failure to meet this expectation (Hardin, 2006; PytlikZillig & Kimbrough, 2016). Echoing this general definition, participants' discussed trust as the confidence or faith that they and their family and friends had in each other: the trust that their closest family and friends did (or ought to) put in them, and the trust that they put in these others. Several participants stressed the importance of their close family and friends trusting their capacities and judgement: “My parents trust [that] I'm safe... because I've told them ‘Yeah, I'm going to be a bit late’ [and] they're fine with that” (Max). Meanwhile, participants also spoke about themselves trusting others' discretion enough to be *honest* about sensitive topics with them: “I wouldn't discuss my romantic life with just any old person. I'd discuss it with someone who I knew would respect that... this stays between us” (Shannon).

Only one participant spoke about the value of trust in a larger community. Val audio-recorded a reflection on his favourite local bakery that he felt frequently made his daily life a more positive experience because of the owners' pleasant and caring manner.

On sharing this recording, Val elaborated that this positive social environment extended to all his local shops:

I [live] on the suburban fringe so it's a little bit country in some aspects in the way we operate our small businesses. Everyone knows everybody by name... and everyone knows like local orders... and they ask you how things are going.

Val thus emphasized that he “definitely trust[ed]” these shop-owners to look out for him. Although no other participants explicitly discussed such trust in larger communities, most reported feelings of connection to such communities, in particular often communities of others with VI.

7.1.3 Inclusion in communities

The current participants also prized positive connection to and participation in larger communities. They most frequently spoke of this in terms of being *included and accepted*. Inclusion, for the participants, meant being able to engage in activities or events, regardless of any differences between them and others. They were not “left out” and avoided “missing out” (Jesse) on any experiences or opportunities. As Jules summarized: “The idea [of inclusion] is that [disabilities] shouldn't actually matter to us in life, and so you're not sort of left out in the world”. An implicit facet of such inclusion was feeling free from judgement from others; in other words, acceptance. Participants enjoyed peer communities in which they felt accepted. Drew reflected upon her audio-recorded choir practice:

It's all really nice and friendly so you just feel included. You never get judged. It's just about your [talent], it's not about what you look like... which is good [so] I enjoy it.

Drew's VI affected her appearance, and so she enjoyed the accepting space provided by her fellow choir members and the resultant feeling of inclusion. Jesse similarly appreciated the non-judgmental culture of his friendship group who were "all different types of people", but nonetheless were "all together, hanging out [and] have each other's backs".

The participants' experiences of inclusion in communities also identified qualities of these communities that they prized, overlapping with those valued in their close bonds. Two qualities of the communities, in particular, contributed to their experiences of inclusion: being valued (or cared about) by the community, and being similar to other members.

Care from and similarity to their communities. The participants' experience of inclusion was bolstered by feeling that their participation mattered to the community. Drew was a talented voice to her choir, while Jesse was a friend worth looking after. This feeling that her community members cared about or were interested in her as an individual was similarly apparent in Frankie's sense of belonging in the VI community: "[VI community events were] a place where people were on the same level with me or... that I can actually help [others]". Frankie felt *valued* at these events, and consequently articulated strong feelings of inclusion. Similarly, the care his local neighbourhood shops showed Val led him to feel included: "It's great being able to go to different places, where you can depend on them and [that] they ask about my sport... it's a real sense of community".

Participants' feelings of inclusion were further contributed to by points of similarity or shared aspects of identity – as discussed with regard to their close bonds in section 7.1.2 – with other community members. This was exemplified in a conversation between Drew

and Jesse. Working towards her aspiration of a career in child-related services, Drew's study gave her a sense of inclusion: "I love working with children [and] just doing something that you love to do... makes you feel included". Jesse extended upon Drew's reflection, explaining that these feelings of inclusion arose because such study makes you feel connected to a community that shares your passion: "When you're doing subjects that you like, you're in a class full of people who like that subject as well [so] you're all included together".

7.1.4 Common elements of connection

Participants, thus, identified common qualities of valuable friendships, familial relationships and community connections, despite their diverse social lives and networks. They desired strong bonds with their friends and family characterized by care, trust, humour, and mutual understanding based in points of similarity. They also prized inclusion within communities that accepted and cared about them, and with whose members they again shared similarities.

These qualities resonated with those previously identified in literature specifically regarding the social relationships and lives of adolescents (Barber & Schluterman, 2008; Matheson et al., 2007). For example, conducting research around the friendships of adolescents with developmental delay, Matheson et al. (2007) provided an overview of the features definitive of friendships that have been consistently identified by adolescents without disabilities in previous research. They reported that adolescents without disabilities have been generally found to highlight common interests and backgrounds (i.e. similarity), a genuine and equivalent interest in each other, reciprocal support, and trust as qualities key to their friendships. Meanwhile, the current participants' senses of inclusion within larger communities echoed theoretical models postulated to capture the

core features that lead to a person's experience of a sense of belonging or a sense of community (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992; Hasford, Loomis, Nelson, & Pancer, 2016; McMillan, Chavis, Newbrough, & Chavis, 1986). In particular, the possession of a shared or similar sense of identity with other community members, and the feeling of mattering in or to the community have been highlighted in these models, with support from research among non-disabled young people. For instance, such validation of one's status as a meaningful community participant – similar to the care the current participants received from their communities – has previously been discussed in terms of feeling influential in the community, at the same time as the community having influences upon the person. Evans (2007) found that the adolescents that they interviewed felt more strongly connected to their local community when representative adults welcomed their voices and gave them opportunities to promote and apply their skills to community issues. Meanwhile, Goodwin-Smith et al. (2017) reported that a group of sighted youth in receipt of welfare services felt a greater sense of belonging when they were able to connect with other young people with whom they shared similarities, in particular those who had encountered similar disadvantage.

This fit of the participants' accounts regarding their close relationships and community participation with previous findings and theorizing continued throughout their discussion of why they considered these social connections valuable.

7.1.5 The value of positive social connections

Participants' considered their relationships with their family and friends and their participation in communities valuable for three main reasons. First, these social connections were identified as something that all people need and that, thus, were inherently enjoyable and salient: "The general feeling of being rejected by another

person... it [negatively] feeds back into the acceptance that we all crave” (Elliot). This aligned with considerable scholarship in psychology (Baumeister & Leary, 1995; R. M. Ryan & Deci, 2000), Second, close bonds with others and inclusion within communities bolstered the participants’ self-esteem; consistent with a well-established link between positive social relationships and higher self-esteem both in theory (Leary, 2005) and research among youth with and without VI (Augestad, 2017; Erdley & Day, 2016). Taylor described how “having friends just generally makes you feel good about yourself”, and Lee offered one explanation for this effect: “If I was just having a pizza by myself, I’d feel a bit sad and sorry [but] if you do it with [others], then it doesn’t feel as bad”. Feeling accepted and valued by his housemates, Lee’s social comparisons between himself and these others were more favourable, in turn promoting more positive self-evaluations (Festinger, 1954).

Participants, however, most predominantly valued their family, friends and communities as these connections facilitated the sustenance and enrichment of the quality of their lives by assisting them to achieve their aspirations or more easily manage the demands of their everyday lives. For example, being on the “same team” with his housemates, Lee was often able to “take a week off from having to clean the toilet... because someone else has already done it”. In short, participants saw their positive social connections as resources upon which they could draw to make their interactions with the world around them easier, consistent with the concept of social capital.

‘Social capital’ captures the impact that social networks have on people’s lives and wellbeing, and should be understood at both the community and individual level (Kawachi et al., 2008; V. Morrow, 1999). A community’s social capital refers to levels of certain resources inherent in its quality and structure – i.e. its members’ trust in each other and community institutions, levels of participation, and norms of reciprocity – that

facilitate collaborative community effort (Kawachi et al., 2008; Kawachi & Subramanian, 2006; V. Morrow, 1999; Putnam, 2000). At the individual level, social capital denotes the resources (e.g. social support, knowledge) that a person can access through their connections to others and communities (Kawachi et al., 2008; Kawachi & Subramanian, 2006; V. Morrow, 1999). A person's social capital is determined by the social capital of their community – the degree to which their fellow community members engage with and trust them and others – and their own levels of participation and trust. Social capital is often further separated into bonding and bridging capital (Engbers, Thompson, & Slaper, 2017; Putnam, 2000). Bonding capital arises from strong connections between individuals within a community and are resources typically for managing everyday life (e.g. practical/emotional support). Meanwhile, bridging capital enables a person to pursue larger goals or targets and is accessed through weaker connections between individuals from different communities (Engbers et al., 2017; Putnam, 2000).

The benefits of their social connections most frequently identified by the participants were those that enabled everyday life management (i.e. bonding capital; Engbers et al., 2017; Putnam, 2000). This included practical assistance with necessary activities of daily living such as that provided to Lee by his housemates, and the emotional support of close friends or family many participants reported: “[Friends] make sure that you’re not like sad... because they actually care about you” (Peyton). Charlie’s inclusion within a local sport club provided him with such emotional support: “[The club] gets me mind off that I can’t play [because of my vision, as] I’ve got... people that are happy to talk about it... They just tell you to keep strong and try and stay happy”. Meanwhile, the positivity of shared humour was an especially valuable way that others could help participants deal with everyday challenges and negative emotions they

produced, as reported by other young populations (e.g. Haraldsson, Lindgren, Hildingh, & Marklund, 2010):

It's funny to laugh at [whoever] knocked into this or... tripped over that...

Sometimes if [one of us walks into something that] can sort of ruin [the night], but most of the time it's a pretty happy sort of supportive environment. (Frankie)

Frankie and her friends could see the lighter side of some difficulties they encountered in traveling around the community, and thus initial feelings of frustration or embarrassment were replaced by happiness. I discuss social support's role in participants' handling of difficulties that they encountered, including the role of humour, further in Chapter 9.

Some participants' social connections also provided them with bridging capital that had a direct "main effect" in promoting positive life experiences for them (Cohen, 2004, p. 678). Maintaining and forging new social connections afforded participants resources to pursue their life goals. For instance, Shannon's ongoing participation in his tertiary education community was important as this would expand his social network:

"The people that you meet [through study] expand that network [and] those three people, they may know another three people, and... it's something that will be really beneficial".

These study connections did not help Shannon's everyday living, but instead represented a potential foot-in-the-door when seeking future employment. Other participants similarly described the bridging capital that family, friends and larger communities provided in aiding their personal growth: "[My friends and I] help each other kind of become the best we can be" (Jamie). Friends and family – if also members of another community, such as a sporting community – contributed to this growth by "encouraging me to come down... and do things that I probably just wouldn't have [done otherwise]" (Alex), as has been described elsewhere (Feeney & Collins, 2015).

Participants, therefore, not only identified similar elements as central to desirable close relationships and community participation as have larger theories and other youth populations (Goodwin-Smith et al., 2017; Hasford et al., 2016; Matheson et al., 2007), but also endorsed both the inherent and instrumental value of these social bonds in line with prominent theories regarding the salience of social connections for people more generally (Baumeister & Leary, 1995; Kawachi & Berkman, 2001; Kawachi et al., 2008). Despite highlighting this positive input that others can bring to their lives including as a form of capital, however, participants' discussions also conveyed that their opportunities for these positive connections were often diminished, in many cases by the corresponding negative impact that other people frequently represented. I discuss these negative interactions with others and other VI-related barriers to the participants' social connection in the next section.

7.2 Living with Vision Impairment and Barriers to Social Connection

Numerous barriers impacted participants' establishment and sustenance of social connections, and attainment of feelings of connectedness. These barriers predominantly comprised the negative reactions of others to the participants' VIs, including special treatment and bullying. Practical barriers to social participation also arose due to the interaction of the participants' VIs with the structuring of social environments for 'normally-sighted' social agents (Butler, 1998; Paterson & Hughes, 1999). These various social barriers represented a strong form of disablism, acting through both practical and psychological channels (Goodley, 2014; Shakespeare, 2006; C. Thomas, 1999, 2007), that impeded the participants' relationships with others and thus their access to the resources these relationships offered (Kawachi et al., 2008; V. Morrow, 1999). In this second section, I unpack the participants' discussions regarding these barriers, before

highlighting the greater and different appreciation for social connection of the participants due to their encounters with these barriers.

7.2.1 Judged as ‘special’

Although desiring social connections characterized by similarity, understanding and inclusion, participants’ interactions with others were often unpleasant due to a focus on the differences related to their VI that others perceived in their participation in activities or settings:

[You get a] handout you have to do. Straight away... pull out my magnifier to read... and crane over it to see what it says, and then straight away the person next to me notices something’s up and then points it out to the person next to them.

(Val)

Through the use of his handheld magnifier, Val had hoped to unobtrusively take part in his classes alongside his classmates at secondary school; however, the visibility of his use of this adaptive equipment immediately made him remarkable to his peers. Following this, Val’s interactions with his classmates then became centred on his VI:

“[Constant questions about my VI] felt like crap.... Whenever someone asked... for them it was the first time you know, but... it could be the 25th time that day for me”.

All participants shared similar experiences to Val of standing out during their participation in activities and settings with sighted others – such as their school classrooms, supermarkets or on public transport – because of their VIs, even though their VIs were differently invisible or visible due to their distinct severities and causes (Lingsom, 2008; Worth, 2013b). Several factors increased the visibility of their VI for all participants. For many, their VI was noticed when they were actively sat out (excluded)

from activities due to VI-related safety concerns – as reflected in Jesse’s experience on a school excursion below – or because they opted out of an activity or setting themselves, such as Ash’s voluntary rest breaks in class.

When I found out that I couldn’t go on that ride [on our school excursion], because I read the sign of all the conditions... I sort of felt, you know, a bit disappointed... Everyone else was getting to go on it, so yeah, I felt left out. (Jesse)

When [my eye fatigue] becomes worse [and] I ask the teacher for breaks... everyone’s like... “Why are they sleeping now?” ... and then I feel a bit too special. (Ash)

Conversely, the way that certain others facilitated the participants’ involvement in these activities and settings, such as teachers and aides in the classroom, was also especially important to the level of undesirable attention that participants experienced. For example, Ash asserted that “sometimes [an aide does] a bit too much of their job and then you feel a bit special”. Similarly, Val reflected on multiple occasions where his teachers would initially forget required adaptations and then, on remembering, would put on “a big sort of song and dance about it in the middle of the class”. These experiences resonated with similar accounts from adolescents with VI identifying the unpreparedness and overbearing practice of teachers or aides in class as drawing attention to their VI and difference (Khadka et al., 2012; Whitburn, 2013, 2014a, 2014b; Worth, 2013a). Furthermore, and as also identified by other youth with VI (Whitburn, 2014a, 2014b; Worth, 2013a), the participants’ use of certain measures (e.g. technologies, task adaptations) to enable their more seamless functional participation alongside sighted peers also simultaneously drew unwanted attention. Thus, despite seeking the participants’ greater inclusion, these measures more often than not led participants, such

as Elliott in his use of magnification software on the train, to feel like an intriguing curiosity for their peers: “Using a magnified screen it does make you different [so] most people are fascinated [and] I don’t really enjoy the fact that you’re special”.

These social experiences in which participants felt that their sighted counterparts were focusing on their VI and the differences related to it in their participation had a negative flavour. Reflected in the quotes from Elliot and Ash above, participants consistently expressed this negativity in terms of feeling or being perceived by others as “special”. Although ‘special’ can be intended to describe something or someone that is outstanding for a positive reason in some situations, for the current participants it was loaded with negative connotations. Participants stressed how others focusing on their use of technology or alternative way of taking part in an activity resulted in them “being judged [by others] as the disability straight away... before being known as the person” (Val). Rather than getting to know him – for example, his interests and his goals – Val reported that, once his classmates had noted his VI due to his different means of taking part in class at school, this awareness then coloured the majority of their interactions with him: “To my peers I was the blind guy and that’s all anyone really knew about me”. Standing out to others in this way for Val and the other participants meant a combination of these others repeatedly asking them the standard “text-book questions that everyone who isn’t that familiar with vision impairment asks” (Elliot) and interacting with them based on their assumed knowledge of what it meant for someone to have a disability. In other words, due to the focus on their VI, participants encountered the prevailing stigma associated with disability (Gill, 2001; Scior, 2016; C. Thomas, 2007).

Popularized in academic social theory by Goffman (1963), stigma refers to the devalued status of a group of people as perceived by a dominant majority because of this groups’ possession of a particular characteristic to which negative meanings have been

socially and culturally attached (Gill, 2001; Scior, 2016). As highlighted in Chapter 2, dominant negative ideas and beliefs about disability remain within majority non-disabled society, and as a result people with disabilities are often perceived as strange, helpless, unattractive, pitiable, inferior and so on (Butler, 1998; Goodley, 2014). Therefore, when people without disabilities meet people whose disabilities become visible (at any point), the former attach these dominant stereotypes to the latter and their social interaction becomes coloured by these negative perceptions. This stigma has been previously identified among youth with VI and other disabilities as a significant disabling force (Green, Davis, Karshmer, Marsh, & Straight, 2005; Hess, 2011; Rosenblum, 2000; Whitburn, 2014a), and this was reaffirmed by the current participants who highlighted how the focus on their VI by others directly impeded their experience of positive connections with others and participation in larger communities, in particular peers their own age.

Participants felt that being judged by their VI and treated as special restricted the social opportunities that the participants perceived as open to them. Focusing on their VI coloured others' perceptions of the participants due to stigmatizing assumptions formed on the basis of their VI and led these others to judge the participants as unsuitable social counterparts for either close relationships or group activities. Lee explained: "I didn't get invited to too many...parties outside of school [perhaps because] people didn't see me as that kind of person or they were just worried if I went somewhere new it would be too difficult [because of my VI]". Lee felt that he missed out on these group events because his peers – in line with dominant perceptions of people with VI as incapable (Butler, 1998; Tuttle & Tuttle, 2004; Worth, 2013b) – questioned his ability to attend and meaningfully participate in these events. Similarly, Elliot recounted a particular

experience in which he felt that the revelation of his VI closed off a potentially promising romantic relationship:

I went on a date with a girl... We'd been speaking for a little bit before that and we seemed to have similar interests and I didn't tell her anything about being vision impaired before we'd met. And I guess it's then when it... came out [she] seemed fairly taken aback by it... And, yeah... well we didn't end up seeing each other again.

Elliot perceived his self-disclosure as the turning point at which this girl stopped seeing him as a potential romantic partner.

Importantly, whether his VI and the young woman's assumptions about him because of it was the factor that inhibited the formation of this relationship was not verified by Elliot; however, irrespective of this fact, his experience is insightful. It is perfectly conceivable that Elliot's assessment of the abrupt end to their interaction was correct, consistent with dominant perceptions of people with disabilities as asexual, unattractive and as recipients of care not romance (Butler, 1998; Kulick & Rydstrom, 2015). However, in the case that it was not, Elliot's experience – and Lee's with his classmates at school – still illustrates the insidiousness of the stigma associated with their VI. Their experiences suggest that repeated exposure to this stigma had led it to pervasively colour their interactions with others, and in some cases also led participants to (partly) internalize the view that they were the type of person with whom it was not worth having a friendship. Val explained: "For me, in the younger years of high school, [my vision] was very much my identity [to others] and there was that phase of going is it actually all I am". Therefore, the participants' accounts suggested that others treating them as special represented both a form of structural and direct psycho-emotional disablism (Reeve, 2012; C. Thomas, 2007).

Having this spotlight on their VI produced further social barriers to the participants' social connection, attracting attention of a more malicious nature.

7.2.2 A target for bullying

Being perceived as special made participants a “target” (Alex) for thoughtless and vindictive responses from others, which occurred in various forms across different settings. The most frequent and significant form of such negative social responses discussed by participants was the considerable bullying many faced at school, also reported by other youths with VI (Hess, 2011; Rosenblum, 2000; Tadic et al., 2014; Worth, 2013a). I thus focus my discussion on such bullying in this subsection to exemplify the significant impact upon the participants of such rude and malicious reactions of others; however, participants also reported rude and ignorant reactions from other members of the community outside of school more generally.

Most participants reported direct bullying (Vessey, Difazio, & Strout, 2013; Wolke & Lereya, 2015): verbal or physical aggression enacted immediately towards them. This included “quite a lot of mental” bullying (Taylor) such as verbal insults, with VI providing only one reason why participants were targeted: “They would call me like [vision-related insult] and because [of my ethnicity] they would call me [racial insult]” (Ash). Participants were subjected to tricks – such as the theft of their belongings that they then were pushed to find – and, in extreme cases, physical threats and violence:

A group of younger students approached me, they had some cigarette lighters and some spray deodorants and [they tried] to waft [flames] at me... because they knew I couldn't see it coming they were aiming to hurt me. (Alex)

Participants also encountered indirect bullying. As described in broader literature, this bullying was severe not in its in-moment intensity, but rather in its highly systemic

nature (Vessey et al., 2013; Wolke & Lereya, 2015). Having been repeatedly singled out by bullies because of his VI, Peyton explained that “one day, it would be someone else, and then another day, it would be another person, [and] they’re in like a group trying to make you upset”. Frankie also experienced ongoing exclusion at school:

I didn’t ever really fit in at high school... I was the one that couldn’t see, but they were always jealous (of the accommodations I received). They just never understood... they saw [them] as [me] getting “special treatment”.

Several participants – such as Frankie in the preceding quote – offered explanations for their victimization. Frankie felt her exclusion was fuelled by her VI causing her to stand out to her peers, and their lack of understanding of her differences in completing school activities. Furthermore, her awareness of this lack of understanding – a quality of close relationships valued by the participants – only amplified the negativity of her school experience. Jordan somewhat echoed Frankie’s explanation, also implicating her visible difference in her appearance associated with her VI and her use of adaptive equipment to participate in school activities when required (e.g. her white cane). Given the stigmatized nature of disability (Gill, 2001; Scior, 2016; C. Thomas, 2007), Jordan felt that her VI meant that her bullies perceived her as inferior to them and thus targeting her as acceptable:

Ross: Why do you think they [bully you]?

Jordan: Sometimes they think that they’re better than you since you, like, look different and act differently because of our vision impairment.

Such intense and ongoing bullying impacted psychosocially upon participants. Supporting associations between peer victimization and depression symptoms in adolescence (Vessey et al., 2013; Wolke & Lereya, 2015), participants reported strong negative feelings as a result of their bullying: “[My classmates] wouldn’t... give me

opportunities to be more involved... and that made me really sad”. Others reported longer-term psychological consequences. For instance, due to her systematic victimization at high school, Alex constantly felt “really unsafe in my own environment”. Even years after secondary school, this insecurity affected Alex’s relationships with close family and friends, and new friends:

I felt really vulnerable and... I'd forgotten how to trust... It wasn't necessarily any problem that a particular friend had caused, but yeah like it just took me so long to learn to let my guard down. When I [went back to study] there was so many good people; I never trusted them.

Driven by prominent stereotypes regarding people with VI (Butler, 1998; Tuttle & Tuttle, 2004), bullying from their peers represented a powerful social force that directly thwarted participants positive social relationships and inclusion in communities. It represented not only a direct social barrier to their social connection as their peers were actively working to demean, harm and exclude them²⁰, but bullying also had psycho-emotional impacts, producing strong feelings of distress and negative self-perceptions among the participants. Furthermore, these psycho-emotional impacts persisted across situations and time, diminishing the participants trust in others they met in the future and thus further inhibited their attainment of positive social relationships, as was also reported by some adolescents with VI who took part in Rosenblum’s (2000) study. Similar long-term social impacts in adulthood of childhood bullying have been found in the sighted population (Vessey et al., 2013; Wolke & Lereya, 2015). For example, analysing data from a large British longitudinal study, Takizawa, Maughan, and Arseneault (2014) found that individuals who experienced frequent bullying in childhood were less likely to live with a partner and had access to less social support in mid-to-late adulthood. These long-

²⁰ Impacts that were highly significant and concerning in their own right.

lasting psycho-emotional impacts from the victimization the participants experienced from multiple members of their school communities may, in part, explain why so few spoke about generalized trust in communities (highlighted in section 7.1). Participants, therefore, were not only disabled in their immediate formation and enjoyment of social connections – including the valuable social capital this provided (Kawachi et al., 2008; V. Morrow, 1999) – by other’s stigmatizing and negative responses, but also by resultant psychosocial effects that acted as a form of psycho-emotional disablism to their social connection in the future (Reeve, 2012; C. Thomas, 2007).

These powerful impacts of this stigma associated with VI and the resultant behaviour of others (e.g. bullying) were further compounded by other practical barriers.

7.2.3 Practical barriers to social connection

Practical barriers to the participants’ social relationships and participation arose from interactions of their VI with barriers inherent in many social settings (Shakespeare, 2006; C. Thomas, 2007). These barriers were both material and social in nature, including, for example, travel distance to events, lighting conditions, and norms governing social interactions (Butler, 1998; Paterson & Hughes, 1999).

Environmental features of common social settings for young people such as parties and nightclubs (Hollands, 2009) – for example, low-level lighting, large crowds, or loud noise levels – posed significant barriers to the participants’ attendance. Jay confessed that “I have never even visited a club because apparently a lot of them are dark, and... all I’d be able to do is sit in the corner”. In consequence, he missed out on time with his close mate, who regularly went to such environments. To employ the concept theorized by Garland-Thompson (2011, p. 591), these difficulties that Jay and other participants experienced in attending or participating in these social settings arose out of a

“misfit”. That is, their means of interacting with and within an environment due to their reduced sight – for example, their greater reliance on sonic information and their use of adaptive equipment (e.g. white canes) to move around by feeling out in front of them – jarred with the particular construction of the space with ‘typically-sighted’ people in mind. Others described similar instances of missing out on social opportunities because their VI presented difficulties to their participation given the nature of the particular activity being engaged in:

I was going to... go go-karting with some of my friends [but] I don’t know if I’m able to go go-karting because of my vision [so] we’re stuck because... they [do not] want to leave me out. (Taylor).

Difficulties in travelling to events also prevented several participants from attending (as reported by other youth with VI; Kroksmark & Nordell, 2001; Rosenblum, 2000; Salminen & Karhula, 2014; Tadic et al., 2014). Jules’ explained how attending social events can be “a bit annoying transport-wise”: “Unless I get a taxi... people have to come from [near the event to pick me up] and then go back to [the event]”. Caelan agreed that transportation was a major barrier to his social life, especially before moving off his parents’ farm: “If I had my own [driving] license, I could like do activities with [my mates] and then [because of my vision loss I was] just restricted to the farm”.

Importantly, while most participants described similar transportation issues, these difficulties were particularly salient for participants like Jules and Caelan due to their regional residence and the associated reduction in available public transport: “Like [in] the rural city... there’s no trains [and] no trams” (Jules).

Even where their attendance at social activities was not prevented, participants often encountered practical restrictions to their full participation in an activity or event. Drew represented this experience through her audio-recording of a movie scene,

reflecting that: “The difficulties about watching movies [with friends] is [in] not seeing in detail. So, when a friend goes, like ‘Oh’ or laughs at something... you’re like, ‘What are you laughing at?’ or ‘What are you pointing at?’”. This experience resonated with Charlie and Jesse who elaborated that they missed elements of everyday conversation with others due to their VI:

Jesse: I have that same problem. Like, I can relate to that.

Ross: *To which part?*

Jesse: To the bit where, you know, they see something and they laugh at something and you don’t know what it was because you couldn’t see.

Drew: Yeah, so you’re just standing [there] looking like weird and not laughing.

Charlie: I agree with them too. I’ve had that problem before.

Ross: *So how do you feel when that happens?*

Jesse: A bit left out.

Drew’s, Jesse’s and Charlie’s experiences highlighted the embeddedness of non-verbal cues (e.g. pointing, gaze direction) in interactions with their sighted friends. This resonated with Saerberg’s (2010) finding that, on asking sighted people for directions, the means by which they tried to communicate them to him – a visibly blind man – still presumed he could read bodily gestures and positioning. Such embedded bodily communication interacted with Drew’s, Jesse’s and Charlie’s reduced vision to prevent their full social participation in the social interaction and thus reduced their feelings of inclusion. The use of such non-verbal gestures and body positioning by sighted people represent “embodied norms of communication” (Paterson & Hughes, 1999, p. 605): socially-produced rules governing how people as physical bodies are culturally expected to interact in-person. For example, people are expected in conversations to speak at a certain rate and keep a certain rhythm (Edwards & Imrie, 2003; Hodge, 2007; Paterson &

Hughes, 1999). These norms are based on the assumption that the participating social agents are able-bodied, and thus when encountered by people with disabilities they present a significant barrier to positive and meaningful social interaction, and their establishment of social connections (Edwards & Imrie, 2003; Hodge, 2007; Paterson & Hughes, 1999).

Another embodied norm of communication preventing participants' full social participation – even when materially present at events – was the challenge associated with locating others (e.g. friends). Physically approaching someone (a bodily gesture) communicates to that person your interest in socializing with them; however, being unable to visually locate particular people made it difficult for many participants to convey this meaning in this way. Caelan succinctly summarized this barrier: “I don't really say “hello” to anyone, because I can't really see them”. Youth with VI taking part in previous qualitative studies have voiced similar difficulties (Salminen & Karhula, 2014; Whitburn, 2014a) Instead, Caelan and many others relied upon other people to approach them. Furthermore, this reliance on others proved especially problematic. For participants with more visible VIs – as discussed earlier – others' approaches typically resulted in stigmatizing interactions accentuating their disability, as reported elsewhere (Rosenblum, 2000). Meanwhile, the distrust in others that some participants had developed from ongoing victimization meant that others approaching them was not welcome: “It got to the stage where... if somebody came up, even in the nicest intentions, I'd just tell them to eff off” (Val).

The participants' establishment of close, caring and trusting bonds, and inclusion and participation in communities was threatened by compounding material, social and psycho-emotional barriers related to the interaction of their VI with their physical and social environments. This included the ‘specialness’ (or stigma) put upon them when their

VI was spotlighted and the negative social interactions (e.g. bullying) that ensued, as well as interactions of their reduced vision with the assumption of sightedness inherent in how common social environments for young people were materially and normatively structured. These barriers blocked participants' connection with others both in the immediate term, and over a longer period of time through their development of distrust in people due to their victimization at the hands of their peers.

As a result, participants had a distinct reason for the value they placed upon positive social connections with others and with communities. This was evident in Val's particular appreciation of the VI-specialized sports community:

Certainly not having [acceptance] for several years in high school and then to be able to go into this setting where it was instantaneous; [it is] testimony to how important it was [that] I'm still in contact with everybody [from that time].

The consistent social exclusion and devaluation due to the stigma surrounding their VI, considerable bullying and practical difficulties in their social participation with sighted peers left Val and many other participants with unfulfilled desires for caring and trustworthy friendships and inclusion, and thus a greater appreciation for the positive social connections they did find. Max's reflections on his social experience at university compared to high school, implicitly and simply summarized the salience of such unmet desires:

[University is] good for other reasons... [My friends] know I'm vision impaired [and] like they are on my side. And that's the thing... some people in high school were a bit of a bitch to me and it was not cool [but afterward] everyone... is really nice to me.

Max especially prized his university social life as he felt his peers accepted and cared about him, an experience which he had desired but had not found at high school.

Goodwin-Smith et al. (2017) obtained a similar finding in their research with a sighted, but differently disadvantaged group of youth. Interpreting the accounts of belonging of young welfare service recipients who had encountered varied forms of childhood disadvantage, Goodwin-Smith et al. (2017) asserted that feeling valued by others seemed especially important to these youth because the encountered adversity had left an unmet need for such social validation.

7.3 Conclusion: Positive Social Connection and Inclusion to Enhance Wellbeing

In this chapter, I present the participants' discussions around the considerable importance of their social connection to their understandings and experiences of their lives when they felt they were doing well. The participants identified the importance of their social connections with other people at two overlapping levels: that of their close one-on-one relationships, and their inclusion and participation in larger groups or communities. Specific qualities were identified at each of these levels across the participants' accounts as representing what they considered valuable social connection. They wanted their close one-on-one relationships (e.g. friendships, familial relationships, romantic partnerships) to be supportive, jocular, trustworthy and to entail a mutual way-of -thinking about the world based upon a point of similarity. Meanwhile, they prized connections with community or groups with whom they shared a point of similarity, and in which they experienced inclusion, acceptance, and a feeling that other community members cared about them and their participation. These qualities of positive social connection aligned with previous literature specifically regarding positive social relationships of adolescents (Barber & Schluterman, 2008; Matheson et al., 2007). Consistent with larger psychological and social theory regarding the benefits of social relationships and community involvement (Baumeister & Leary, 1995; Feeney & Collins, 2015; Kawachi

et al., 2008; Leary, 2005), possessing positive social connections with these qualities was not only inherently desirable and supportive of their self-esteem, but also promoted the participants' wellbeing by providing them with useful resources. Thus, the contribution of social connection to the participants' wellbeing strongly aligned with the concept of social capital (Kawachi et al., 2008; V. Morrow, 1999). Understood in this way, the level to which they experienced connections with others and groups characterized by these qualities represented an important indicator of wellbeing for the current participants.

The participants, however, also reported a distinct reason for appreciating such positive social connection when they experienced it. This was because living with VI gave rise to many interacting and compounding barriers that had often left their desires for such social connection unmet. This occurred predominantly through social barriers: the confused, ignorant and malicious responses to their VI of others. These social barriers simultaneously acted as forms of both structural and psycho-emotional disablism (Reeve, 2012; C. Thomas, 2007): excluding or limiting the participants' participation in social settings and thus ability to connect with others, while leading them to feel special, unwanted, and like they could not trust even close family and friends. Practical barriers to the participants' participation in social events – due to the interaction of their VI with the material or normative structuring of the events – then further compounded on these social barriers.

The direct psycho-emotional disablism that impeded the participants' social lives discussed in this chapter, was mostly enacted by people with whom the participants were regularly in contact, but with whom they did not feel especially close (e.g. peers at school). Family and (legitimate) friends were not party to such negative social interactions. However, a more pervasive form of direct psycho-emotional disablism

impacted upon the participants' evaluations of their own competence and achievements, as I discuss in the next chapter.

Chapter 8

Capability and control: More than the performance of tasks

Ideas of being in charge of their life's direction, interwoven with a sense of achieving relevant milestones and goals, were centrally important to participants. Participants prized their ability as individuals to decide what they did in their life and then to bring about these desirable ends themselves. These notions of autonomy and independence – with the latter discussed in terms of being able to rely on their own skills, knowledge and resources to exert their volition – were captured within the thematic life domain of control identified in the participants' discussions. Related to this domain of control, all recognized the value of their success obtained through their participation in their many undertakings, whether it was their schooling or employment, a sport they played or a hobby they enjoyed. In short, they relished moments and feelings of progress and achievement, and emphasized how such success enriched their lived experiences; a consistent idea reflected by the identified thematic life domain of capability.

Although the participants felt that such independence, autonomy and success were elements of life that most people – irrespective of their personal circumstances – would find valuable, they also noted distinct VI-related influences upon their experiences of these elements. They reported everyday barriers associated with their VIs that influenced their performance of daily tasks, such as travel, shopping and cooking, as well as their participation in activities or settings, including sports, their lessons at school and the paid workforce. Further VI-related differences were also borne out in the distinct influence of interpersonal forces on participants' senses of fulfilment in specific hobbies or pursuits (e.g. education, employment) or in their life more generally. Many highlighting their

distinct awareness of other people's prejudgments of their incapacity. Others' negative judgements represented a detractor from participants' self-perceptions of their own competence:

[Others questioning your abilities feels like] the opposite of feeling competent or... like you're good at something... When other people see you as incapable or helpless [then] you often feel resentment towards them for seeing you as lesser
(Harper)

For Harper, being pitied directly reduced his subjective experience of competence, and coloured his desires for success and independence with frustrated defiance. I expand upon these multiple factors impacting the sense of capability and control the participants felt in this chapter.

The first section of this chapter describes the individualistic discussions around the themes of capability and control of the participants, centring on the experience of success in their activities and endeavours through their reliance on their own skills and knowledge (independence). I highlight how these conceptions resonate with dominant understandings of success, independence and autonomy (Arnett, 2000; Bell & Menec, 2015; Cardol, De Jong, & Ward, 2002; C. Thomas, 2007). In the second section, I elaborate the range of barriers the participants encountered in relation to their VI that impacted upon their experiences of capability and control, and how they worked to find alternative means of participating in their pursuits in order to promote their independence and success despite these barriers. In particular, I illustrate how participants faced compounding environmental and impairment-related barriers in the contexts of their everyday lives. Finally, in the chapter's third section, I draw on the concept of direct psycho-emotional disablism (Reeve, 2006, 2012) to highlight how participants' experiences of capability and control were additionally threatened by dominant

perceptions (held by others) that their VI made them dependent and helpless, and again how they sought to rebuff the self-disparaging thoughts about their own capacities they produced.

8.1 Capability and Control: The Importance of Successful Independence

Participants emphasized their performance of and participation in various activities and their larger undertakings – such as their education or career – as important elements enriching their lived experiences. These activities and endeavours discussed by participants covered a broad range across different participants and for each individual. They varied in formality – ranging from paid/voluntary work to informal pastimes – and in the scale of their implications – from career-grounding education to mundane daily tasks such as cooking a meal. Two consistent themes regarding the value of their participation in such activities and pursuits ran through the participants' discussions, which reflected two broad life domains that presented as important to the participants. That is, the participants prized these activities and endeavours as they contributed to both the *capability* and *control* that they demonstrated and experienced in their lives. Multiple subthemes captured in the participants' reflections that fell within these larger thematic domains (e.g. progress, independence) are elaborated below.

8.1.1 Capability: Experiencing success

The thematic life domain of capability captured the consistent emphasis the participants put on the importance of being effective in bringing about outcomes or results that they desired when engaging in their activities and pursuits. Demonstrating and knowing that their performance or effort was proving fruitful was valued. Taylor, for instance, reported the pleasure he enjoyed when the work he put into his mathematics led to success in his

class tests: “I started [with] no idea at all about... math[ematics, so] I worked towards it and I tried and then... I achieved my first 100% [and was] happy with my result”. Similar sentiments were echoed by all participants with regard to success in their participation in their sports, their practicing of music and their contributions in their paid employment. In describing the importance of this success to their evaluations of the quality of their lives, participants spoke specifically both about how they evaluated this success in their endeavours and why this success was important.

Evaluating progress and accomplishment. Participants spoke about success in their activities in two main ways. First, and as evident in Taylor’s quote above, they discussed having made *progress* towards goals. Gaining ground towards their goals gave participants a subjective *sense of accomplishment*, while “going backwards or being static... wouldn't be good for my wellbeing” (Elliot). In other instances, participants also articulated more open-ended commitments to undertaking an endeavour in a certain way; what Lee called “personal standards”. Upholding these standards represented the maintenance of a desirable outcome and thus success, producing similar senses of accomplishment.

Divergent ideas of successful participation in physical activity nicely illustrates this distinction between evaluating success through progress towards one’s goals and upholding one’s personal standards. During her adolescence, an overarching goal for Alex was “to get a bit fitter” and so she set concrete goals to track her improved fitness, including “doing ten more push-ups... next week”. Alex enjoyed meeting these goals, feeling that it was good to “actually *achieve* better personal fitness”. In contrast, Harper considered a successful swimming session, as one he had approached in the right way: “I could relax into [swimming] so I did it with the mindset of wanting to swim well and with

good coordination... rather than making sort of like goals in the sense of how many laps I do”. As opposed to the successful progress towards concrete goals reported by Alex, Harper felt successful when he swam in a relaxed and mindful manner. All participants made reference to both improvement-focused goals and maintaining personal standards in discussing their successful participation in their pursuits.

These goals and standards were influenced by participants’ senses of identity (discussed in Chapter 5), through which participants referred to a sense of who they were, including their values, traits, aspirations, competences, social positions and belongings. Their identity directly informed how participants evaluated their success in their endeavours. For example, Jules elaborated that initially committing to his religious beliefs was like taking on a “new identity” – his identity “in Christ” – and explained that committing to this new identity “means that I want my life... to represent [Jesus and so] every day you have to choose to [live] the way God wants you to”. Jules’ religious beliefs were central to the criteria he used to evaluate how he managed his interactions with others during his daily life, providing him with personal standards he should aim to meet: “I think Jesus was a pretty big defender of... social justice issues [and so] if I see something that’s really not right, if it harms other people... then I would want to interfere with that [and in doing so I’m] fulfilling... why I’m here [on earth]”. Jules felt a sense of accomplishment from living up to his personal standard – that he should stand against social injustices – derived from his religious beliefs and related sense of identity.

Participants’ goals and standards were also multi-levelled: some reflected shorter-term intentions, while others reflected bigger picture aspirations. On the largest scale, participants discussed their progress towards an overall view of the life they desired, typically informed by their senses of identity which included knowledge of their future aspirations. Peyton and Pat, for example, both held clear pictures of who they were and

what major dreams they held. Peyton repeatedly stressed that he was a basketball player. Between focus groups, he audio-recorded the dialogue of a highlights video produced by the National Basketball Association in the US, and himself rapping about basketball.

Furthermore, he asserted the centrality of basketball to his life:

Basically, basketball for me is like... if you don't play basketball you're missing your breakfast, you're missing your lunch, you're missing your dinner, and your supper [because] basketball's all those things to me.

Unsurprisingly, Peyton continuously reiterated one concrete, big picture goal towards which he was actively working: "I have a goal to get to [play professional basketball]. So, I've trained myself [by] getting my three-point play better and better". Similarly, Pat perceived himself as a sportsman, and shared an audio-recording of himself lifting weights at the gym, which fit with his overarching, salient dream: "I'd like to go to the Paralympics and [this] is training for that".

Within these bigger pictures, participants recounted shorter-term moments or indicators of progress and accomplishment with regard to smaller goals or in specific tasks and activities. These benchmarks were valuable as proximal milestones for their larger aspirations. For example, obtaining personal bests during his training let Pat know that he was progressing in his sporting ambition: "If I'm running at, say 20 seconds over a hundred meters and then I run 19, it's better; it's just something to be proud of".

Finally, how participants evaluated their progress and accomplishment with regard to their goals or personal standards was also layered. Their subjective perceptions were most central to their feelings of accomplishment. Pat articulated how it was more important to him that he felt he was improving in his sports, even if some external indicators seemed to contradict this: "Even if you're losing every time, but you're still improving yeah, you're still doing better than what you did the last time". However, in

making self-evaluations about their progress and accomplishment, participants considered external indicators, including Pat's improved sprint times (above), milestone events such as "graduating from uni[versity or] getting a first job" (Elliot), and others' recognition:

Feeling good about myself because I know I've done... something good, but it's also having other people notice that you've improved. (Alex)

Alex enjoyed her participation in a particular sporting program she had commenced at the time of the research project as she felt as though her abilities in the sport were improving, because of her own self-assessments, but also because of the feedback she had received from the other program attendees and staff. I return to discuss the importance of others' recognition and judgements to the participants' experiences of success in greater detail in section 8.3.

The value of progress and accomplishment. Progress and accomplishment from taking part in their activities or endeavours – irrespective of whether it occurred in reference to goals or personal standards – was valuable to participants because it afforded them evidence of their capability. That is, their ability to successfully bring about desirable ends in the undertakings in which they engaged (R. M. Ryan & Deci, 2000; R. M. Ryan et al., 2008; Sheldon, 2002). Participants verbalized their subjective "senses of accomplishment" as feeling like they had done or were "doing something and [it was] something that I felt good at" (Jesse). For example, Harper was "a very high-achiever in my mind", which encapsulated his feeling "confident and competent". Similarly, ideas of demonstrating her competence characterized the sense of accomplishment that Ash got from trying out new activities, such as hiking: "You didn't think you could do it, then you know you can do it [and] you feel good about yourself". Consistent with theories positioning experiences of competence as a base psychological need for people (R. M.

Ryan & Deci, 2000; R. M. Ryan et al., 2008; Sheldon, 2002), this evidence of their ability to successfully interact with their world held inherent value for the participants, and as a result produced varied positive feelings (e.g. enjoyment, self-esteem).

Such positive experiences of success were, however, not the only element of participating in their various activities and pursuing their larger endeavours that the participants' discussions highlighted as valuable. Participants frequently spoke around the importance of their level of control over these pursuits, and thus in their lives overall, as key to their appraisals of how their lives were going.

8.1.2 Control: The key to success

Participants repeatedly highlighted the importance of feeling as though they were in charge of and responsible for what they did and what happened in their lives; a pervasive theme within the participants' discussions that was interpreted as reflecting an important domain of life for the quality of the participants' lived experiences. In short, the thematic domain of control. Participants – as Harper declared – did not want to feel like “a leaf in the wind”, in which life choices happened to them without volition. Rather, they wanted to have agency, to “think about [things], and decide whether... to exercise my right to say no, [to] indulge or [to] let someone else make a decision” and then enact the decided action. Participants' discussions highlighted two interrelated factors (subthemes) that facilitated this control over their participation in their activities and larger pursuits: independence and freedom.

In the member-checking phase of the project, the participants' discussions of independence were presented to the participants as a subtheme within their larger discussions of their progress and fulfilment, due to the prominence in the participants' accounts of increased independence as a facilitator of their success (discussed below)

identified through my initial thematic analysis (Braun & Clarke, 2006). However, in response to this presentation, several participants asserted that “independence [was not] really covered... as much as I would put a focus on it [in talking about what is important to me]”, and that while it “does come under each of those [other important aspects of life, I] would almost put it as its own category” (Lee). In response to this importance the participants placed upon it in their member-checking conversations, I then re-examined the data collected in the project’s first data collection phase in order to explore the participants’ discussions around their independence and the associated concepts of freedom and choice. Rather than viewing independence and freedom as mere tools for the participants’ success, I was prompted to go back to the data to reconsider what these terms meant to the youth specifically and how this related to their VI.

The meaning of independence and freedom. Participants defined independence as their own ability to operate as a distinct individual. For example, Jordan defined independence as when “you don’t need anyone’s help, just you’re doing [the task]”. Being independent thus meant not being reliant on other people for their participation in their activities and undertakings. Harper elaborated somewhat on this definition: “Logistical and physical independence [is] being able to get around [and] do things without or with minimal reliance on others, and... for me, the less reliance I can have on certain things as well”. Harper’s extension of his conception of independence to include avoiding reliance on objects was manifested in his complicated relationship with public transport, which he felt both promoted his independence and sustained his dependence in his mobility (discussed later on).

Harper’s definition of independence also explicitly flagged the particular importance that mobility held in the participants’ understandings of what it meant for

them to be independent. To take part independently in their activities and endeavours, one had to be able to travel to the destinations they needed and desired with no (or minimal) assistance from others, such as their parents, other family or friends. Lee, for instance, reminisced about the defining moment of independence that he experienced in his teenage years:

Independence, as well... probably the biggest one was when I was able to get the train from [my home in regional Victoria] to [the city]. Because now I could go to places myself, when I wanted. Because most of the things I wanted to [do like playing my] sport [or] spend some time with some friends, it meant going to [the city]. So, being able to get the train by myself was a huge step forward.

Lee – like all of the participants – experienced the acquisition of the skills to travel to wherever he wanted without his mother’s help as definitive of what it meant to be independent as a young person with VI.

This pivotal positioning of mobility in the participants’ discussions of independence was directly tied to their preclusion from driving due to their limited vision. In developed Western societies, a continued cultural association exists between car ownership and the ability to drive with ideas of independence, freedom, accomplishment and successful transition into adulthood (Delbosc & Currie, 2013; Jablonski & Martino, 2013; Lowe, Dillon, Rhodes, & Zwiebach, 2013; van der Waard, Jorritsma, & Immers, 2013). This is especially true in the Australian context – that of the current participants – with Australia recognized as possessing a powerful car culture (Dowling & Simpson, 2013; Klocker, Toole, Tindale, & Kerr, 2015; Redshaw, 2006). Redshaw (2006) explained that, historically, the car’s (image of) indispensable value in Australia was rooted in the relatively low population sizes of Australian cities and the spread of their citizens over geographically sprawled suburbs. The car, as a facilitator of point-to-point

travel and quicker coverage of these distances, adopted the status of primary mode of transport for Australians and, in turn, supported the continued planning and development of these suburbs further outwards, entrenching its own inextricableness from perceptions of an efficient and capable Australian adult. Moreover, Redshaw highlighted that as the car rose to this prominence due to its practical benefits, politically its position as the primary mode of transport in Australia became further cemented as influential motorist lobby groups underlined the car and related infrastructure as key means to promote each individual's freedom and daily convenience. In line with this history and resultant cultural importance of the car and driving in Australia, a majority of Australians continue to perceive their ownership and use of a private car as central to their performance of daily tasks and social roles (e.g. paid work, parenting; Klocker et al., 2015). In 2012, 71% and 88% of Australians aged 18 years of age or older reported predominantly travelling by private car to work/study and to other locations (e.g. shopping centres, social events) respectively (Australian Bureau of Statistics, 2013a). Furthermore, this prominent cultural significance of cars remains in Australia despite recent declines in the uptake of driving and car ownership by young Australians (Delbosc & Currie, 2013; Dowling & Simpson, 2013). For instance, Delbosc and Currie (2014) reported that 33 Victorian youth that were engaged in online discussion forums about their driving choices and behaviour – including a group without licenses – described driving as an essential skill for participation in contemporary society, and critical to what it meant to be independent, responsible and an adult.

Growing up in this Australian car- and driving-centric culture, the current participants articulated how being precluded from attaining their driving licenses – a direct consequence of their VI, even where they were not legally blind (Austroads &

National Transport Commission, 2017) – was a direct threat to their capacities for independence:

That's a pretty frustrating part of being vision impaired... Not really having the same amount of independence as someone who's able to get a driver's license.

(Elliot)

As a result, it was crucial to them that they developed alternative strategies for travelling to diverse destinations, and their capacities for mobility held special importance in their evaluations of their independence: to be mobile was to be independent. I return to discuss these alternative means of moving around further in section 8.2.

Although a prominent element, the participants did not conceive of independence entirely in terms of their mobility; independence also meant being able to perform other 'activities of daily living' necessary for self-care (e.g. bathing, preparing food), and 'instrumental activities of daily living' which contributed to functioning within the community (e.g. managing their communication with others, use of communication technology; Scheiman et al., 2007). This broader consideration of what it looked like to be independent was somewhat related to the participant's age. Younger participants (<18 years of age) primarily spoke of their independence in terms of mobility, while older participants (>18 years of age) more often discussed a broader range of daily tasks, although still highlighting mobility as key. Alex explicitly outlined this role of her age in her considerations of her independence:

Not long ago I would have said that mobility was everything; now I tend to disagree... I still do need help in a lot of ways but I do want to get independent with cooking meals and all that sort of stuff as well... they're all skills that I'm learning and developing.

In her teenage years, Alex had primarily framed her independence in terms of her ability to move around and travel with minimal support, but as she got older this narrower view of what it meant to be independent began expanding as the need to develop other life skills, such as cooking, became more salient.

The ability to rely on their own skills and knowledge in day-to-day life was described by participants as fundamental to them taking charge of their participation in their activities and endeavours. For instance, Peyton took charge of his participation in school activities through acting independently: “[Teachers and aides] don’t have to be worried. I just say, “Go away. I don’t want to be near you.... I want to do my own thing, just get away”. Peyton felt that it was only by taking part in the activities without assistance that he was less restricted in his class participation and could take part in his schooling in his own way. Practical independence, therefore, gave participants greater control over their activities and endeavours as it afforded them greater freedom in their action.

Participants’ discussions of freedom reflected well-established definitions tied to notions of negative liberty (Brymer & Schweitzer, 2013; Vellone, Piras, Talucci, & Cohen, 2008). Understood in this way, freedom refers to an individual being able to choose how they act, because of the lack of external factors forcibly directing their decisions (Edge, 2013; Hirschmann, 2003). Participants similarly described the absence of influences, restrictions or obligations due to external sources – including institutions and most commonly, other people – as central to their ability to make decisions about what they did in their life. Such conceptions of freedom were evident in the discussion between Drew, Jesse and Charlie about Drew’s move out of her parents’ home to live independently:

Drew: You can cook for yourself. You can get around by yourself. You can just do all that stuff without having someone there following you.

Jesse: You don't have to be bossed around by parents.

Drew: Well if you want to put it that way.

Jesse: That's how I would have put it.

Charlie: Wake up whenever you want to. Watch what you want to. Go to bed when you want to.

For these participants, moving out of the parental home represented an increase in their independence and thus an increase in their freedom: that is, enhanced possession of control over decisions which affected them, and also the capacity to decide what they would do with their time, however mundane those choices were (e.g. waking and sleeping times). Consistent with the positioning of choice as central to freedom (Edge, 2013; Hirschmann, 2003), several participants also explained freedom in terms of having options or opportunities. For example, Caelan recorded himself eating and drinking. He reflected that these sounds represented the importance of “being an Australian” to him because of “the opportunities we’re given in this country”. Caelan identified that, in Australia, he felt that people with VI are “free to do what we want”, before later describing how “being blind [in other countries], you’d just be restricted to your room”.

Practical self-reliance (independence) was essential to the participants’ freedom and choice in their endeavours as it enabled them to untie themselves from the support of others, and thus their accompanying influences and restrictions. For Harper, being independent in his transportation was important, because when he was unable to rely on his own capacities to travel to a destination he had to give up some of the decisions regarding – i.e. some of his influence over – the process and experience of this travel:

Independence kind of enables freedom... If someone else is driving you somewhere then you go when they're ready not just when you're ready and... you might be listening to the music that they want to listen to in their car, or it might be that you converse with them or that you leave a bit earlier than you had to or a bit later... I guess whatever it might be. If you have more independence then you have more freedom to do things your own way and... the more you have to compromise for other people the less you feel in control of your life.

In conceptualizing practical independence as central to their control in this way, participants affirmed the prominent conception of autonomy in contemporary Western societies. This is reflected in the underlying assumptions of rehabilitation services for people with disabilities, where a person's ability to successfully operate practically as a self-contained individual is commonly positioned as essential to being autonomous in their life (Cardol et al., 2002; Gibson et al., 2012; McPherson et al., 2016). In other words, if a person is unable to participate in activities without assistance then (it is presumed) they would also be unable to freely act upon their own preferences and desires. Harper's assertion above echoed this view: due to his inability to travel to certain locations without assistance from a friend or family member, he felt that he may not leave when it suits him or pick the music he listens to during the trip.

Participants' discussions not only portrayed independence and the freedom it afforded as foundational to their control over their participation in their activities and endeavours, but also outlined the reason why they considered such control valuable.

Independence and freedom as central to success. Participants perceived independence, and thus freedom from the restrictions resulting from reliance on others, as inextricable from their ability to progress towards their goals or meet their personal standards in their

pursuits. This was recurrently evident in participants' accounts of why they needed to be able to travel with minimal to no assistance from others. In not requiring others to get around, participants, such as Frankie, identified the broader freedom and greater accomplishment that they could then achieve in, for example, their education:

Getting around uni[versity] is important to me because [it does not] have a campus like [others]. I would have one class that was next to [this particular shopping centre], and then I would have another class straight afterwards which would nearly be all the way up [on another street] and [so] you'd have to be navigating yourself back and forth... You can't rely on others to be taking you from class to class.

(Frankie)

Having independent mobility skills was necessary for Frankie's timely class attendance, and thus her successful progression through her undergraduate degree. Val, similarly, articulated how his own self-perceived capacity for self-reliance, including in his travel, was indispensable to his continued success in many significant endeavours in his life:

I guess now that I'm [a little older], I'm looking to probably move out of home at some stage... and you know, get a job, get a career. Like, I can't be holding my parents hand to get around everywhere, and certainly my [parents are getting older, so] they're certainly not able to keep up with me travelling across to [all these different countries] and all these other places I'm going to. And so, to be able to know that I can [do it] myself... that's definitely important. (Val)

The fact that Val felt he no longer needed to depend on his parents' support was, in his mind, not simply beneficial to the success that he both had already obtained and hoped to achieve in the acquisition of employment, moving out of home and travelling internationally; rather, it was essential. If he remained reliant on his parents, he would be unable to pursue his aspirations in these multiple endeavours as – even if willing to put

their own lives on hold for his own – his parents’ advancing ages meant they were unable to support these pursuits. Thus, for Val, his own capacities and resources allowed him to avoid these restrictions on his freedom so that he could take charge of his life and pursue these endeavours under his own steam.

For Frankie, Val and the other participants, the ability to rely on their own capacities and resources, and thus take charge in driving their own participation in their endeavours (control) was closely intertwined with their definitions of success in these pursuits and in their lives overall (capability). In short, they felt that they needed to be able to take part in the necessary activities or endeavours through the use of their own skills in order to truly be effective in achieving their goals or meeting their personal standards, Lee explained:

Independence is actually being able... or capable... You actually could go and do it right now. [Whereas, if you do] not feel you have the independence... you might wait until someone else [does it because] you feel like you don't have the ability.

The participants, therefore, not only echoed an understanding of agency rooted in practical independence, but also endorsed the view dominant in contemporary Western societies that such independence is essential for one to be a successful and capable person (Bell & Menec, 2015; Hammell, 2006; C. Thomas, 2007). It was for this reason – its perception as an inextricable facilitator of larger accomplishment and progress – that developing and then maintaining independence in itself was experienced by participants as personal growth and accomplishment: “I caught the bus out here... and it was the first time I actually caught the public bus by myself... It made me feel independent [and] like I was growing up” (Jesse).

8.1.3 A common conception of capability through control

In discussing the value of their participation in their activities and endeavours to the quality of their lived experiences, a consistent image of individualistic *capability* through *control* was identifiable in the participants' discussions. Through the exertion of their own practical skills and knowledge (*independence*) and thus avoidance of others' restrictions (*freedom*), participants wanted to make *progress* towards certain goals or maintain certain standards that were personally meaningful to them in order to experience an inherently pleasurable and positive *sense of accomplishment*. This aligned with ideas well-established in self-determination theory and related work regarding the importance of goals to wellbeing (R. M. Ryan & Deci, 2000; R. M. Ryan et al., 2008; Sheldon, 2002). Such work has long recognized not only the importance of goal attainment, but also direct benefits to wellbeing that arise from goals being autonomously pursued irrespective of success.

Identifying the two interrelated notions of capability and control as key thematic life domains important to how well the participants felt their lives were going also echoed previous empirical research among young people with and without disabilities. Such research has highlighted the same importance of experiencing success and competence to young people's conceptions of a good life (Bourke & Geldens, 2007; Fattore et al., 2009; Scott, Foley, Bourke, Leonard, & Girdler, 2014), and the positive association of such experiences with their life satisfaction ratings (Crede, Wirthwein, McElvany, & Steinmayr, 2015; Proctor, Linley, & Maltby, 2009). Positive beliefs about one's own capacities in particular areas or pursuits (e.g. sport, schooling) have also been found to produce positive feelings in research conducted with other sighted adolescents (Fattore et al., 2009; McCarthy, Jones, & Clark-Carter, 2008; Smith & Wilhelm, 2004). Finally, ideas of independence have previously been identified as salient among young people

both with and without VI. For instance, Khadka et al. (2012) found that, when asked in focus groups what activity they most strongly wished they could participate in, adolescents with and without VI indicated the activity of driving, as this would bring them greater independence in their travel.

Although emphasizing the value of self-governed and successful participation in their activities and endeavours through their reliance on their own skills and knowledge, in the participants' realities such success and independence was not attained unproblematically. Instead, participants encountered various barriers and difficulties in their pursuits and as a result had to compromise with regard to their individualistic ideal of valuable participation, as I now discuss below.

8.2 Difficulties and Differences in Being Capable and in Control

Living with VI presented many barriers to participants' control over and experiences of success in their schooling, careers, sports and other pastimes. Barriers that frequently interacted and combined, as was evident in Lee's experience of job-hunting:

After finding [a job] that was suitable, [I would] then have to consider [the] sort of computer software it would need; anything too graphical would be too difficult to use, and as well it's hard to find out just if something like [my adaptive software] would work... because a lot of big businesses have in-house computer systems. How do you know if [my adaptive software] was going to work until you get there and try it? So that was another barrier.

Ross: Some element of uncertainty?

Yeah, like even if I do get the job am I going to be able to use the software I need to use when I get there. And another barrier was [going through] disability employment services... How do I say this? If an employer goes to a disability

employment provider, they're not usually going to be going there looking for [the] top notch people in their grade.

In addition to the uncertain information technology environments of potential employers, Lee also felt that his pursuit of employment was impeded by the dominant social perception of people with disabilities as helpless that he believed many employers held (Butler, 1998; Gibson et al., 2012; C. Thomas, 2007). Lee encountered this lesser image of people with disabilities among the disability employment services themselves, which he described as “nurturing caring environment[s]” that focused on telling him that “You’re doing so well, staying so positive” rather than offering him constructive advice on how to improve his job applications. Furthermore, Lee’s mindfulness of this perception of people with disabilities as incompetent, itself, impacted his job-hunting: contributing to his reduced engagement with the resources offered by disability employment services to avoid dealing with this stigma. Finally, Lee’s VI meant that he was unable to perform certain visual tasks required in many advertised positions:

A lot of roles especially the beginner ones, [had] a lot of ad hoc admin[istrative work] that involved paper, so anything that involves paper, rule that job out straight away. I wasn't able to do it.

Evidenced in Lee’s job-hunting experience, four types of barriers were consistently reported by participants to their success in activities and endeavours. Participants faced barriers located in material or institutional environments that arose due to a presumption of sightedness in the structuring of settings and systems, such as the potential incompatibility of employer’s in-house computer systems with adaptive software. Second, dominant social attitudes regarding disability evident through others’ over-protectiveness of the participants, or their ignorance regarding participants’ capacities or required accommodations also presented barriers, like the attitudes that Lee

attributed to employers and staff of disability employment services. Third, barriers arose from the direct impacts of participants' VIs on their ability to perform certain tasks, such as Lee's inability to work with hard-copy print material and thus perform the administrative components of entry-level jobs. Finally, exemplified in Lee's decreased engagement with disability employment services due to his frustration with their coddling approach he felt was associated with the stigma of incapability attached to disability, participants identified psychological factors that acted against their productive participation in their activities and endeavours (psycho-emotional barriers). In identifying these four barrier types, participants' accounts aligned with relational models of disability which position the 'disability' experience as being produced through interactions between a person's individual bodily differences and their physical and social environments (Shakespeare, 2006; C. Thomas, 2007). Similar material, institutional, social, impairment-related and psycho-emotional barriers have been documented in the job-hunting process for other people with disabilities (Lindsay, 2011; McDonnall et al., 2014; Shier, Graham, & Jones, 2009). In this section, I elaborate on how these barriers impacted on participants' experiences of successful participation in their activities and larger pursuits, and how the participants responded to these encounters with these barriers, drawing upon their discussions regarding their education and their mobility.

8.2.1 Multiple barriers in education settings

The educational experience of several participants had been negatively impacted by inaccessible classroom environments (material/institutional barriers) and the non-adapted practices of individual teachers (social barriers), both of which made it harder for the participants to fully engage in school activities. Open learning spaces²¹, in which multiple

²¹ Such open plan classrooms represent a recently resurgent innovative pedagogy in Australia (Mealing, Buchholza, Demuth, & Dillon, 2015)

classes are simultaneously taught, presented particular challenges. Val found it difficult to understand activities set by the teacher because of the size of the room:

When [our classroom is] ten times the size [of standard classrooms and the teachers] would only use one white board up the front, and of course our class area was up the far back, and so you know it's like I can't make out what's on there.

This was compounded by some teachers' unwillingness to adapt their practices for accessibility. Val found that, even though adaptive technologies were available and relatively simple to use – “[it was placed] on the whiteboard [so that] anything [written] on the whiteboard turn[ed] up on your laptop screen” – this was not always matched by teaching practices. He described how one teacher refused to adapt his accompanying verbal communication to the class:

I'd be watching on my screen, and then [the teacher would] just go “You add this to that and that to that and there's your answer”. And of course, I'm staring at my screen, I miss all of what he actually did, and a number would appear across the bottom.

Similarly, Taylor's teachers also failed to adapt their practices: “[The teacher] knows I don't bring folders to class... and she still gives me printouts... I don't think it's that hard to scan something”. For both Val and Taylor, limited use of inclusive teaching practices created considerably more work in order for them to succeed at school. Other students also posed social barriers to learning, as Val reported: “[I'd be] copying off the whiteboard, you know binoculars [out] and then all of a sudden they weren't there anymore. [A classmate] was off with them”. Val not only had to contend with the difficulty of learning the class material in the face of non-inclusive practises, but also

often had to put additional effort into locating his binoculars when stolen by his classmates.

Not all education settings had these material/institutional and social barriers, yet participants still experienced difficulties directly related to their reduced sight (e.g. ocular fatigue). Ash recorded the sound of a book's pages turning very quickly and explained:

In school when I'm like reading a book... sometimes my eye gets a bit strained and that's because I'm using the one eye too much.

Her school was supportive, providing class material in her preferred format, the presence of an aide when required, and provision of rest-breaks to manage ocular fatigue.

Nonetheless, Ash perceived her fatigue as a barrier, making her completion of her study more difficult: "[The eye fatigue] is kind of annoying because, you know, I want to keep going but I can't because it hurts".

These multiple barriers also impacted participants' experiences of success at school through a reduction in their school-related opportunities and freedoms: to participate in specific class activities/excursions; to trial particular tasks independently; or to decide how and when to study. For example, Taylor felt that his VI directly precluded him from making the A-side in his school soccer team (his personal goal) – and thus experiencing success in soccer: "It will probably never happen [because] my vision does sort of limit me a little bit... [If] someone's like [kicked the ball a really long way], I can't really see, you know, like where it's gone".

Social barriers also reduced school-related freedoms. Due to (unwarranted) concerns about her safety in travelling home, Jordan's teachers often held her back at times when her classmates had the freedom to choose to head home: "In Year 12... when [my friends] have like a period off, they're allowed to go home, but [the teachers are] not letting me". Jordan therefore perceived that teachers were directly impinging upon her

freedom to control when she did and did not study, and thus her opportunity to demonstrate her capacity to both travel home safely and manage her study load. Lee and Jordan further elaborated on this “cotton wool issue”:

Lee: Sorry, just to paint a verbal picture... You're going to be okay, Ross. I know you haven't walked to school by yourself before, if you just be careful and make sure you check both ways when you cross the road just like we practised. Now, you are turning 17, so you should be just fine, okay? Make sure you call me when you get there.

Jordan: Don't forget now.

Lee: And I packed your lunch for you, you've got a little juice and some biscuits. Lee and Jordan intended this humorous depiction to illustrate the pervasive overbearing reactions they encountered from parents, teachers and others at school – and in other areas of their life – also reported in previous research among youth with VI (Khadka et al., 2012; Whitburn, 2013; Worth, 2013a). This over-protection represented a major social barrier that reduced their opportunities to work through activities their own way and led them to miss out on valuable learning experiences so that “by the time you get to 17... you're not able to do that much for yourself” (Lee).

These multiple barriers thus combined to impact upon participants' demonstrations and experiences of independence and success at school in two ways. First, they increased the difficulty of participating in a specific activity by requiring the participant to perform extra tasks or invest additional effort in their participation. Second, they reduced the opportunities for participants to try their hand at certain tasks or activities, and thus have experiences of success and develop their capacities for future activities.

The intersection of these barriers and their impacts through these mechanisms were also evident in participants' discussions regarding their mobility. Below, I discuss mobility as a case study of VI-related barriers to the participants' experiences of capability and control in their activities and endeavours, and how the participants responded to these barriers to reconfigure an alternative form of independent and successful participation.

8.2.2 Independent mobility: Difficulties and different means

Participants described how their travel to necessary destinations – to support their engagement in their larger endeavours (e.g. education, employment) – was impacted by many barriers. One major barrier included the inaccessible built environments through which they often had to pass (as discussed by Emerson & McCarthy, 2014). This was evident when Val first visited the passport office. The location and architecture (both material barriers) clashed with his reduced capacity to visually scan environments (an impairment effect), making it hard to locate:

Tried to find the passport office today and that was an adventure. I got to the location where it was at and it was in some funky, new-designed building which made no sense... It was actually located in the middle of a food court. [It would have been nice to be able to find it] without having to blunder around, back and forth, across multiple levels like an idiot. (Val, recorded reflection)

That this was Val's first trip to the passport office was also significant. Youth with VI have been found to develop spatial-memory maps for navigating familiar locations (Allen, 2004), and thus journeys to unfamiliar locations were particularly problematic for participants. Without this familiarity, the material barriers that the participants would encounter in that environment were unknown and thus participants were less able to

prepare for them. In line with the original social model of disability that repositioned disability in the construction of the material and social environment in a way that is exclusionary for people with disabilities (Goodley, 2011, 2014; Shakespeare, 2006), material barriers such as those highlighted by Val emerge as prominent forms of structural disablism to opportunities for the youth with VI to engage in independent and free travel. Because of these material elements of the environment, the participants could not simply travel to or participate in new locations without extra effort or consideration.

In addition, the participants' inability to attain independence and freedom in their travel through driving as did their sighted peers (discussed in section 8.1) was compounded by their frequent experiences of their alternative means of travel as restricted and as keeping them dependent. Public transport was the most common alternative and was often experienced as fraught. Elucidating this, Elliot explained that "not being able to get to where you want to go, point to point [on public transport] is a pretty big drawback, and everything just taking longer than if I were driving is another fairly significant drawback". Moreover, and in line with concerns regarding the impact of an inability to drive on their future careers reported by other youth with VI (Khadka et al., 2012; Rosenblum, 2000; Tadic et al., 2014), participants' reliance on public transport had broader implications for their enactment of their independence and ability to successfully reach their goals or meet their standards in their endeavours. The limited public transportation infrastructure of certain areas (institutional barriers) narrowed the locations where participants could choose to live, study and work: most participants who had moved out of home chose to live in areas that were well serviced with public transport, although this often meant that they had to make compromises in other aspects, such as paying higher rent. In considering where to undertake tertiary study, Max recounted that transportation was a major restricting factor: "I was just not... considering my course, I

was considering can I get to this place safely and come back home every single day”. Being occupied with such practical considerations increased the stress he experienced: “[I] was just more concerned [and] didn’t know where I was heading” which left him “thinking extra about my future”. In turn, this elevated the difficulties he faced in completing his secondary studies, to then successfully transition into the tertiary study required to enable him to accomplish his goal of attaining his preferred job in business. Barriers and difficulties to mobility faced by the participants also made it harder to attend locations or events focused on their social relationships and physical health (discussed in Chapters 4 and 6).

Given this significance of their independent mobility to their (experiences of) control and success in the many activities and pursuits in which they were engaged, participants developed specific alternative strategies for enacting this necessary travel that challenged, removed, avoided or compensated for the various and compounding barriers.

Alternative means of mobility. The adaptations participants developed to maximize their independence in their travel involved the use of a combination of equipment, aids or advocacy as individuals, as well as larger infrastructure or support systems (discussed further in Chapter 9). For example, most participants – 19 of 21 (90.5%) – received and stressed the importance of one-on-one training in O&M. Jules, in particular, recorded the sound of an O&M training session, reflecting that:

Doing orientation and mobility is something that is important I think for [the] wellbeing of a person with a vision impairment because it enables them to actually orientate themselves and move about in the world and go wherever everyone else is going.

As asserted here by Jules, O&M training provided participants with different skills, strategies and equipment to exercise similar independent mobility and thus take control over their successful participation in society like “everyone else”. Much of the training was focused on individual-level techniques and technologies for navigating their immediate environment: the use of white canes, transport-related smartphone applications, cognitive or behavioural tactics for orienting themselves in an environment, and – for some participants like Charlie – echolocation: “I can do the tongue [thing] like echolocation. So, you do that when you’re close to a building and it can tell you where you are”. In particular, Shannon emphasized that it was by getting him to think about his surroundings differently to sighted people that O&M training had enabled his independent mobility:

Dad will say to me, “Okay... go west and walk down the hill” and that doesn’t help. Whereas, [my O&M trainer would talk about our surroundings like] “Okay, you’re going to come out and you’re going to see a big cream building [that] should say [Superstore] on it and then once you see that, turn right and walk down the path” ... They use landmarks a lot more than my Dad does for one [because] he doesn’t understand the importance of a landmark to a vision impaired person.

Shannon’s experience resonates with other similar research that has emphasized the difference in how people with and without vision impairment learn to navigate and communicate about their physical environments (e.g. Saerberg, 2010).

In addition to such individual-level technologies and strategies, through this O&M training participants received instruction in the use of public transport (i.e. larger infrastructure). As aforementioned, public transport represented the main alternative means for travelling between locations for participants given they were unable to obtain a driving license. Although some participants critically reflected on the limitations of the

public transport system as expressed by Elliot on page 273, all acknowledged that public transport gave them a (different) means of the independent mobility that they perceived as central to being in control and experiencing success in their life. For example, despite recognizing his possible travel restrictions when deciding upon his preferred university, Max was optimistic that greater instruction regarding train lines would afford him greater freedom in his life:

My mobility [instructor is] going to help me get used to having two [train lines] because... if you're more familiar with the system you can get anywhere.

The participants' accounts regarding their mobility also illustrated the differences that existed across the participants with regard to their alternative means of pursuing self-governance and success in their activities and endeavours.

Differences across participants. Different participants described individualized visages of independent and successful participation in their various pursuits: such as their visages of what it meant to be independently mobile. These differences were influenced by both variations in participants' VI histories (further indicating the role of impairment effects; Shakespeare, 2006; C. Thomas, 2007) and several other non-vision-related factors in line with previous work recognizing the need to understand disability through a lens of intersectionality (Goodley, 2014; Reeve, 2006). The participants' VIs varied in their ages at onset, time periods of occurrence and severity. Meanwhile, the participants' living arrangements; local infrastructure; and, their financial resources also shaped their mobility.

The participants' independent mobility was influenced by their remaining vision and age at their impairment's onset. Harper – who had considerable residual sight – added skateboarding to his travel techniques to reduce its arduousness: “I picked up

skateboarding... between public transport... and it just made things so much easier”.

However, for totally blind participants this was not a viable or safe option. Meanwhile, participants with later-onset VI had less exposure to training and resources to enable them to take (or feel in) charge of their mobility compared to those who experienced an earlier onset: “I did receive [O&M training] from the age of four so... I’ve always had people sort of showing me how to use my cane and... go about walking places” (Jules).

The participants’ enactment of independent and effective mobility was also shaped by the stability of their childhood living arrangements, where they currently lived and their financial resources. Despite both growing up in more regional locations, Jay reported less exposure to mobility training than Jules (above). Jay attributed this lack to the fact that he would “move every two or three years [and so] wasn’t able to be taught a lot about the areas that I was in”, while Jules recounted a constant family home.

Irrespective of this level of stability, however, unlike those residing in urban settings for whom public transport was essential, Jamie highlighted that this alternative means of mobilizing was not as useful or viable for more regionally-located participants, such as Jules, Jay and herself: “It is so hard in [my town as] we’ve got one town bus that takes like almost an hour to do a full route”. With the absence of frequent and reliable public transport, these participants listed a collection of other compensatory strategies: car-pooling with friends; forgoing events; and, performing tasks over the internet. Finally, the participants’ relative socio-economic statuses (SES) were influential. Charlie lived in an area of lower relative SES and explained how “taxis are like \$25” and so were not feasible transportation as “if you’re [out] and you get a call from someone... you can’t go see them because you end up spending \$50 or \$60”. In contrast, Lee – who lived in a relatively high SES area – reported that if “in a tight spot, especially now I am working and have the income, I probably will take the taxi option... because it is easier”.

Encountering multiple VI-related barriers challenged and restricted the participants' abilities to take part in their diverse activities and pursuits (e.g. school classrooms, their workplaces) – especially in a way that they perceived as them being in charge (control) – and thus threatened their experiences of success that they desired (e.g. attaining an education, establishing a career). These barriers arose from the material/institutional environments (e.g. built environments, employer policies), the social responses of others (e.g. others' over-protectiveness, teacher stubbornness), and their VI itself (e.g. ocular strain, inability to drive). By both restricting the freedoms and opportunities participants had to participate in activities, especially on their terms, and making it harder to be successful when they did have the opportunity, these barriers impacted the participants' experiences of capability and control. Nonetheless, influenced by their personal characteristics (e.g. cause of VI) and circumstances (e.g. SES), the participants were not resigned to the will of these barriers, and actively sought to develop alternative means of maximizing their independence, control and thus (experiences of) success in their pursuits, including through the use of both individual-level strategies and larger systems.

Participants' accounts of the multiple barriers they faced and their responses to them also problematized a key assumption underlying the provision of rehabilitation services – including vision rehabilitation (Binns et al., 2012; McGrath et al., 2017). Hammell (2006) argued that a central assumption of rehabilitation professionals is that it is their role to work to enable a person's performance of tasks and participation in activities, through the provision of adaptive strategies, supports and technologies, as this in turn will lead to a direct increase in the person's subjective experience of independence, success and thus wellbeing. This simple and linear connection between functional strategies and improvements, and the person's experience of independence and

satisfaction, however, was contradicted in Elliot's comments on the limitations of public transport (page 273). Similarly, Harper identified a paradox in his use of public transport as "something that [he has] to be dependent on", which simultaneously provided a source of increased control: "in some ways it's been very liberating as I have gained all this knowledge and... experience that makes me feel very empowered". Thus, while on the one hand, being independently able to use public transport enabled him to feel in control and capable, Harper's reliance on public transport at times appeared to evidence his lack of control and thus diminished his sense of capability. For both Harper and Elliot, their enacted pursuit of their endeavours and their experiences of capability and control was anything but straightforward. One factor further complicating this association was the participants' constant encounters with the dominant perception that people with VI are incapable (Butler, 1998; Tuttle & Tuttle, 2004; Worth, 2013b).

8.3 Capability and Control: Managing Psycho-Emotional Disablism

The most frequently cited barrier that participants reported was the assumptions and judgements of other people. Based on dominant beliefs that people with VI are helpless and in need of care (Butler, 1998; Tuttle & Tuttle, 2004; Worth, 2013b), others' assumptions represented a powerful detractor from participants' experiences that they were taking charge and succeeding in their activities and endeavours, and thus represented a prominent form of psycho-emotional disablism (Reeve, 2012; C. Thomas, 2007). These social assumptions were important: despite many participants' endorsements that they primarily evaluated their performance in various endeavours through self-evaluations (discussed in section 8.1), control over and success in their participation in their pursuits were by no means wholly intra-subjective. In moving beyond their offered initial and abstract discussions of the value of their participation in

their activities and their endeavours to discuss this participation in the specific context of their everyday lives with VI, it became apparent that the participants' experiences of independence and success in their activities and endeavours were directly affected by their interactions with others.

8.3.1 Assumptions of incapability: A form of psycho-emotional disablism

Participants' interactions with others – including unknown members of the community, as well as close family and friends – were often informed by the assumption that their VI made them incapable. Other people often directly and deliberately expressed this assumption to participants, such as through being over-protective; an experience shared by youth with VI in previous research (Khadka et al., 2012; Whitburn, 2013; Worth, 2013a). Typically acting out of concern for their safety, parents, siblings, teachers and – less frequently – friends clashed with participants, actively undermining their judgements about what they could and could not do:

In Year 7, I didn't ever use my cane because I just didn't need it, and then because [the school was] doing building works [my parents and teachers] wanted me to be safe so I "had to use it", but I didn't really use it. And then I kept on getting in trouble because I wasn't using it... and [my parents] got all the teachers to spy on me. (Jordan)

Jordan's parents and teachers unified to consistently drive home their perception that she was not able to move safely around her school when it was under construction, even though Jordan herself felt more than up to this task. Similarly, other participants endured frequent and overt patronization or pity from others, in which they felt "too babied" (Ash); such actions also reflected the others' belief that they could not do very much at

all. Alex's new colleague, for instance, chose to complete the work that Alex had successfully performed for months because she assumed that Alex would need practice:

I came in[to work] one day [and] all the [work had] been done... So, I go off and call [another employee] and... she said "Oh, I'm sorry Alex, I left them there for you to practice on" ... I was really angry; I was like "How dare you! You know, like I've been working here for three months and I wasn't given work to practice on the first day". (Alex)

Assumptions of the participants' diminished knowledge and capacities were not always so overt. Many participants were approached by strangers, or even acquaintances, who provided them with unwanted help: "[These people on the street] didn't even ask if I needed help... they just took me [because] they just thought 'Oh, he's vision impaired, we better help him'" (Charlie). Similarly, family and friends often spoke on the participants' behalf even though the participants themselves wanted a voice: "I was never really involved in [my mum's] little meetings... with my teachers which used to quite frustrate me" (Frankie). Several participants interpreted this as doubly indicating the other's perception of their helplessness: assuming both that self-advocacy was beyond them, and that they could not identify the supports they needed.

These assumptions were founded in cultural understandings of what it means to be an agentic individual capable of success in contemporary Western societies (discussed above), and the emphasis placed in these understandings on practical independence (Bell & Menec, 2015; Cardol et al., 2002; Hammell, 2006; C. Thomas, 2007). Disability is perceived as a precondition resigning its 'sufferers' to a life of incapability, and thus non-accomplishment by 'normal standards' (Gibson et al., 2012; Hammell, 2006; C. Thomas, 2007). In short, people with disabilities – like my participants – are seen to be less

capable and less successful because their need for assistance is visible and so it is assumed that they cannot pursue their goals.

The invisibility or visibility of one's disability demonstrably influences the extent to which patronization and stigmatization are experienced (Lingsom, 2008). Some participants managed the psycho-social effects of other's assumptions through the invisibility of their VI: where their disability was not readily observable to others, several chose to 'pass as non-disabled', and thus escape the disability-based judgements of others (echoing previous work regarding youth with VI; Jessup, Bundy, & Cornell, 2013; Uttermohlen, 1997; Worth, 2013b). These participants had greater residual vision and thus chose not to utilize any adaptive technologies or supports that would signpost their vision impairment (as discussed in Chapter 7). For example, "having been fully sighted and then that changing but not to a point where it was obvious to other people", Harper still pushed himself to pursue the same practical independence in his endeavours (e.g. study, music). In so doing, he did "not [ask for help or use adaptations] because I know that people don't understand, [which] contributed to other people expecting me not to be tired or expecting me to be able to function as any regular sighted person would". Harper was thus able to reduce the frequency with which he directly confronted assumptions of his reduced capacities.

Passing, however, involved a different kind of social 'work' (Lingsom, 2008; Worth, 2013b): even while passing, participants sought to consciously manage the dominant belief that people with VI are incapable, as Elliot explained:

I won't just disclose that [I'm vision impaired] straight off the bat, like if I'm going in a shop [when I] get to the cash register... I might just say "Can you hit the right button... my eyesight's not that great" [but] if I disclose that information from the very start I'm afraid of getting treated a bit differently.

Therefore, even where they were not directly expressed by others, negative stereotypes continued to act upon participants' feelings and thoughts about their participation in everyday activities. Furthermore, while passing enabled some participants to reduce the direct impact of others' assumptions, it did not free them from the influences of dominant assumptions of helplessness associated with VI. First, participants could not conceal their VI in all situations and from all people, and so were still directly exposed to others' concerns or assumptions about their invalidity, as has been well-documented in previous literature regarding passing (Jessup et al., 2013; Lingsom, 2008; Uttermohlen, 1997; Worth, 2013b). In fact, such assumptions were often made by those to whom they were closest or they presumed to be more understanding of VI, including family members or service providers. This was particularly confronting and distressing:

I see a psychologist at the moment and they asked me recently, you know, "Do you really think it's a good idea to be skateboarding?" And I just felt this like wave of kind of *sighs*, of just, "how dare you!" Like, "how dare you question my judgement!". (Harper)

Similarly, Max described how self-doubt arose if his parents or teachers expressed doubt over his independence: "Some people can doubt you... because you have to [catch public transport] every day and these people can't trust you [to catch it] ... how are you going to pursue your other goals?". He elaborated further:

Max: [If] people don't trust you then, yeah makes you a bit doubtful, doesn't it?

Ross: So, it increases your own doubt? Doubtful of what?

Max: Not really doubt, more like if... people are not going to trust you then you start going "Oh, should I prove them wrong or... not do this because maybe they're right?".

Such self-doubt had a detrimental effect upon Max's self-perceived competence and represented a pervasive form of direct psycho-emotional disablism (Reeve, 2006, 2012; C. Thomas, 1999, 2007). Like Max, several participants internalized (to some extent) others' negative perceptions of their capacities, and in turn began to consider similar negative views of themselves. As a result, they directly experienced a lesser sense of their own skills and achievement in their activities and endeavours. For example, Taylor described how his peers at school refused to acknowledge his success in the sports he played, dismissing any suggestion that these accomplishments reflected his own skill, commenting instead that "it's blind [sport] so no-one plays it, so you're guaranteed to get [into the top team]". Despite rebuffing this belittlement, Taylor began to diminish his sporting success and thus his own skill: "Making states for [VI-specialized sports] is an achievement but it's a lot... easier sort of than to make like a state [team] for soccer". This example demonstrates the (negative) power of psycho-emotional disablism in shaping lives, which arises as dominant negative assumptions about people with VI are internalised by the young person with VI. Continuously encountering other's assumptions that they were helpless represented significant negative experiences that had direct implications for the levels of control and capability that the participants felt they possessed. Many experienced strong negative feelings of anger and frustration when others expressed or implied that they were incapable, as discussed above.

Aware of these psycho-emotional impacts of others' assumptions upon their experiences of capability and control, however, the participants actively resisted the dominant perception of them that others held: that they were dependent and thus incapable due to their VI. I conclude this section of this chapter by describing the two forms of resistance enacted by participants.

8.3.2 Proving other people wrong

Others' opinions occupied a nuanced and fluctuating relationship with the participants' evaluations of their capacities and accomplishments in their schooling, at work and in their pastimes. Participants did not see themselves as a "possessed show-off who has to 'up-one' [other people] all the time" (Val); nonetheless, they also emphasized the contribution of others' recognition of their demonstrated competence:

Max: At valedictory, regardless if the teacher taught me or not, all the teachers stood up for me when I went up to get my certificate, because they knew that I worked hard, and they knew I proved people wrong. And, you know... that felt good for me, Ross.

Ross: *Why did that feel good for you?*

Max: Because I know [that] I've proven to the school that [even] with a disability you can still achieve.

The recognition Max received from his teachers was a powerful contributor to his experience of accomplishment and sense of capability, in particular because he felt that his success and this recognition challenged and changed the belief equating disability with incapability that had been prominent at his school:

My school's going to start encouraging more kids with disability [to attend] believing that they have the capability of going all the way because I've done it. And, you know... It took my school a long time to realise that.

This special value of others' recognition – couched in this sentiment of proving others wrong – pervaded the participants' accounts of the importance of their participation in their activities and endeavours and was one way participants managed the prejudgments of their dependence and incapacity by others.

Many participants described relishing opportunities and actively working to disprove others' negative assumptions, and thus demonstrate skills and competence to a level that they perceived others would recognize, even by dominant standards. Referencing frequent encounters with patronization and doubt, participants pronounced their extra motivation to exhibit their capacities and success in order to dispel these negative judgements: "When someone says "You can't do this" that actually just encourages me even more to go and do it, because I'm stubborn and I want to prove them wrong" (Frankie). Alex, for example, reflected that her patronizing co-worker, who had left her completed work upon which to practice, "really motivated me to come and prove myself; you know, next time that [client's work] came along I went and did [it] straight away and obviously [it was completed] fine" This gave Alex "a sense of satisfaction out of making [my co-worker] look an idiot" by demonstrating that she could match the standards of work that this co-worker assumed she could not.

Mindfully working towards and finding extra value in their success from proving naysayers wrong protected the participants against the psycho-emotional impact upon their evaluations of their independence and success from others' assumptions in two ways. First, the emotion-fuelled drive to invalidate others' disparaging aspersions upon their capacities provided a protective buffer for their own perceptions of their competence in their study, work or hobbies, as exemplified in Alex's encounter with her co-worker. Alex's outrage and subsequent motivation to make her co-worker "look an idiot", meant that Alex did not internalize the negativity of her co-worker's assumptions. Instead, she directed this negativity outward in a constructive fashion, harnessing it to drive her demonstration of her capacities. Second, participants' experiences of success in proving people wrong provided them with powerful evidence upon which they drew to bolster their self-perceptions of their capacities and achievement in the face of others' doubts:

[Performing my skills in my hobby for] a bunch of sighted people, [I am] able to show off the tricks I can do. [And] there's a part of me..., that is just kind of getting back at all those guys that said I couldn't [do anything]. (Val)

For much of his childhood, Val's peers had constantly undermined his capacities and accomplishments, barraging him with comments like "You're blind so you can't drive a car, you know you can't do this, you can't do that, what can you do?". However, Val's considerable success in his personal hobby, and his resultant exhibitions of his prowess to people who were frequently and (he felt) genuinely impressed by his demonstrations allowed him to defiantly refute the lingering psyche-emotional impacts on his sense of capability from his peers' negative reactions to his VI.

These benefits, however, came with a cost. A discussion between Jamie and Morgan regarding asking for and accepting assistance from others highlighted this cost:

Jamie: [If] I feel like people are pitying me [like when they say] "I'll help you with this because you need it" when I don't actually need it... I just don't like it.

Ross: *Why don't you like it?*

Jamie: I really don't know; I just hate accepting help... even when I do need it sometimes. I'm just too stubborn.

Morgan: Feels like a loss of autonomy.

Jamie: Yeah, I just don't like it.

Ross: *So, you said loss of autonomy... what do you mean by that?*

Morgan: Well... exactly that: a loss of independence -

Jamie: Yeah, feels like I'm giving up.

Morgan: Exactly... it can feel like admitting defeat and saying "Look I can't do this on my own, please will you help me" ... which is a really tough thing to admit. And I think humans naturally don't like admitting defeat; probably people

with various disabilities would be even less likely to because they feel like “I should be as independent” ... to prove themselves to themselves... Thus, when you accept help that’s admitting – or feels like admitting – that you’re no longer able to do this [and] I don’t think people like being defeated by anything less than other people.

Ross: Jamie, is it the same for you?

Jamie: Yeah, I really agree with Morgan... I don’t want to admit defeat and actually accept that sort of help.

Jamie often refused assistance to participate in activities (e.g. cycling with her family), even when it was necessary or would be beneficial, due to her desire to resist and disprove perceptions of her helplessness. For Jamie, Morgan and many other participants – the centrality of practical independence to their evaluations of the quality of their participation and experience in these activities became reinforced through the active effort of defying others’ negative assumptions. The need to perceive that they could rely on their own capacities and knowledge in taking part in their endeavours was strengthened. As a result, when the participants encountered situations in which they were not able to rely on their own skills and resources, the negative impact of needing to ask for support from a family member, friend or even stranger was intensified. This was reflected in Morgan’s and Jamie’s characterization of such moments through the powerful imagery of “admitting defeat”. Morgan and Jamie experienced asking for and receiving help as giving in to others’ assessments of their diminished capacities and resigning oneself to being less accomplished than sighted others.

Asking for and accepting help from others, moreover, was for all participants an unavoidable and valuable strategy for overcoming barriers presented by the interaction of their physical and social environments in order to successfully take part in many of their

activities and endeavours (as I discussed in section 8.2). Therefore, although helpful to repudiate disparaging perceptions of their incapability due to their VI and combat associated self-doubts, seeking out and relishing others' recognition of their prowess and capacities in their pursuits, and thus reinforcing dominant ideals of independence, ran the risk of exposing participants to greater psycho-emotional upheaval. As a result, this strategy of proving doubters wrong and savouring resultant feelings of additional satisfaction was not the only way that the participants managed the psycho-emotional disablism threatening their experiences of control and capability presented by others' assumptions of their incapability.

8.3.3 A different meaning of capability and control

Participants did not just look for different means by which to take charge over and be successful in their activities and endeavours; they also actively interrogated their own understandings of independence and success. In particular, recognizing that their alternative means of pursuing their endeavours in their everyday lives did not fit neatly with conceptions of agency grounded in practical independence, several participants problematized the primacy of such practical independence in their views of what it meant to be in charge and thus able to successfully take part in activities. These participants emphasized the compatibility of being able to utilize other people' support and resources whilst still being independent, as succinctly exemplified by Ash:

Ross: Can you accept help and still be independent?

Ash: Yeah. So, like you can still request [help without it being] someone... spying on you constantly. But like if you need help than you can ask for help [because] you have that flexibility.

Ash did not see being independent and receiving support as mutually exclusive. Frankie, similarly, reframed her understanding of what it meant to be independent:

Frankie: So, for me it's really important that I can do as much as I can, but also to know that there are things that I'm just never going to be able to do, so you know I might need to ask for help... as much as I don't like it.

Ross: So, you're saying that's part of independence, do you think?

Frankie: Yeah, yeah.

While participation in activities under her own power remained important to the definition, Frankie also felt that to be independent – and therefore in control and successful – also meant knowing when to draw on support from others.

This reconciliation of notions of independence with the act of receiving support represents a shift in thinking that fits with understanding the everyday functioning of people in terms of interdependence as opposed to independence (Hammell, 2006; Manderson & Warren, 2013; C. Thomas, 2007; Watson et al., 2004). The dominance of conceptions of independence as an individual's capacity to rely on their own skills and capacities to practically enact tasks without assistance – a definition offered by many of the participants themselves (see section 8.1) – has long been recognized as problematic within disability studies and overlapping scholarship (Bell & Menec, 2015; Hammell, 2006; C. Thomas, 2007). In contrast to such a notion of independence, the concept of interdependence highlights the fact that all people are reliant on the effort and support of other people in the complex web of society, irrespective of their status as “disabled” or “non-disabled” (Hammell, 2006; C. Thomas, 2007). Some participants explicitly voiced this base tenet of interdependence, highlighting that their reliance on support from others as young people with disabilities made them no different to sighted others: “I think even sighted people need help” (Drew). The difference arising between people with and

without disabilities then is that certain forms of reliance on others are culturally understood as ‘normal’ and thus become invisible, while others – those associated with disability – are seen as extraordinary and problematic (C. Thomas, 2007). Therefore, in asserting the compatibility of their independence and the support they received from others, the participants were rejecting this labelling of the assistance they received as meaningfully different from that received by sighted people.

Participants did not perceive the support they received from others as a threat to the core of what it meant to be in control and thus competent in their participation in their activities and endeavours, as Val explained with regard to his personally-significant participation in his local community by shopping at his local shops:

The distinction for me [between dependence and using supports is that] you know I’m able to get myself down to that [shop]. I know when the bus comes [and] I can get myself down there... and then once I’ve got there the [shop displays] will change depending on what [products] are available [and then] instead of being able to look at the labels and see what there is, then I kind of ask for assistance, but I’m still independently having to ask.

Val challenged the notion that complete self-sufficiency in executing tasks was the foundation of independence and control, and thus did not perceive his use of social support as a contradiction to his fulfilment of either. Perceiving the support of others as social capital that he chose when to mobilize (Kawachi et al., 2008; V. Morrow, 1999) – in line with my argument in Chapter 7 – Val asserted that the core of being independent (and thus in control) was that he as an individual still chose how he approached his endeavours. In other words, being in control for him was grounded in “decisional autonomy” rather than “executory autonomy” (Cardol et al., 2002, p. 972) Adopting this alternative understanding of independence and control meant that Val still experienced a

sense of capability even though he did not materially navigate his shopping alone. Charlie, similarly, did not see asking for help in order to facilitate his navigation as undermining his competence in mobilizing so that it represented a lesser level than that enacted by sighted people. Instead, he perceived such support as an inherent quality of society (i.e. interdependence):

I get asked [by sighted people], “How do you [travel here by yourself]?” And it's like, ‘Well, it's the same as how you got here, except if I need help, I ask; because there's people in this world that [will] help you in any situation”.

This redefinition of what it meant to take charge and successfully participate in their activities and endeavours enabled participants to maintain experiences of capability and control despite constant reminders of discrepancies between dominant conceptions of autonomy and achievement rooted in practical independence (Bell & Menec, 2015; Cardol et al., 2002; Gibson et al., 2012; McPherson et al., 2016; C. Thomas, 2007), and their alternative means of participation.

Taken together, participants’ discussions of others’ pre-judgements illustrated how their evaluations and experiences of their independence, success and the quality of their lives were intersubjective experiences. Whether they felt that they were demonstrating capability and control was dependent, in part, on how they managed the psycho-emotional impact of dominant beliefs that people with VI (and other disabilities) are incapable reinforced through their interactions with strangers, but also family, friends, educators, and service providers. Participants handled these psycho-emotional impacts both by striving for and relishing instances in which they dispelled others’ doubts about their capacities, and by amending the criteria by which they evaluated their own success and control in their activities and endeavours so that that they were less grounded in notions of practical independence. Thus, in addition to finding alternative means of

pursuing their endeavours (discussed in section 8.2), the participants' accounts suggested that they also stood up defiantly against and problematized the beliefs underlying others' assumptions of their helplessness in order to promote their experiences of capability and control.

8.4 Conclusion: Capability and Control as Intersubjective Experiences

This chapter illustrates the importance placed on experiencing capability and control as two important life domains contributing to the quality of the lived experiences of young people with VI. Echoing accounts of success and competence found in other sighted populations (Bourke & Geldens, 2007; Fattore et al., 2009; McCarthy et al., 2008; Smith & Wilhelm, 2004), participants articulated the inherent significance and pleasure of making ground towards various intertwined short- and longer-term aspirations or meeting their own personal standards in their various activities or undertakings, which gave them a sense of accomplishment and thus evidence of their competence (the domain of capability). Participants' accounts further complicated this straightforward relationship between the success of their performance in their endeavours and their senses of capability. In particular, they emphasized that self-governance – characterized by individual freedom to act in their own way due to their reliance on their own capacities rather than others (the domain of control) – was central to the feeling that their participation in their activities and endeavours was successful. As found in vision-specific QoL measures recently developed for younger populations with VI (e.g. Rahi et al., 2011), progress and accomplishment in meeting their own goals and standards, as well as freedom from restriction and practical self-sufficiency represent important indicators of wellbeing for these young people.

Participants also illuminated multiple factors at play in their experiences of capability and control in their daily life. In a practical sense, their efforts to progress towards and accomplish ends that they desired (capability) by relying on their own capacities to take charge of their participation in their pursuits (control) were often complicated or restricted by material, institutional, social and impairment-related barriers. Psycho-emotional disablism was also a pervasive social barrier to the participants' sense of capability and control in their endeavours. Not only did others' unfavourable assumptions about what the young person could do impose additional barriers or restrictions to their pursuit of independence and success in their endeavours, they also represented a powerful factor influencing participants to doubt their own attainment of autonomy and accomplishments. This suggests that to be able to work to promote wellbeing among youth with VI, the life domains of having capability and control in pursuing endeavours should not just be seen as a question of promoting their individual functioning as is often the case in the discipline of rehabilitation as I identified earlier (Binns et al., 2012; Hammell, 2006; McGrath et al., 2017). Instead, it management of their encounters with direct psycho-emotional disablism is also required, which the current participants did through both relishing opportunities to prove doubters wrong and the redefinition of their own understanding of independence and competence.

In the following chapter, I discuss further the specific strategies identified by my participants to not only address structural barriers to their practical efforts to maintain their wellbeing, but also to manage this powerful notion of psycho-emotional disablism more generally.

Chapter 9

Adaptability and self-reflection: Participant-identified strategies to maintain wellbeing

The preceding chapters have highlighted the difficulties the participants encountered to their attainment of valuable life elements across four key thematic life domains of physical health, social connection, capability and control identified in their discussions. In line with the two types of disablism identified by C. Thomas (2007) introduced in Chapter 2 – structural and psycho-emotional – this included two overlapping types of difficulty. First, participants encountered difficulties to performing tasks of their everyday lives (e.g. travelling, shopping, cooking, completing their homework) and to participating in many social activities or settings, such as their school lessons, sports games, social nights out and paid employment. These difficulties arose due to the interaction of their VIs' effects with material, institutional and social features of their environments (Shakespeare, 2006; C. Thomas, 2007), and had implications for one (or more) of the life domains contributing to their wellbeing. I term these *practical difficulties*. They also encountered *psychosocial difficulties*: that is, the threatened or actual diminishment of their sense of fulfilment with regard to valuable life elements, within one (or more) of the thematic life domains, by the various negative reactions of others to their VI. These latter difficulties primarily acted by producing negative feelings and self-perceptions in the youth.

Difficulties, while recognized by the participants, did not determine their wellbeing. In this final results chapter, I engage with the particular strategies and

resources that the participants identified as useful in responding to these difficulties in order to maintain a life in which they felt they were doing well.

9.1 Moving On: Wellbeing despite Difficulties

Participants did not require their life to be hassle-free in order to feel that they were doing well: wellbeing was maintained despite the fact that they faced difficulties, not present because of a lack of them. In fact, participants reported that they were *generally well*, consistent with previous findings that youth with VI report equivalent life satisfaction to sighted youth (Kef, 2002; Pinquart & Pfeiffer, 2011). Despite acknowledging moments of difficulty in her life, Alex explicitly articulated that “I don’t see myself as an unwell person because of my vision impairment”. Similarly, Morgan recognized that while he sometimes faced frustrating challenges related to his VI (e.g. difficulty in identifying items when shopping), this did not colour his whole existence. Rather, these difficulties were transient:

I don’t feel (negative about my vision] generally and overall [or even] retrospectively; if I’m not currently engaged in an activity where it [is] detrimental, then I don’t really perceive [my vision] as a really negative component [of my life]. I don’t sort of sit there doing nothing but resenting it. But, obviously if there’s a specific instance then I will just be like “God damn... this would be so much better if I had eyes”.

Thus, participants reported a general resistance to the negative impacts of such momentary difficulties and perceived their lives as being of a good quality.

This resistance, however, did not mean that participants were never confronted by VI-related difficulties that had significant negative impacts on their lives. Persistent

experiences of difficulty represented prolonged threats to or diminishment of one or more of the aspects of their lives that participants valued, such as Val's sport on the weekend:

I guess [my VI-specialized sports are] important to me because I didn't have [sport] for a while and I had nothing really to look forward to on the weekends, I just kind of sat at home, sat in a room and just passed the time away. Just listening to music, and that was basically my weekends for four or so years.²²

After his vision had begun to prevent his competitive participation in his preferred sighted sport, Val had been unable to find an alternative sport or activity for some time, leaving him feeling isolated and flat. Similarly, Alex described an extended period during which she struggled to find employment – something she considered very important – due to multiple barriers²³:

Being at home, looking for jobs, getting constant knock-backs, it became really depressing to be honest. You know I became really bored and stagnant, just sort of lay around watching movies all day... It affected all aspects of my wellbeing, as I had no self-esteem.

Neither Val or Alex was able to move past the difficulties they encountered and thus these difficulties significantly impacted on how positively they felt about themselves and their lives.

Comparing Alex's experience of her life during the time when she was encountering barriers to her employment, and her perception of herself as not an "unwell person" at the time of her focus group, further underlines the importance to the participants of maintaining a sense of personal balance among the elements of their life that they prized. As discussed in Chapter 5, participants considered it particularly

²² I removed the specific types of sport to which Val referred in order to protect his confidentiality and anonymity.

²³ I have discussed the structural barriers to employment encountered by older participants with VI (>18 years of age) in Chapter 8, drawing in particular on the job-hunting experience of Lee.

important to a good life to maintain such a sense of balance because these various valuable elements fed into and helped sustain each other, providing them with the sense that overall their life was going well. In contrast, the prolonged difficulty Alex faced during her search for employment completely disrupted her experience of balance in her life, resulting in a marked drop in her evaluations of herself and how she was travelling in life:

When I was out of work, it wasn't because my situation was a little bit difficult... it was because "I'm a stupid blind idiot anyway and no-one will ever employ me, so I might as well just go back and study and stop wasting time" ... It just gets you into these really negative thought patterns, which affect your mood, which affects your overall wellbeing.

The ongoing battle for employment and the negative impacts it had on other elements of her life (e.g. her social and physical activity, diet), led Alex to a situation in which she interpreted any set-backs as her own fault due to her vision impairment, meaning that they had a damaging effect on her experience of wellbeing. In other words, it led her to internalize and view her life through the personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000).

This situation, fortunately, turned around for Alex when, after much continued effort, she successfully obtained her part-time job. Obtaining employment restored that experience of personal balance into Alex's life:

So, gaining some employment, even if it is only on a part-time basis... I've enjoyed the feeling that I've made a contribution to my community and you know that I'm valued in some way [and] I'm obviously a lot more active now... so [getting my job has] been a really positive change in my life of late.

Alex experienced greater levels of connection to her community and physical activity just throughout her everyday life. This restoration of the various elements that she valued in her life to the levels she was happy with – in other words, her sense of balance – changed Alex’s overall view of herself and her life as it “just changed my mood completely”. It also afforded Alex a more positive outlook on momentary difficulties she continued to encounter, so that she experienced them as “chance[s] to learn... or to just do something and... who cares, come back tomorrow”. In short, feeling that her life was in order again enabled Alex to “be a little bit less harsh on myself”. Alex’s job-hunting journey illustrated that feeling that their lives were in balance – that they had everything that they considered important at the levels that they desired – provided participants with a buffer against any moments of difficulty. This was further exemplified by Lee:

I’m happy where I live, happy where I work, I’m fit and healthy, playing lots of sport, great people to work with [and I] get on well with my family... So, I don’t think I have too many issues right at the moment with my vision impairment [and when I do] go somewhere or do something outside [for which I might not be prepared] that’s just more practise for me.

Lee’s personal sense of fulfilment across his life meant that he interpreted difficulties associated with his VI as momentary obstacles to be overcome and from which to learn.

Participants, therefore, engaged in the process of *managing and moving on from difficulties*. In so doing, they sought to ensure that the difficulties they did encounter were indeed passing:

Lee: So, I'd tell someone about [the difficulty I am having] first, then maybe work out what... can I do to sort this out. [Then] I might maybe do something physical, like go to the gym or... What else might I do maybe?

Ross: [Your favourite sport]?

Lee: Yeah [or] maybe just go outside and smash out a few push-ups... to get that kind of anger or energy out.

Ross: *How does that help?*

Lee: Yeah, I find [that] after I'm finished the physical exercise I'm not as angry anymore, just tired. [Then] I'll actually go and start doing whatever I need to do to fix the issue, so maybe start the suggestions that I went through in the conversation at the start.

Ross: *What if there's something like a vision barrier that there isn't a solution to?*

Lee: There isn't a solution? Something there isn't a solution to *long pause for thought* I need like an example but...

Ross: *It's a good thing that you're struggling with thinking of an example of that.*

I'm not going to give you an example if you can't think of one.

Lee: Yeah... if it just something quite difficult that I'm going to have to do or... some sort of sacrifice I have to make, after I've got rid of the anger and just calmed down... then I'd say to myself, "Okay well let's get this over with" basically. Not really one for putting things off.

When presented with a problem, Lee set about figuring out how to resolve any practical elements of the problem to move past it. Furthermore, even when the problem was not easily resolved in a practical sense, Lee identified the importance of finding a way to move beyond it. Thus, managing and moving on from difficulties did not necessitate the successful *practical* resolution of the responsible barriers, or even excising all associated negative feelings or thoughts (as I discuss later in this chapter). Rather, it was about using whatever means was most appropriate to put the difficulty behind them, so that it did not continue to disrupt their lives and give rise to unpleasant thoughts and feelings.

Two elements, in particular, were identified as essential to this process of managing and moving on from difficulties: *adaptability* and *self-reflection*. I discuss each over the remainder of this chapter.

9.2 Adaptability: A Set of Strategies and Resources

Adaptability was integral to the process of managing and moving on from difficulties. Participants identified that they had to be willing and able to continually change their approach to the barriers they faced in order to find a successful strategy that matched the particular situation in which they were confronted by the difficulty. Vulnerability was created by reliance on one solution: “The more dependence you have on particular things, or structures or people or whatever, the less you feel like your resilience... comes from yourself” (Harper). Harper wanted to know that his ability to manage the difficulties he came across was not predicated on one particular resource, and rather was seated in his own capacity to change up how he responded to such difficulties depending on what resources were available to him; in other words, his adaptability. As Frankie summarized, this capacity was thus essential to handling VI-related difficulties: “It’s the ability to be able to change ... If you rely on one certain way it’s not always going to be there”. Frankie further articulated how she enacted this adaptability when facing a particular difficulty in order to put it behind her:

[To adapt] you’ve got to... acknowledge that you can’t actually do that anymore... It’s probably the hardest part... accepting that. Then [you begin] thinking about the task, you know, “Do I have a piece of equipment?” [or] it might be a matter of using your connections... and I think being really aware of your environment, it’s really important as well. I’m not sure if there’d be an exact

process that I'd go through, but they're sort of some of the things that I'd certainly consider [in order] to move forward.

As illustrated in this quote from Frankie, participants needed to have available to them an array – i.e. a “repertoire” (Bonanno & Burton, 2013, p. 598) – of strategies and resources that they could employ as required in order to facilitate their adaptation. In particular, this array had to include strategies for addressing both the practical and psychosocial difficulties they faced. To be adaptable, Frankie both had to find ways to accept the difficulty confronting her, as well as to practically respond to the difficulty in order to move past it. Participants, therefore, used both *practically-focused strategies* and *psychologically-focused strategies*, consistent with the well-established binary of problem-focused and emotion-focused strategies in scholarship regarding people's coping with stress (Carver & Connor-Smith, 2010; Folkman & Moskowitz, 2004). Problem-focused strategies target change in the actual cause of stress – the stressor – while emotion-focused strategies seek to minimize the distress experienced itself.

Various resources helpful to each of these processes were identified by the participants. I discuss the participants' practically-focused and psychologically-focused strategies, and supporting resources, over the next two subsections.

9.2.1 Practically-focused strategies and resources

The participants specified two broad strategies for handling practical difficulties arising from the interaction between their VI, and material, institutional and social environmental barriers (Shakespeare, 2006; C. Thomas, 2007). First, finding *work-arounds* was identified as integral: in this, participants sought alternative ways of pursuing blocked endeavours that took varying forms. Several participants reported relying on their other capacities, such as their memory: “Add [it] into your memory [that] the bus leaves there

at that time” (Caelan). More commonly, external resources, technologies or systems were identified. For example – discussed in greater detail in Chapter 8 – most participants used the public transport system to travel to destinations given their inability to drive, and various aids at school, such as “a laptop and... glasses with a monocular on them” (Taylor). Money also represented a resource some participants could draw upon to find alternative ways of performing tasks, as exemplified in Lee’s comfort in using taxis as a means of travel if he felt like it, since he had obtained full-time work and felt he had sufficient income to fund these trips (discussed in Chapter 8 on page 277).

Despite searching for work-arounds, participants could not always directly resolve practical difficulties. Adapted strategies often fell short of overcoming all the structural barriers the participants were facing or were simply not an option. For these situations, the participants engaged in *advocacy and self-assertion*. This was a versatile tool with the participants reporting its wide application: finding out “what’s on [a] menu” (Harper); standing up to your teachers to tell them that the “red [whiteboard marker] is a bad colour, don’t use it” (Val); or, asserting to family that “if I need a cane, I will take it” (Jay). Speaking up frequently represented a useful means of avoiding or removing structural barriers. They could use it to gain assistance from others who could help resolve or remove these barriers (e.g. by reading an inaccessible menu), or to challenge the person whose actions contributed to their exclusion or restriction (e.g. ignorant teachers, over-protective parents).

Support from others also played a key role in their resolution of practical difficulties. In particular, participants highlighted both support from family and friends, and *engaging with services and programs* as helpful; somewhat consistent with the distinction between informal and formal forms of care and support (Barrett et al., 2014; C. Thomas, 2007). Although for many this distinction was blurry as they reported close

relationships with particular service providers: “[My service provider, Kai, is] vision impaired... and [they see] that as an advantage in [their] job since [they’re] able to be a bit more open with [their] clients, in particular, like me [and act] as a [service provider] and also as a friend” (Max)²⁴. This resonated with the work of Watson et al. (2004) highlighting that even formal care relationships, between paid providers and people with disabilities, entail emotional and personal investment in many cases.

As discussed in Chapter 7, participants obtained considerable support through varied social connections. This included multiple forms of support that served as a protective buffer for their wellbeing when confronting adversity (Feeney & Collins, 2015; Kawachi & Berkman, 2001). In doing so, they echoed typologies of social support that have previously been identified (Cohen & Wills, 1985; Feeney & Collins, 2015). In particular, the types of support described by the current participants overlapped with those identified by Chang and Schaller through semi-structured interviews with 12 adolescents with VI regarding the valuable social support they received from their parents, friends and teachers (Chang, 1998; Chang & Schaller, 2000). For example, one major category of social support highlighted by the current participants was practical support.

Family and friends often directly applied themselves to resolving the practical difficulties arising from the interactions between the participants’ reduced vision and externally-located barriers that inhibited the participants’ performance of a particular task or participation in particular setting. Resonating with Chang’s (1998) conception of tangible support, this practical support often took the form of another person’s active material intervention in the task facing a participant. For example, Taylor’s brother was

²⁴ I so heavily edited this quote to remove any indication of the service provider’s gender in order to protect Max’s anonymity and confidentiality. Few service providers are also vision impaired in Victoria, Australia, and I wished to broaden the pool of potential specialists by removing any other identifying information, so as to avoid the deduction of who this specialist was and, by extrapolation, Max’s identity.

often able to “do a lot of things for me that... my vision impairment can hold me back from”, including helping him “make... breakfast [because] my fine motor skills are terrible [and it is awkward] watching me spread stuff on toast”. Assistance with transportation – in other words, receiving lifts from friends or family – was another example shared by many participants. Meanwhile, where others could not intervene by performing a particular task themselves – such as in the participants’ schoolwork – they also materially aided the participants’ performance by “putting things in place like the adaptive technologies (I needed to make] things easier in that sense” (Elliot).

Parents, service providers and, in some cases, other older family members also actively intervened and thus practically supported participants by directly adding their voices to the participants’ advocacy for the provision of certain resources, or removal of certain material or social barriers. For instance, Val’s “parents [were] very switched on [and] if there was a repeat offender, a teacher, [who] just kept [using] the same [inaccessible practises like the red whiteboard marker] over and over again [then] straight away... I’d be drafting up an email with my dad, sending it off to the school”. Furthermore, in providing this advocacy support throughout the participants’ transition through adolescence into young adulthood, these family members or service providers served as valuable role models from which participants learned to speak up for themselves, as Frankie reflected about her mum: “My mum always advocated for me [so] I... learned from that” (Frankie). Other participants found such role models in their older peers with VI in attending regular group programs. As discussed in Chapter 8, however, some participants did highlight how this supportive advocacy could be taken too far, leaving themselves without a voice, and thus family and friends had to ensure they advocated alongside – as in the case of Val’s father – and not for participants.

The provision of practically-focused advice and information from others represented one final form of practical support, and thus the participants' discussion of practical support also reaffirmed the value of Chang's (1998, p. 61) concept of informational support identified by their participants: "Any information provided by people to define, understand, solve or cope with problematic events". In particular, the current participants described receiving guidance from others regarding services or technologies that were useful in resolving or managing barriers; guidance that participants could then choose whether to apply. Others with VI were valuable providers of such advice and information. Max, for instance, felt that it was Kai's lived understanding of VI that made their advice – as a service provider and friend – especially useful:

Like I said, Kai's a good friend of mine... and [they're] a big help, because [of their own vision impairment], I can say "This has happened, what can I do about the situation?" and [they] can give me some advice saying "You should write it down like... it works most of the time".

This value of shared experience to the practical advice others can provide has been well-documented in previous literature (Suitor & Pillemer, 2000; Thoits, 2011). Although, the advice of friends and family without VI was still appreciated by participants: "[When I was bullied, I spoke to my parents and they gave me] some tips on how to like, work things out. So, they told me, you know, the 'Sticks and stones can break your bones but words can never hurt you', so then I just ignored [the bullies]" (Alex).

This informational support – to invoke the label used by Chang and Schaller (1998, 2000) – was also formalized in the participants' engagement with services and programs. Formal vision rehabilitation and educational support services that participants found useful were those that exposed them to various strategies, technologies and resources, thus encouraging flexibility in their approach to dealing with practical

difficulties. The participants emphasized “the importance of being made aware of different ways of doing something” (Val) and service providers giving them “options” (Max) across situations. They commended practitioners who raised various strategies and resources, providing an “armoury” (Val) toward managing VI-related difficulties. For instance, Frankie’s aforementioned ability to adapt “built up over the years” through “a few services... with their self-advocacy [and being] given a cane [and being shown] how to navigate public transport”. Similarly, Shannon explained that, having acquired many skills and strategies through his engagement with VI services, he felt quite confident in his adaptability – for example, in being able to navigate through different environments – because he had these strategies and skills to draw upon:

Even though you [move] from place to place, the strategies that you [have] help you... So, for example, and I’m starting to learn this with going up to [other cities more] regularly, the [mobility mnemonic that I was taught by one of the service providing organizations] I just, I have it in the back of my head, you know, as a back-up should I need it.²⁵

Such engagement with services and utilization of support from others, as well as role models were also helpful to participants in dealing with psycho-emotional impacts they experienced, which are discussed below.

²⁵I removed the specifics of the mnemonic from this quote for three reasons. First, the actual mnemonic itself is immaterial to the point I am making; it is just one strategy that Shannon was taught which represents one resource for problem resolution across situations. Second, this mnemonic was the initiative of a particular VI service organization and thus including it would have indicated the particular provider from which Shannon receives services. This would increase the likelihood of Shannon’s identification; therefore, I removed the mnemonic to help preserve Shannon’s privacy and confidentiality. Finally, throughout this thesis I am seeking to keep my commentary on VI service provision in Victoria, Australia, impartial with regard to the particular organizations, and removing information that identifies the organization from such quotes was one such strategy I employed to achieve this.

9.2.2 Psychologically-focused strategies and resources

Participants outlined strategies and resources for moving past negative feelings or thoughts produced by the threat or diminishment of valuable aspect of their life due to a VI-related difficulty. These strategies were important as the participants not only encountered practical difficulties which could produce such negative psychological impacts but were also (more) frequently confronted by psychosocially challenging interactions with others that acted to directly produce disparaging self-evaluations in the participants. Two prominent strategies were “venting” (Val) the negativity through *outlets* and finding an *escape or distraction* that generated unrelated positive feelings or allowed the negative feelings to abate.

Much like the significance of practical support from others in their responses to practical difficulties, participants highlighted the central role of emotional support (another category demarcated by the youth with VI in the work of Chang and Schaller 1998, 2000) in their use of both outlets and escapes or distractions. Outlets often took the form of another individual willing to listen and respond in a caring way to the challenges encountered by participants. Parents and close friends were major outlets. Ash explained how talking to her parents about being bullied provided her “reassurance”, relieving stress as “I had told them once [so] that reassured me that I could tell them again”. Just the knowledge that her parents were there for her, and that she was not alone was beneficial to Ash; such knowledge of the stable presence of family and friends was also central to the conceptions of emotional support of the youth in Chang and Schaller’s work (1998, 2000). When encountering difficulties alone, negative feelings and pessimistic thoughts, often about themselves, collected in participants’ minds. Talking through these difficulties with family and friends – in addition to representing a potential avenue for

receiving useful practical advice – allowed these negative feelings and thoughts to be released so that participants did not stew on them:

I go amazing for a few months, you know, everything bad that happens I just push it away, like it sort of gets pushed to my back of my mind. And then, you know, probably once every three months, I'll have a massive cry for three days straight. And just you know, lie in bed, eat lots of chocolates, sook to my girlfriends just about everything in life that sucks, and then, I get up, I dust myself off and I keep going. (Jamie) Jamie found this regular debriefing with her friends as invaluable to handling her negative thoughts and feelings. Despite often coming away from these discussions with no new practical insight regarding “everything in life that sucks”, Jamie found that in just voicing this negativity she was able to keep going. Alex also stressed that “it’s important to talk about how you’re feeling [with others because] bottling things up doesn’t help in any way; and... more to the point, talking to the people who are encountering the same situations”. As suggested here by Alex, again, participants highlighted others with VI as particularly helpful forms of emotional support because of their lived experience and understanding of VI, as has been reported by other youth with VI and other disabilities (e.g. wheelchair users; Goodwin et al., 2009; Goodwin et al., 2011; Goodwin & Staples, 2005). In line with the experiences of the adolescents in Chang and Schaller’s (1998, 2000) study, the current participants found that voicing their negative feelings and thoughts to another who indicated their understanding, legitimized the difficulty they were experiencing and informed them that encountering this difficulty did not undermine their worth: It makes me feel less bad about not being able to do something, knowing that someone else has trouble doing it as well. (Morgan) Parents, friends and other family also

emotionally supported the participants by serving as an escape from the difficulties they faced. Friends, for example, often deliberately distracted participants by engaging them in light and pleasant conversations or activities. Participants were afforded a reprieve from the particular negative experience they were having. This was nicely captured in the support Caelan's friends showed him immediately following his sudden vision loss in late adolescence. Despite feeling "down", Caelan "did not really tell [my mates] about it", and yet he identified them as providing valuable support in handling these negative feelings:

Ross: So, when you say [your mates] were being supportive then?

Caelan: Yeah, they were just supportive, no matter what... like they didn't know that I was down, but somehow, they knew, kind of...

Ross: Okay... how did they help?

Caelan: Oh [they were] just being like mates, just joking around and talking about footy or movies or whatever. Just doing what mates do.

Caelan both had to quickly come to grips with a change in identity as he no longer felt that he could become a farmer as he had always envisaged (discussed in Chapter 5) – in other words, he had to navigate biographical disruption (Bury, 1982) – but also had to relearn everyday living skills which he had previously performed with sight. Caelan further explained why he found his mates just "being like mates" emotionally supportive:

Let's put this in context, like the first time they put like images of war on the TV during the Vietnam war... it was just like *feigns shock by gasping* "Oh my gosh, what's going on here?" ... that's like what it was for me going blind. [But] let's say you put on another channel, you know like a comedy... then my mates were the comedy [and by] joking about [my] canes and... about other stuff [I] got used to [my VI].

By joking around with Caelan, rather than engaging directly with his challenges, Caelan's friends provided him with a pleasant space of respite, balancing out the difficulties he was facing in his life with more enjoyable moments, while the sadness he was experiencing dissipated with time.

Evident in Caelan's experience, several participants asserted the special importance of shared humour in their emotionally supportive interactions with others (with and without VI). Although not necessarily appropriate immediately following major negative events – “if it's something serious where potentially I could have been hurt... sometimes I'll be like ‘Nah, sorry guys, it's too soon to joke about’” (Frankie) – humour provided participants with a less intense way to directly address difficulties. As such, it operated both as an outlet enabling participants to express their feelings and thoughts, and an escape as the positivity of the shared mirth represented a reprieve from the seriousness and heaviness of the difficulties they were facing. This dual benefit of humour in managing the negative feelings was evident in Val's experience with his friends at a regular VI activity group:

Val: When you're in a group with other people who are vision impaired... who actually get the difficulties with having vision impairment... you can share stories like that annoying bus driver [who was rude to me as he did not understand that I was vision impaired, because I did not use a cane, with] them. And then you can go around the table and you have a laugh about it and... everyone's got a story of somebody doing something stupid to them or acting stupid in front of them.

Ross: You talked about irritation a lot today, does that outlet help with that irritation?

Val: Yeah, I mean... it doesn't take much to turn [bad experiences] into a fun kind of story... and of course, you know it just sparks conversation... Someone else

[might be] like you know I think you know every time someone asks [us a stupid question] we should be able to sue for discrimination... It's just, you know, fun around the bar.

In actively looking at the lighter side of his and his friends' negative interactions with sighted others – the psychosocial difficulties they encountered – Val both expressed his frustration and converted it into a funny story, but also found this time with his friends to be simply a “fun” and relaxing space. The participants' active use of social humour aligned with previous findings that, by providing means of positively reappraising and distancing oneself from the intensity of a situation, humour and laughter aid in the coping of people with negative emotions (Keltner & Bonanno, 1997; Samson & Gross, 2012), including youth with VI or people with other disabilities (Bingham & Green, 2016; Foley et al., 2012; MacPherson, 2008; Worth, 2013b). However, the emotional support participants received from others, including their engagement in shared humour, were not the only outlets and escapes participants utilized.

Activities and interests (e.g. craft, music, sports) were also outlets and escapes: “Sport... has given me the balance between... think[ing] about these issues [to] address them, and... cut[ting] myself away [to] focus on something... that I'm good at” (Alex). Although some were developed through sighted friendships, family or independently, many activities or pastimes had been suggested by service providers or were run specifically for people with VI. For example, Harper took up music after a “counsellor suggested I join the choir” which he found was “a good outlet for... not so enjoyable emotions”, while practicing “blind sport” gave Val a space to “forget about everything”. While some participants described passive activities (e.g. listening to music) that let them temporarily “go into [their] own little world [of] enjoyment for three-and-a-half minutes” (Shannon), several emphasized the valuable activeness and productiveness of their

pursuits. They provided an avenue for “cutting [their negative feelings] away” or “setting [them] on fire” (Morgan) in “constructive” (Harper) ways, thus promoting the elements of life they valued and associated positive feelings and self-cognitions. As described in the preceding chapters, participants’ recreational activities frequently offered them one means through which to strive towards and accomplish personal goals or standards, to develop and practise their independence, be socially connected, and engage in physical activity or relaxation.

Alongside these varied outlets and escapes, approaching moments of difficulty related to their VI from particular *mindsets* was also helpful in moving past any negative feelings accompanying challenges with which they were confronted. The participants identified two particular mindsets as beneficial: *acceptance* and *resilience*. Several participants asserted that VI-related difficulties did not psychologically bother them because they had accepted their VI. For some and often regarding specific difficulties, this mindset of acceptance meant a sense of peace and understanding, as evident in Max’s explanation of how he moved past the bitterness he felt about his inability to drive: “[My safety] is the reason [I can’t drive] and yeah it’s a pretty good reason why I can’t” (Max). More frequently, however, participants discussed acceptance as becoming or being “used to [their VI]”. Participants’ articulations of acceptance varied with their vision loss histories; participants with greater residual sight or later-onset loss discussed acceptance in terms of having “adjusted” (Caelan) to disruption (Bury, 1982; Tuttle & Tuttle, 2004), whereas those with congenital or earlier-onset loss subtly expressed ideas of their “normal”: “I don’t really get upset about [my vision] because it’s always been that way” (Jules).

Often coinciding with acceptance, many participants also found adopting a mindset of resilience as helpful as well. Such resilience was characterized as

determinedly holding the self-belief that “you don’t let the little things get you down, you just push through” (Jamie) and you “can do anything you put your mind to” (Jay). Becoming or being used to their VI (acceptance) did not remove the negativity from participants’ experiences or memories entirely, but rather captured their nuanced experiences of adversity. This was reflected in Alex’s description of her acceptance of her victimization during her school years (discussed in Chapter 7): “I’ve learnt to accept it [but] not necessarily to be okay with it, because I don’t think anyone should have to be okay with some of the things that have happened to me”. Thus, moving on did not reflect a life free of negativity, but rather one in which participants were driven to succeed despite the difficulties they had encountered and that would recur. Alex explained further that while she was “not okay” with the hardships she had faced, “I moved on from [them to] make myself a better person because of the things I have dealt with”. Therefore, occupying either or both mindsets – acceptance or resilience – enabled Alex (and other participants) to focus on promoting the positive attainment of the elements of life that were important to them, rather than being psycho-emotionally disabled by distress and outrage from the difficulties or injustice to which they were subjected and that which may not be resolvable (Reeve, 2006, 2012; C. Thomas, 1999, 2007).

Multiple factors involved in the development and maintenance of acceptance and resilience were highlighted by participants. Several implicated time and personal maturity in these mindsets, while regular outlets or escapes – as discussed earlier – enabled the replenishment and thus maintenance of resilience: “Knowing that even though I had to get through [school that] I did have friends... and I was doing stuff outside of school... I just knew that I don’t quit [so I was] just hanging in there” (Frankie). Frankie’s mindset of hardy resilience was drawn from her extracurricular activities at which she had many positive friendships with others with VI and served as a protective buffer at school where

she was the victim of systemic bullying and exclusion (see Chapter 7). The inspiration offered by role models was also salient in developing both acceptance and resilience, and several participants articulated the critical value of meeting and observing peers with VI at group programs or events:

To see people who maybe even are older that have vision impairments but are doing quite well, it gave me the feeling that "Well, things will probably be okay then". (Elliot)

As reflected in Elliot's quote, finding role models with VI enabled participants to envisage a narrative to their life going forward that encapsulated a hopeful future in which their VI did not prevent their success and happiness. Such narratives have been identified as central to rehabilitation services as they are recognized to enable people with disabilities to adopt a more positive outlook on their situation and thus to motivate people to work to overcome practical difficulties (Warren & Manderson, 2008). Thus, these role models inspired and promoted acceptance and resilience by prompting the participants to reflect on their own situations and question their negative feelings and thoughts regarding the difficulties presented by their VI. Some participants described similar benefits from deliberately employing cognitive strategies to consider their difficulties from different perspectives. One such strategy – also previously identified by Tuttle and Tuttle (2004) – was intentionally focusing on positive experiences associated with VI: "Well, I know like in some things, like if someone's puking or if there's some gross things, it's like 'Oh wow! I don't have to see that one'" (Jordan). The value of such mindful self-reflection in the process of managing and moving on from difficulties was, however, not limited to the promotion of such positive mindsets.

As is summarized in Figure 9.1, the participants possessed a broad set of both practically-focused and psychologically-focused strategies for managing VI-related

difficulties. These strategies were also supported by various material and social resources. However, while this set of strategies and resources afforded participants adaptability in the face of varying difficulties, it alone was not sufficient. To manage and move on from practical and psychosocial difficulties they encountered in a way that best preserved their sense of balance required the selection of the most appropriate strategies and resources in the given situation. Thus, self-reflection was also essential to the process of managing and moving on from difficulties associated with their VI.

9.3 Self-management through Self-reflection

Self-reflection was a key strategy allowing participants to work through and move on from the difficulties they encountered. Participants actively gave thought to how they responded to difficulties, drawing upon what they knew about themselves (i.e. their sense of identity) and the particular situation in which they were confronting the difficulty. For example, Jay explained that, given his own knowledge of his quick temper, he actively monitored his own thoughts and behaviour during difficult discussions with others: “If someone annoys me, I’ll walk away [and say] ‘Okay, I’ll tell you what, I’ll call you tomorrow and we’ll discuss this again after I’ve cooled down, because I know I’ve got a hot head’”. Actively reflecting on his behaviour throughout these conversations, Jay used his knowledge of his short temper – a trait in his sense of identity – to make the decision to step away from the situation and seek a distraction in the form of listening to music that “clears my head”. Self-reflection enabled Jay to engage in self-management. This was a point summarized nicely by Alex: “Self-awareness is also pretty important I think [to finding ways to manage obstacles]. You know, understanding yourself as a person [and] how you deal with situations”.

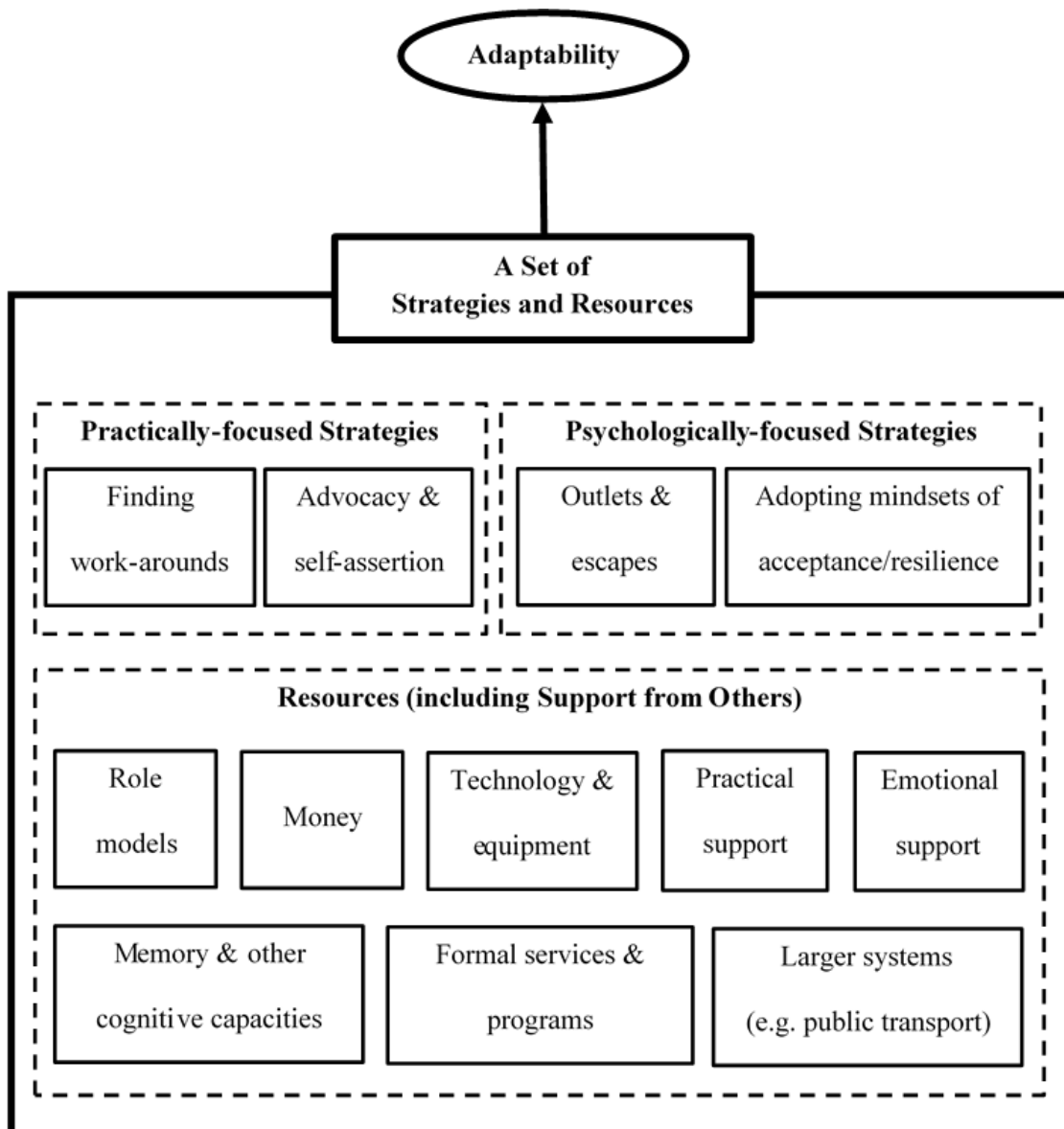


Figure 9.1. A diagram summarizing the set of strategies and resources identified by the participants as contributing to their adaptability in responding to the VI-related difficulties they encountered in different situations.

This self-reflection was put into practice in different ways by the participants, varying in particular with regard to its temporal relation to the difficulties that they came across. In some instances, participants recounted finding time and space removed from the difficulty in order to think through the particular situation, what they wanted from it

and how they could achieve this. Elliot prized his time at the gym because “when I’m there... I’m always sort of thinking about something else just sort of pondering”. The gym was a useful space to work through difficulties in other areas of his life:

[When I leave the gym] there seems to be less things to worry about... Before the gym, [I might have] been stressing about this big list of stuff I’ve had to do in the week and then while I’ve sort of just been mulling it over without... any sort of distraction I’ve been able to think about everything... and then I have a bit of a plan.

Some participants also described active in-moment self-monitoring. Similar to Jay’s monitoring of his temper, this in-situ reflexivity was central to Harper’s navigation of all situations:

Even now I’m thinking about [what I’m doing]. That skill of [inhibiting your habitual response to something is] really useful in any kind of situation that might call for changing your perspective... In situations of conflict or stress, [I] stop and reconsider whether or not the way I’m responding... is actually going to be useful to me, and I can then make a choice as to whether I want to try and change that.

Harper specifically identified this self-monitoring as invaluable in responding to the chronic pain and associated distress that he experienced, in part, because of his poor ergonomics in using inaccessible school computers with his reduced vision (discussed in Chapter 6). He knew that “my old habitual response [to my pain] was often to feel really upset about that and that would cause me to tense up even more and that would usually result in more pain”. Aware of this, Harper monitored his own thoughts, feelings and behaviours, reflecting on “how you hold yourself and the amount of tension and coordination with which you do all your activities”, which enabled him to reduce the pain he experienced by approaching his activities in a “very sort of limber and relaxed” way.

Self-reflection – whether removed from the setting or in-moment – enabled participants to manage the impact of difficulties they faced upon the elements of life that were important to them. Participants’ reflections guided how and when they employed various strategies and resources – described above – in response to their own appraisals of both the given situation and what they wanted or needed from it (e.g. inclusion, success). The latter included considerations of both the relative value that they, as an individual, placed on various valuable life elements in general (i.e. their personal definition of balance in their life), but also whether a particular element was in need of promotion or protection in a particular situation. This was especially evident in the participants’ discussions around concealments and disclosures regarding their VI.

9.3.1 Social performances: Concealments and disclosures

Concealments or disclosures regarding their VI – of varying degrees and kinds – through deliberate social performances were central to the participant’s management of their VI in varied social situations in line with their priorities at the time. In particular, the participants described differently employing many of the strategies and resources described in section 9.2 depending on the situation in order to facilitate a form of concealment or disclosure.

Several participants deliberately employed assistive devices, such as white canes, to “advertise [their VI] on those days when [they] could use it” (Jay). For instance, Frankie – who had sufficient remaining functional vision to move around independently without a cane – often still visibly used her cane in order to flag her VI to others in situations in which she felt that receiving support or assistance would make a task easier to perform:

Sometimes it's good to stand out. I don't need my cane during the day, but I have it so I do stand out so I can get the help [I need to perform a task], so I can be different.

This echoed Worth's (2013b) finding that some youth with VI mindfully displayed their VI to the broader sighted community through the use of a cane in order to avoid interrogation about behavioural signs of their reduced sight or to receive beneficial special treatment from others. In other situations, in which receiving such help was not her priority and she was more focused on attaining a sense of inclusion, Frankie conversely stowed her cane away and thus reduced the additional attention from others that she wished to avoid at that time. She explained: "I think it's good to have a balance, because sometimes it's really good to stand out to get the things that you need and then other times you want to blend in a bit more". Further still, participants identified other technologies as direct enablers of concealment of their VI, as reflected in Jamie's explanation to Morgan regarding her covert means of completing the grocery shopping, while avoiding unwanted attention regarding her VI:

Jamie: Unless [my vision] concerns them, I don't think that [people] need to know. Unless I, like, actually need their help.

Morgan: Yeah, well, if they're looking at you askance because, you know you can't read something in the supermarket –

Jamie: That's where I usually use my phone and pretend I'm texting and like... check out [the] pack of noodles.

By using the camera on her smartphone to photograph items and then zoom in on their ingredients with the phone's in-built accessibility software, Jamie was able to conceal her VI while shopping. Enacting this concealment of their VI when performing such everyday tasks was important in many settings to participants, such as Frankie and Jamie,

as it enabled them to participate in the setting without being subject to others' staring and stigmatizing presumptions based on their VI (discussed in Chapter 7). This helped them avoid direct impacts upon their feelings of inclusion and acceptance in these settings.

Advocacy also represented an equally versatile tool for both concealment and disclosure, with the participants' discretionary use of their own voices influencing how others perceived them. Participants commonly employed advocacy as a straightforward form of disclosure through which they could make their VI known and inform individuals of the particular accommodations or supports that they required. For example, moving house a lot during his childhood and adolescence, Jay engaged in self-advocacy to deliberately disclosed his VI to each school so as to ensure they permitted his exemption from sports classes, due to his concerns about his physical safety: "I got in the habit of telling schools after [I was hit in the face with a dodge ball] and luckily most of them sort of said 'Yeah you can avoid sport if you want to'". Many participants also described instrumentally using humour to manage the disclosure of their VI to sighted others. Making "sight jokes" (Jay) not only put the other person at ease regarding their VI, but could also still serve to educate them, as Drew explained:

Like with the "blind leading the blind" [joke]. I do still lead people [with VI despite having VI myself] ... Like it does teach [sighted people] that we can still do stuff even though we're joking about it. (Drew)

However, participants also engaged in a more nuanced form of self-advocacy in which they asked for assistance from others but did so in a way that allowed them to conceal, in full or in part, their VI. For example, Val recounted how when out at restaurants or food courts he would negotiate around his inability to read the printed menu by asking staff what it contained, but "trying to make it sound like you're just trying to have a conversation". In so doing, Val emphasized that you are "sort of disguising what your

vision limitation is to an extent”. These decisions around concealment and disclosure were complicated by the particular type and severity of VI as has been previously discussed in literature regarding disability and ‘passing’. Since its initial popularization in discussions of stigma by Goffman (1963), the concept of ‘passing’ – the act of concealing stigmatized characteristics that one possesses in social settings to avoid the negative judgments and reactions of others – has received considerable attention in academic literature regarding VI and disability more generally (Gill, 2001; Lingsom, 2008; Sacks, 2010; Tuttle & Tuttle, 2004; Worth, 2013b). People whose disabilities leave no outwardly visible signifier, and that do not necessitate the constant use of visible technologies or equipment (e.g. wheelchairs), can choose to pass as normal as did Uttermohlen (1997) and her sister as youth with VI, while those whose conditions are visible do not have this option. As such, one view asserted in this literature is that “nonvisible or partially apparent impairments are often associated with additional layers of social tension” (Gill, 2001, p. 361). This refers to greater misunderstanding and scepticism among the non-disabled population about less visible disabilities, and the resultant near-constant decision-making between disclosure and passing for people with such invisible conditions (Lingsom, 2008). People with more apparent impairments are (implicitly) assumed not to engage in an equivalent level of social self-monitoring. Partly consistent with this previous literature on the concept of passing, the current participants with greater remaining vision often had more options as to whether to disclose their VI or to conceal it, like Jamie’s fake-texting or Frankie’s decision not to use her cane when it did not suit her. However, the accounts of the current participants challenged the idea that people with visible impairments do not engage in similar forms of social navigation. The participants with more severe VI, such as Alex, asserted that for them it was more “acceptable to be different” from sighted people than for other participants with less

visible VI, as evidenced by the greater ease that they encountered in soliciting help from sighted strangers. Alex articulated that “no-one’s going to look at me twice [because] they’re going to see me walking with a cane [and so they will go] ‘Okay, she’s blind, she needs help’”. This acceptability was important as the observable difference of these participants was less optional due to their need to use visible assistive equipment, such as canes, and because, even if they chose not to use such equipment, having “a lot less sight, it’s going to become way more apparent [as] I’m tripping over or missing something right in front of me” (Morgan). However, the ready acceptance that sighted others showed toward their VI did not mean that these participants with visible VI had to engage in reduced social navigation. Although they could not conceal their VI itself, this acceptability, instead, served as the focal point requiring them to perform different forms of concealment and disclosure regarding their VI.

Sighted others were readier to provide assistance to these participants as they conformed with dominant cultural images of blind people (i.e. as carrying canes), and thus it was associated beliefs about the helplessness and incapability of people with VI that justified the participants’ requests for help (Butler, 1998; Tuttle & Tuttle, 2004; Worth, 2013b). Thus, the acceptability of their difference also meant increased encounters with stigmatizing assumptions from others that had direct implications for how they felt about themselves and their lives, such as directly reduced feelings of success due to repeated exposure to others’ doubts as described in Chapter 8. Therefore, as opposed to the decisions around ‘passing’ of those with less visible VI, participants with more apparent impairments described the more frequent need to choose between disclosing their personal reality of VI through advocacy and thus “attempt[ing] to correct the misapprehension [of others]” (Morgan), or deliberately concealing this and exhibiting their VI in a way that aligned with dominant beliefs about their helplessness. Again,

participants emphasized that the choice that they made about which image of VI to perform was informed by their reflection on their particular situation and which portrayal would serve them better in attaining what they wanted or needed from it. For instance, Alex recounted situations in which, consciously reflecting upon how sighted others respond to her VI, she would instrumentally accentuate her VI through the use of her cane in order to affect social situations in line with her own interests:

[I went to] a demonstration to do with gold. It was about melting it down and making a bar of gold. And I knew that if I sat there with my cane out that I would get to touch [the gold]. So, in those respects, I embrace my blindness [because I am] using it to try and get what other people are getting out of something.

Reflecting on dominant social imperatives to help people with VI due to the dominant social perception of their incapability (Butler, 1998; Tuttle & Tuttle, 2004; Worth, 2013b), Alex intentionally influenced the exhibitors by signposting her VI – by “playing the disabled role” (Porter, 2000, p. 41) – to gain the equivalent inclusion in the demonstration to her sighted peers that she wanted.

In addition to the severity of their VI, other factors were also influential in the participants’ deliberations about how to manage their concealment or disclosures regarding their VI through the use of their available collection of strategies and resources. This included factors that contributed to the value they as an individual placed upon privacy or social conservatism (i.e. a value located in their sense of identity), with, for instance, their family’s attitude regarding openness proving especially important for some participants: “My mum... got with a good guy who was absolutely shameless [and] just being around someone like that [you go] “It’s not that embarrassing... that you’re blind” (Jay). Meanwhile, specific characteristics of the social context were also considered. For example, geography played a significant role in whether participants felt their VI should

be concealed. Because of the nature of smaller town life, Jamie felt that the concealment of her VI was more important as people were a lot more presumptions in intervening in others' lives; in contrast, the anonymity afforded by a larger city during her temporary move away from home made concealment less important:

In [a larger city] you can be in the supermarket trying to read the ingredients... like up to your face... But if I did that back home [where people] know you [then] I would have people... giving me strange looks. (Jamie)

The participants variable use of (assistive) devices or the strategy of advocacy to make concealments or disclosures regarding their VI demonstrated the key role that self-reflection played in the process of managing and moving on from difficulties. In short, it allowed them to monitor their situation and how they were travelling to determine how they should respond to a difficulty in order to best promote or protect the elements of their life that contributed to their positive lived experience. In discussing his own decision-making regarding when he would pass (in his words "be the same") or disclose his VI ("be different"), Harper explained:

A different day might call for different situations and different needs... I mean, ultimately, I'd love to feel confident asking for help anytime I need it... but a lot of [whether I do ask has] to do with, like, you know, how much energy I have or all these other things we were talking about... You know, if I'm feeling really disconnected from people, I might start feeling down and I might start feeling like I don't want to risk alienation, so I'm just going to continue to be the same. But, if I'm feeling really quite okay [socially] then I might feel empowered to ask for what I want and be okay with being different... in that situation.

As indicated here by Harper, deliberating over these decisions was important as, in many, the way participants chose to respond to the difficulties associated with VI had

contrasting implications for distinct but equally valuable elements of their life (e.g. their subjective energy levels, social connections). Managing the difficulty associated with living with VI – for example, the difficulty in ordering from an inaccessible restaurant menu when out with people – by passing allowed Harper to prioritize smoother interactions with others and his feeling of social connection on the days he felt they were under threat. Meanwhile, on other days, he opted to disclose his VI to receive the necessary aids and supports to optimize his participation, which in turn reduced the impact of participating on his energy levels. Self-reflection therefore enabled Harper and the other participants to make and monitor trade-offs between important elements of their life in managing and moving on from difficulties by the use of the strategies and resources, so that they could maintain their personal sense that their life was in balance.

9.3.2 Supporting self-reflection through services.

Several supports for the valuable process of self-reflection that could be provided within vision rehabilitation or educational settings were identified by the participants. In addition to role models with VI (as Elliot described at the end of section 9.2 above), discussing their individual situation with another person also facilitated participants' evaluations of their identity, skills and circumstances. Family and friends – especially with VI – offered different perspectives on issues the youth faced: “My friends... will always have to rein me in and... make me rethink something that I've done... because they have a different idea” (Jamie). Some participants also highlighted some service providers as offering similar reflexive discussion, but stressed that more need to be aware of this potential role:

I don't think service providers are really conscious... that I can choose to make my difference obvious or not obvious, depending on when it suits me. [They can be] a bit like... ‘Why don't you do this when it could help you?’ [It is important]

understanding... and actually being able to have those conversations and encourage kids to manage it constructively. (Alex)

Alex stressed that staff providing VI services needed not just to see their role as providing instruction and thus pushing their young clients to utilize various strategies or resources to manage the difficulties of living with VI in a straightforward functional sense. Rather, they need to be aware of the complexity of the participants' lives and be willing to engage with the participants in regard to how they may variably use available strategies and resources depending upon the social context and the element of their life that is their priority at the time. Finally, alongside these conversations, regular productive outlets (e.g. a diary, music-writing) were also identified as encouraging their self-reflection, while some participants found strategies for activities enabling present-mindedness especially useful at promoting in-moment self-monitoring. For instance, Jamie employed the breathing techniques from her yoga in "chaotic situations" in order to stay focused on what she was doing: "This morning I went into work... and it was just madness [so I was] focusing on... like writing an order, making the coffee, taking it out [and] just getting like a rhythm going and sort of breathing with my rhythm [as it helps to] have something centring you".

9.4 Conclusion: The Need for Psychologically-focused Services

The participants' process of managing and moving on from practical and psychosocial VI-related difficulties allowed them to maintain a general experience of wellbeing. They did so by putting such difficulties behind them and thus sustaining their personal sense of balance between the elements of their life that they considered important. Flexibility in their response to such difficulties across situations was key to this process. This flexibility was supported by their possession of a set of practically-focused (e.g. work-arounds,

advocacy) and psychologically-focused (e.g. outlets, escapes) strategies that drew upon many material and social resources, including several well-documented within research regarding VI services for younger populations (e.g. assistive technologies, peer group programs; Chavda et al., 2014; Lewis et al., 2014). In particular, the participants' accounts echoed previous findings suggesting the psychological and broader QoL benefits of recreation programs for young people with VI, including as a means of bolstering social support (Jessup et al., 2010; Perkins et al., 2013; Qasim et al., 2014). Furthermore, engaging in self-reflection – on their general values, traits and capacities (within their sense of identity), on their priorities in any particular situation in which they were confronted by difficulty, and on the contextual specifics of that situation – informed this process. It enabled participants to manage their difficulties with their VI, through their flexible use of strategies and resources in line with their personal values and current priorities. These insights fit within larger discussions around living with disability (Albrecht & Devlieger, 1999; Gill, 2001; Lingsom, 2008), including literature – emerging over the last two decades – problematizing the priority disability studies has given to structural elements of disablism to the exclusion of its psycho-emotional impacts (Prilleltensky, 2009; C. Thomas, 2007)

The participants' maintenance of their wellbeing by managing and moving on from difficulties also aligned with recent theoretical discussion in psychology around the concepts of coping and emotion regulation (Bonanno & Burton, 2013). In particular, the resonance of the participants' use of both practically-focused and psychologically-focused strategies and resources in responding to difficulties with the well-established dichotomy of problem- and emotion-focused coping strategies is significant (Carver & Connor-Smith, 2010; Folkman & Moskowitz, 2004). Recent literature has identified an entrenched tendency in theory and research to position problem-focused strategies as

inherently more adaptive than emotion-focused ones (Bonanno & Burton, 2013). This view has been challenged with evidence demonstrating that the effectiveness of problem-focused and emotion-focused coping strategies is dependent on the particular context and thus they represent complementary approaches as originally theorized (Folkman, 1984; Lazarus, 1966). The current participants, similarly, positioned both their identified practically-focused and psychologically-focused strategies as important in responding to the difficulties that confronted them. Furthermore, the current participants' accounts also endorsed Bonanno and Burton's (2013) proposition that successful coping or emotion regulation should be understood as a process of "regulatory flexibility" (p. 591), rather than being represented in terms of certain types of strategies. That is to say, adaptive coping or emotion regulation entails a cyclical process in which the individual enacts particular strategies, from within a personal repertoire, that match the context in which they are facing the stressful or emotion-provoking event because of their consideration and monitoring of the situation (Bonanno & Burton, 2013). This notion of regulatory flexibility was foundational in the current participants' maintenance of their wellbeing, as they too stressed the integral value of a set of strategies and resources which, guided by their own self-reflection, they used to respond to difficulties

As with those presented in the preceding results chapters, the discussions of the participants regarding the maintenance of what they considered important to a good life despite VI-related difficulties presented in this chapter have implications for VI-related services provided to youth. These are discussed in the next and final chapter of my thesis, in which I outline the overall conceptualization of what it meant to 'live well with VI' for my participants and discuss its implications for VI service provision to youth with VI.

Chapter 10

Fresh eyes on ‘living well with vision impairment’

In contemporary worlds, the term wellbeing is typically understood to refer to the extent to which a person’s life is characterized by positive experiences and an enriched quality, and not just the absence of negative or detracting experiences and factors (Ben-Arieh et al., 2014; Manderson, 2005; R. M. Ryan & Deci, 2001; Wallander & Koot, 2016).

However, the exact image of a life that satisfies this vague definition inevitably differs across cultures, groups of people, and individuals. This thesis presents my collaborative explorations of the concept of wellbeing with 21 youth with VI with the goal of contributing to the development of the theoretical underpinnings of VI service provision in this population. This was done as a response to research highlighting their inconsistent effectiveness at promoting psychological and QoL outcomes (Binns et al., 2012; Rees et al., 2010). This study was specifically designed to achieve the following objectives:

1. To understand how youth with VI conceptualize wellbeing;
2. To outline the indicators of wellbeing considered by youth with VI as the most salient for its measurement;
3. To describe specific factors and their interactions involved in the relationship between their VI and their wellbeing as they conceptualize it; and,
4. To identify resources and strategies they have found useful in dealing with the effects of their VI on their wellbeing.

To achieve these objectives, I examined what young people with VI perceived to be the elements of their lives that they felt were important and enriched its quality, and thus could serve as useful indicators, of wellbeing for them. It also involved exploration

of the significant factors that they identified as influential in the interaction of their VI with these life elements, including the positive strategies and resources they identified for the promotion of their positive experiences. Bringing together participants' emergent ideas discussed in the preceding chapters, in this final chapter I present an overview of the image of 'living well with VI' that I identified from the youths' discussions and explicate the value of the insights this provides for approaching wellbeing among youth in the VI service provision context. First, I present a summary of the thematic conceptualization of wellbeing developed from the participants' accounts, before I conclude this thesis by outlining the specific implications for VI service provision, engaging with previous literature both regarding VI service provision and the larger concepts of wellbeing and disability.

10.1 The Ongoing Process of 'Living Well with Vision Impairment'

For my study participants, wellbeing was an ongoing process of maintaining a sense of personal balance among various important life elements across four key thematic domains that they felt all people valued – physical health, social connection, capability and control – but which they valued, pursued and experienced somewhat differently due to the influence of their VIs and other factors. This conceptualization of wellbeing directly responded to the first objective of my thesis: to understand how youth with VI conceptualize wellbeing. However, this definition contains many aspects. Below, I provide an overview of these aspects.

10.1.1 The four important life domains

Participants in the current study discussed their lives, and the assessments of their quality, as multifaceted. This multidimensionality reflects prominent theoretical understandings of

the concepts of wellbeing and QoL (Ben-Arieh et al., 2014; R. M. Ryan & Deci, 2001; Schalock, 2004; Wallander & Koot, 2016). In particular, the valuable elements of life identified by the participants centred around four life domains: physical health, social connection, capability, and control. Their understanding of *physical health* (Chapter 6) was broad, emphasizing the importance of maintaining both the biophysiological functioning and structural integrity of their body, as well as subjective feelings of energy, through a combination of physical activity and relaxation. Desirable *social connection* (Chapter 7) entailed trusting, caring, accepting and humorous relationships with others, both in more intimate one-on-one bonds and within larger communities. They especially highlighted the valuable social resources they gained through these relationships, in line with work around the concept of social capital (Kawachi et al., 2008; V. Morrow, 1999). Finally, participants considered it inherently valuable and thus important to their evaluations of how they were travelling to succeed in endeavours across various arenas in their life that they considered important (e.g. school, work, sports), in order to experience feelings of accomplishment and, thus, evidence of their *capability* (Chapter 8). Central to such experiences of success was the participants' exertion of their own choice and self-direction, primarily discussed in terms of their own practical independence, rather than passive reliance on others (*control*). The elements identified within each of these domains represented important indicators that participants felt needed to be considered when evaluating how they were going, thus contributing to the fulfilment of my second thesis objective to outline the indicators that the youth emphasized as important for the measurement of their wellbeing. In the latter part of this chapter, I engage with the fit of these domains with existing models of wellbeing or QoL (Bourke & Geldens, 2007; Fattore et al., 2009; Schalock, 2004).

10.1.2 Living with vision impairment and maintaining wellbeing

In their discussions captured within these four thematic life domains, participants also identified difficulties that living with VI posed to their attainment and maintenance of the valuable life elements related to each. These difficulties were not discussed as an inevitable consequence of VI. Rather, difficulties were produced by multiple factors, resonating with relational understandings of disability as arising from the complicated interaction between a person's bodily impairment and their physical and social environment (Prilleltensky, 2009; Shakespeare, 2006; C. Thomas, 2007). Features of material, institutional and social environments acted as barriers in the efforts to maintain the elements of life that they prized. This occurred alongside direct impairment effects that participants acknowledged as resulting from their VI (C. Thomas, 1999, 2007). Partly addressing my third thesis objective to identify influential factors involved in the relationship between the participants' VI and wellbeing, these barriers and impairment effects represented one major set of important factors.

Two overlapping forms of difficulty arose through the combined effect of these environmental barriers and impairment effects. First, *practical difficulties* arose, where participants' performances of particular tasks, or participation in certain activities or settings was negatively impacted. This in turn led them to feel that one (or more) important elements of their life was under threat. For example, participants' engagement in physical activity and thus promotion of their physical fitness was impacted by multiple barriers as evidenced in Chapter 6. This included their exclusion from sporting activities by their peers, or by themselves due to concerns about their peers' reactions to their VI, reduced physical skills and capacity to participate in sighted sports due to their VI, and the existence of fewer accessible physical activity options. The presence of multiple barriers to physical activity participation is consistent with previous findings among

youth with VI and other disabilities (Augestad & Jiang, 2015; Haegele & Porretta, 2015; Shields et al., 2012).

Participants also encountered *psychosocial difficulties* where they felt that one (or more) of the elements that they felt enriched the quality of their life was diminished or under threat as a result of the negative reactions of sighted others to their VI. These others included members of the broader community, teachers, friends, other peers and family. Others' responses frequently conveyed dominant misguided and demeaning perceptions of VI (Butler, 1998; Tuttle & Tuttle, 2004; Worth, 2013b), which in turn negatively impacted upon participants' self-evaluations with regard to many of the valuable life elements they identified. A pervasive example of such a psychosocial difficulty was the impact of overt expressions or implied assumptions by others regarding the participants' helplessness resultant from their VI which impacted on their own senses of independence and thus success at school, at work or in their hobbies. Such social 'othering' effects have been reported in other research with youth with VI (Hess, 2011; Rosenblum, 2000; Tadic et al., 2014; Worth, 2013b). The everyday experience of such assumptions not only produced powerful feelings of indignation and anger among participants, but also led many to doubt their own capacities and downplay some of their achievements.

These two overlapping forms of difficulty resonated strongly with the two facets of disablism (Goodley, 2011, 2014; Shakespeare, 2006; C. Thomas, 2007). Structural disablism refers to the ways in which material, institutional, economic and social forces act to constrain people with disabilities from performing certain tasks and social roles, including participation in particular activities. Such structural disablism directly shaped the practical difficulties faced by participants. Associated with this, psycho-emotional disablism is the diminishment of participants' emotional state and sense of self through constant and consistent exposure to disparaging cultural beliefs and practices regarding

disability. Such beliefs are expressed through interactions with others and are represented in the material and social structures of society. Psycho-emotional disablism refers directly to the psychosocial difficulties – and emotional challenges – that confronted participants. These two forms of disablism – which represent the practical and psychosocial difficulties encountered by participants – were manifested uniquely with respect to the valuable elements clustered within each of the important life domains. Some of these manifestations are summarized in Table 10.1.

Despite encountering practical and psychosocial difficulties, however, participants felt that their lives were going well and were of a high quality. This is in line with previous findings among youth with VI and people with disabilities more generally (Albrecht & Devlieger, 1999; Kef, 2002; Pinqart & Pfeiffer, 2012b; Prilleltensky, 2009). Participants did not deny the significance of the various VI-related difficulties; rather, they described a process of *managing and moving on from these difficulties*. How they achieved this through performing certain strategies and by drawing upon several resources, in order to maintain the positivity of their lived experience, was elucidated in Chapter 9. This directly addressed objective 4 for my thesis: to described strategies and resources the participants found useful in handling the impacts of living with VI.

Table 10.1

Major VI-related Difficulties Encountered by Participants in Each Life Domain by Type

Domain(s)	Difficulty Type	Difficulty They Encountered
<i>Physical health</i>		
	Practical	Ergonomic issues from contorting body due to reduced vision in order to visually use non-adapted learning materials (e.g. school computers without adaptive software)
	Practical	Difficulty in navigating material environments with reduced vision producing pain and injury (e.g. bumping into obstacles, tripping over)
	Both	Fatigue from ocular strain, and effort needed to navigate material, institutional and social barriers
	Practical	Reduced physical activity due to practical skill limitations and fewer accessible activity options
	Psychosocial	Persistent feeling of threat to safety from physical victimization by peers at school due to VI
<i>Social connection</i>		
	Practical	Difficulty in travelling to social events due to inability to drive and limitations of public transport
	Practical	Difficulty in attending/participating in social events due to interaction between VI and features of event location (e.g. dim-lighting of nightclubs)
	Practical	Difficulty in navigating sighted norms of communication (e.g. gestures) due to reduced vision
	Both	Exclusion from social events by peers due to stigma attached to VI
	Both	Target of verbal and physical bullying from peers at school due to VI
	Psychosocial	Distrustful of others due to victimization from peers at school due to VI
<i>Capability and Control</i>		
	Practical	Difficulty in independently performing participating in activities/settings when pursuing endeavours (e.g. study, work), due to reduced sight and material, institutional and social barriers
	Practical	Restricted opportunities to pursue endeavours due to material, institutional and social barriers
	Psychosocial	Negative self-evaluations of own capacities following frequent assumption of their incapability by others

Note: VI = Vision Impairment.

Adaptability was key to their articulated process. Participants enacted differing strategies in order to respond to the specific difficulties of a given situation. Having a broad set of strategies and resources was identified as important so as not to continuously rely on one strategy. Such findings resonate with recent literature in psychology acknowledging the importance of a person's repertoire of strategies in enabling their flexibility in managing stress and their emotions (Bonanno & Burton, 2013). In particular, matching the two types of difficulty they faced (practical and psychosocial), participants highlighted their usage of both practically-focused and psychologically-focused strategies. Practically-focused strategies enabled the participants' performance of tasks or participation in an activity or setting despite practical difficulties. This included both finding alternative ways to perform the tasks or participate (e.g. using a laptop with adaptive software to complete their schoolwork), and advocacy or self-assertion in order to request others to either amend prohibiting features of the environment or change their own restrictive reactions to the participants' VI. Meanwhile, psychologically-focused strategies sought to combat negative feelings and thoughts, most frequently arising in response to psychosocial difficulties²⁶. Finding outlets and escapes through which to express or seek respite from these negative feelings or thoughts were common examples, alongside the adoption of helpful mindsets of acceptance of and resilience to difficulties.

A range of resources supported the participants' use of these strategies. This included many recognized in existing literature regarding VI service provision to young people (Chavda et al., 2014; Lewis et al., 2014): adaptive technologies/equipment (e.g. white canes): formal instruction in certain skillsets (e.g. mobility training): and, larger systems (e.g. public transport). Furthermore, participants also emphasized the resources

²⁶ Although not as frequently discussed, participants also used such psychologically-focused strategies to manage negative feelings and thoughts that arose due to their confrontation with particularly significant practical difficulties. These negative feelings and thoughts represented a form of indirect psycho-emotional disablism (Reeve, 2012).

they gained through their relationships with others. Family, friends and service providers acted as role models from which to develop skills (e.g. advocacy). They also directly supported the participants' enactment of practically-focused and psychologically-focused strategies through the provision of support. This occurred in the form of their own material intervention to resolve practical difficulties, and the provision of information, advice and by serving as an outlet for or escape from the negative feelings and thoughts accompanying the difficulties the participants encountered. This, echoed the types of social support found to be valuable in previous research among both youth with VI and other populations (Chang, 1998; Chang & Schaller, 2000; Feeney & Collins, 2015).

Self-reflection was a fundamental strategy in the participants' process of managing and moving on from difficulties. Considering their own values, capacities, and priorities, their current sense of how they were travelling and the particular situation in which they were being confronted by difficulties enabled participants to determine how to respond. This was in line with the recognized importance of similar processes of appraisal in theories of coping or self-regulation (Bonanno & Burton, 2013; Carver & Connor-Smith, 2010). In short, having a range of strategies and resources afforded participants a latent adaptability which they decided how to mobilize through a process of self-reflection in response to presenting difficulties.

The participants used this process of managing and moving on from VI-related difficulties in order to maintain their overall sense that their life was going well. This represented a central aspect of the participants' conceptualizations of wellbeing, and was informed by experiences of such difficulties, and their expectations that they would confront similar difficulties in the future. This understanding was captured in particular by the three overarching themes that framed their accounts: a personal sense of life in balance; a sense of identity; and, situated sameness.

10.1.3 Wellbeing and balance

Wellbeing as *a personal sense of life in balance* was an omnipresent theme. The concept of balance is not uncommon to literature regarding wellbeing. The image of a good life as balancing out the factors that are perceived to put a young person at risk of ill-health or disadvantage, with those associated with good health and success pervades literature regarding youth wellbeing (Cahill, 2015). Meanwhile, Dodge et al. (2012) defined wellbeing as a state characterized by balance between life's demands and one's capacities and resources for meeting these demands. Ideas of balance, however, ran through the current participants' discussions in a different way, and was fundamental to understanding both their experiences of wellbeing (i.e. as an outcome) and the process by which this experience was obtained.

Having a personal sense of balance between the valuable elements of life (across the four key domains) was central to participants' notions of their lives going well. The appearance of this balance was distinct for each participant as they differentially prioritized particular elements: while they often gave one primacy (e.g. their friendships), all recognized the need to seek to maintain some engagement in or attainment of several others (e.g. exercise, down time and success in their study). For example, success in his career held considerable primacy to Lee (Chapter 5), and he found it essential to exhibit competence and be seen as a contributor at his workplace. Nonetheless, he enumerated many benefits of his relationships with others. He noted the practical resources he gained from his housemates, as well as the pleasures provided by shared humour and laughter (Chapter 7). This was in line with the concept of bonding social capital because it emphasised the instrumental benefits of connections within community relationships (Kawachi et al., 2008; V. Morrow, 1999).

Maintaining this personal balance in their pursuit and thus experience of the elements they considered important in their lives was crucial because these elements were interconnected (discussed in Chapter 5). For example, participation in physical activity programs not only supported participants' fitness and subjective energy levels, but also promoted their social relationships and provided them with an avenue through which to set and successfully achieve goals. Furthermore, attending these programs was supported by independent mobility (a central subtheme of control) or utilization of accessing transport help from others (social capital arising from social connection). Conversely, detractions from valuable feature in their life often produced threats to others. In short, participants' discussions suggested that maintaining a sense of personal balance between the various elements of life that they valued then allowed them to establish an overall positive spiral of wellbeing, in which attaining one element would support attainment of others and so on. This image of balance as enabling a self-perpetuating cycle of wellbeing fits with similar ideas of the circularity of health and wellbeing found in previous research among people with and without disabilities. For example, Helseth and Misvær (2010) found that non-disabled youth described their experience of QoL as "a positive cycle" in which they were "living life in balance" (p. 1456). This contrasts the recursive cascades of chronic conditions, in which health compounds with social adversity to enhance suffering and undermine wellbeing (Manderson & Warren, 2016).

The thematic image of this positive cycle of wellbeing, supported by this personal balance, was also evident in the participants' encounters with the practical and psychosocial difficulties associated with VI described above. As discussed in Chapter 9, maintaining a sense of balance across the important elements of their life provided participants with a buffer when confronted with difficulties. The participants' accounts suggested that they experienced their life as positive overall due to the sense of having

their life in balance. Thus, even when they encountered adversity related to one (or more) valuable element in their life, this balance allowed them to weather these short moments of difficulty without experiencing a diminishing their lived experience.

Given its fundamental importance to their wellbeing, participants were active in the maintenance of their personal sense of balance across their life. They described a continual, self-motivated and often routinized process of balancing their pursuit and sustenance of what they considered salient. The process of managing and moving on from (VI-related) difficulties articulated by participants represented a key aspect of this overall deliberate effort to maintain their sense of balance. While momentary difficulties could be weathered, if not managed and moved on from, lingering difficulties unsettled a participant's overall sense of balance, and thus led them to look upon how they were travelling more negatively. Therefore, by flexibly drawing upon the strategies and resources summarized in the preceding subsection, participants sought to put such difficulties behind them.

Furthermore, participants used self-reflection to examine the difficulties they encountered with regard to the aspects of their lives that they valued, and the balance between these elements, in order to prioritize how to respond. In perceiving their wellbeing as an ongoing process, participants recognized that they did not neatly encounter difficulties one at a time, or only at times when they felt that their life was in balance and thus were experiencing a sense of wellbeing. For example, as discussed in Chapter 7, some participants simultaneously reported peer victimization at school (a barrier to their potential friendships and inclusion at school) and practical difficulties due to inaccessible classrooms, material or teaching practices (a barrier to their independent and successful participation at school). How the participants then chose to manage this depended on their own reflection on both the life element they prioritized more generally,

but also their current sense of balance across these elements. Where a participant prioritized their sense of social connection or felt particularly alienated at particular times, they would choose to forego supports that could enable them to more independently and successfully participate in order to not risk further diminishment of their social connection by standing out. Self-reflection on their process of maintaining a sense of balance in their life, therefore, often resulted in compromises in the attainment and maintenance of the various valuable life elements.

As suggested by these ideas of ‘personal balance’ and ‘self-reflection’, a second overarching theme that framed the participants’ discussions of wellbeing was *a sense of identity*, which I summarize in the next subsection.

10.1.4 Knowing the journey

Heterogeneity characterized participants both in terms of their VI and other personal characteristics or circumstances. Their VIs were diverse in terms of cause, history, and severity. Several non-vision-related factors emerged as sources of differences between them: age; family history; rural/urban residence or upbringing; SES; religious beliefs; and, other health conditions. Moreover, these varying vision- and non-vision-related factors influenced and shaped participants’ experiences of the important elements of their life individually, and through effects arising out of their interactions. Concurrent medical conditions, for example, generated additional barriers to participants living the lives they desired: for example, greater experiences of pain and difficulty in participating in physical activity. Meanwhile, growing up and living in regional small towns – as opposed to more urban environments – shaped how the participants’ understood what it meant for them to both be successful in their lives, as well as how they involved themselves in larger communities.

The influences of these factors extended beyond their significance in the immediate situation. As elaborated in Chapter 5, through their ongoing intersections these factors produced a unique history of experiences for each participant from which they got a sense of who they were and how they fit within the social world around them. Thus, over time, these factors informed (and reformed) the participants' senses of identity: their understanding of their traits, values, competencies, social roles and memberships, and desirable future lives (referred to as self-concept in broader psychological theory; Oyserman et al., 2012; Tuttle & Tuttle, 2004). This fit with previous depictions of people's senses of self as grounded in their particular circumstances, including their interactions with other people and groups (S. Atkinson, 2013; Stets & Burke, 2000).

Living in line with this larger sense of who they were was central to participants' understandings of living a good life. This resonated with well-established ideas regarding self-congruence, self-determined action and self-discrepancy (Higgins, 1987; R. M. Ryan & Deci, 2000; R. M. Ryan et al., 2008). The participants drew upon their senses of self in articulating what they perceived to be a desirable balance among the many salient elements of their lives (as discussed above), as well as what it looked like for them to have each of these important elements. Many valuable activities, endeavours or social settings were prized because they facilitated self-expression, self-development or self-fulfilment, captured in Peyton's and Pat's drive to play sports due to their images of themselves as sportsmen (on page 253 in Chapter 8). Meanwhile, the individuals and groups with which the participants felt connected – such as Drew's sense of belonging among her children's services classmates due to their shared passion (mentioned in Chapter 7 on page 225) – and the goals and standards upon which they evaluated their performance in their activities and endeavours – like Jules' commitment to standing up

for social justice due to the centrality of his religion to his identity (discussed in Chapter 8 on page 252) – were both rooted in their senses of who they were as well.

This interrelationship of their wellbeing with their broader circumstances, histories and resultant senses of identity entailed that the maintenance or promotion of their wellbeing required greater knowledge and consideration of these wider-reaching factors. In short, understanding participants' individual life journeys through their own unique set of factors and experiences was important to understanding their wellbeing.

10.1.5 Being same but different

Overlapping with these themes of balance and identity, the themes of sameness and difference were also prominent in the participants' accounts of what was important in their lives when they felt they were going well. As outlined in Chapter 5, participants stressed that the elements they felt contributed to the positiveness of their lived experiences were not elements uniquely valuable to youth with VI. Namely, they underlined that all people desired physical health, social connection and wanted to feel in control and capable in their pursuits. This emphasis on the 'sameness' of these valuable elements aligned with similar findings that other youth with VI or other disabilities wish to be considered as "ordinary" (Asbjørnslett, Helseth, & Engelsrud, 2014, p. 369) rather than identified as different/impaired (Priestley, Corker, & Watson, 1999; Tadic et al., 2014; Watson, 2002; Whitburn, 2014a; Worth, 2013a). Indeed, some semblance existed between participants' understandings of many of their important life elements and those found among sighted populations. For example, sighted youth have been consistently found to value trust, care/support, similarity, and shared humour with their friends in line with the qualities of the participants' valuable close bonds, as described in Chapter 7 (Barber & Schluterman, 2008; Haraldsson et al., 2010; Matheson et al., 2007).

Meanwhile, the central importance participants placed on being able to rely on their own skills and capacities – at least, as an ideal – to be in control during and fruitful in their participation in at school, work or in their pastimes (capability) as discussed in Chapter 8, aligned with the dominance of practical independence in (Western) cultural understandings of autonomy and success (Bell & Menec, 2015; Cardol et al., 2002; C. Thomas, 2007).

However, participants' emphasis on this sameness of the elements of life that they valued came into tension with their further elaborations regarding their pursuit and experience of these elements. Their discussions highlighted distinct features of their own understandings and experiences of these elements associated with their VI. Living with VI – and encountering the many associated difficulties described earlier – provided participants with distinct reasons for valuing many of the important elements that they identified in their lives. For example, their distinct appreciation of inclusion and acceptance because of considerable experiences of exclusion discussed in Chapter 7, or the distinct significance of physical activities that involved free and safe movement in space due to their wariness of environmental obstacles in many other settings (discussed in Chapter 6). Participants' lived experiences of VI also shaped what it meant to them to attain or maintain many of the elements they prized. They engaged in non-visual forms of relaxation and adapted forms of physical activity, and sought connection with others with VI largely within accessible social settings (e.g. quieter bars rather than dark and loud nightclubs). Furthermore, despite commonalities of experience, the particular 'differences' associated with their VI for each participant also, in itself, varied as a result of their distinct characteristics of their VIs and the other personal characteristics or circumstances that shaped their experiences – and thus identities – as discussed above.

The participants' discussions, thus, placed their wellbeing in a thematic space of *situated sameness*: they positioned the elements important to the quality of their lives as the *same* as those valuable to most (sighted) people, and yet simultaneously outlined *differences* to an extent in why they valued and how they understood or experienced them, due to the effects of living with VI and other intersecting factors. For example, participants emphasized that they, like most people, wanted to be and feel successful in their endeavours – such as, their study, paid employment or pastimes – and, in particular, generally (and initially) highlighted during their discussions their control over their participation through their practical independence as key to this success. However, discussed in Chapter 8, due to the interactions of inaccessible material settings (e.g. classrooms, information technology environments), the restrictive actions of others (e.g. teacher stubbornness) and impairment-related factors (e.g. ocular strain), the enactment of this independence and attainment of this success was commonly made more difficult for participants. As a result, participants sought to take charge and succeed in their activities and endeavours through different means: namely, their greater use of external supports and systems, with the type of external supports and systems influenced by the cause and history of their VI and intersecting personal circumstances. For instance, participants whose vision loss had occurred at an earlier age or gradually over a longer time period discussed how this often meant that they had been engaging with services for longer and thus had developed a bank of strategies to rely on, while those who lived more regionally had less access to VI services and other local resources (e.g. public transport). Finally, recognizing their own greater use of external supports and systems, and frequent encounters with the dominant idea expressed through others' assumptions that this need for external assistance due to their VIs made them less capable as they were not practically self-sufficient, led some participants to reconsider how they evaluated their

success in their activities and endeavours. Although they still positioned their control as central to their notions of successful participation, several participants offered alternative notions of such control as rooted in their autonomous decision-making within an interdependent network rather than idealistic self-sufficiency. Therefore, similarities to dominant images of agency and success through independence were evident and emphasized in the participants' discussions within the thematic domains of capability and control (Cardol et al., 2002; Gibson et al., 2012; Hammell, 2006), while influences of their lived experiences of VI and their broader personal situations on their perspectives on these important life elements were equally identifiable.

Importantly, consideration of this example highlights how this dialecticism apparent in the participants' accounts of what it meant for them to be living well – this tension between their sameness and difference – was not simply something that happened to them. Participants were not passive objects upon whom the differences of their lived experience and wellbeing were thrust by the interaction of their reduced sight and material, institutional, and social forces. Rather, they were active agents in the production and navigation of their difference. They redefined important elements of their life, such as control in and over their pursuits. Similarly, as was evident in participants' discussions of responding to VI-related difficulties (Chapter 9), they mindfully chose to employ certain strategies and resources in particular ways in response to the difficulties of a given situation in order to manage these difficulties, including for example their intentional concealments or disclosure regarding their VI. Discussed in previous literature as 'passing' as sighted (Sacks, 2010; Tuttle & Tuttle, 2004; Worth, 2013b), in some instances this meant intentionally avoiding the distinct impact of social judgement upon their wellbeing, but frequently this entailed greater practical difficulty to participating in an activity. Similarly, intentionally acting up their VI in line with their knowledge of how

other people generally perceived people with VI – “playing the disabled role” (Porter, 2000, p. 41) – involved a choice which allowed them to participate with greater practical ease yet simultaneously exposed them to the influence and impacts of others’ assumptions.

This nuanced and complex depiction of wellbeing drawn out from the participants’ lived experiences through the themes presented in the preceding section offers useful insights for guiding ongoing development of VI services, which I now discuss.

10.2 Implications for Vision Impairment Services for Young People

The thematic model of wellbeing derived from the participants’ lived experiences represents a direct contribution to the theoretical development of a working theory of living well with VI as a young person. Such insights have utility in informing VI services. Furthermore, the many components of this conceptualization of wellbeing – summarized above – overlapped with and built upon previous work regarding the positive management of VI-related difficulties (Tuttle & Tuttle, 2004). They also resonated with broader theorizing and academic work regarding concepts such as wellbeing, QoL, disability, and adjustment (Prilleltensky, 2009; Reinders, 2014; Schalock et al., 2016; Wallander & Koot, 2016). In this section, I engage with these overlaps and draw out the practical implications that participants’ understandings of wellbeing held for the provision of VI services to youth: commencing by outlining the unique lens through which the emergent themes allow us to reconsider the disability paradox (Albrecht & Devlieger, 1999).

10.2.1 Relocating the disability paradox

Introduced in Chapter 2, the disability paradox is the observation that people with disabilities rate their wellbeing higher than outside observers or ‘objective’ measures (Albrecht & Devlieger, 1999), and can be seen as representing the longstanding conflict between ‘objective’ and subjective theories of wellbeing (Reinders, 2014). Through the lens of situated sameness, this tension between subjective and objective approaches to theorizing and measuring wellbeing can be framed, instead, as the tension between the sameness and difference of the person’s notion of the good life, compared to dominant cultural images of a quality life. That is, measures and conceptions of subjective wellbeing enable people with disabilities to evaluate their life quality through their own distinct criteria, while objective measures hold them to the assumption that the evaluative criteria of wellbeing are the same for everyone (Bickenbach et al., 2014; Parfit, 2003; R. M. Ryan & Deci, 2001; Wallander & Koot, 2016). Yet, the current participants’ discussions around what they value sat wholly on neither side of this theoretical fence.

The participants’ accounts raised challenges to both subjective and objective wellbeing theories. On the one hand, the ‘differences’ they described in why they valued and how they understood and experienced the elements that they considered important in their lives contradicted the fundamental assumptions at the heart of objective theories of wellbeing. That is, that the various valuable elements that contribute to wellbeing are universally conceived and experienced, and that their representation in utilized measures are equally sensitive and applicable across people and contexts (Bowden & Fox-Rushby, 2003; Epstein et al., 2015; Herdman et al., 1997; Warren & Manderson, 2013). However, it would also be inappropriate to completely disregard such notions of universality and similarity given the participants’ own explicit emphasis on the sameness of what they considered important in their life compared to what they felt the general (sighted)

population valued. Thus, it appears that for the current participants neither an objective or subjective approach to understanding and promoting their wellbeing by service providers will capture its full picture.

My participants' accounts suggest that the disability paradox – reinterpreted through the lens of situated sameness – should not just be seen as the observation of paradoxical ratings of the wellbeing of people with disabilities. Rather as has also been argued by Reinders (2014), the disability paradox highlights the inevitability of the tension between the normativity and exceptionality of people with disabilities and is something that needs to be incorporated into and managed as part of our efforts to support their wellbeing. The disability paradox, therefore, must be seen as a paradox of practice as well as of measurement. Services provided to promote the wellbeing of a young person with VI – or, I would argue, a person with any disability more generally – must simultaneously (and somewhat paradoxically) address and manage both the sameness and difference of what is important to them compared to people living without disability. Over the remainder of this chapter, I discuss some recommendations derived from the participants' accounts for how this tension can be managed in the context of VI services for youth.

10.2.2 The 'sameness' and the 'difference' of their important life domains

The current study participants did not outline a new model of wellbeing in the sense that one may envisage a set of novel life domains of value and associated indicators. As stressed in the overarching theme of situated sameness, the four thematic life domains that captured what participants identified as valuable – physical health, social connection, capability and control – do not represent aspects of life uniquely valuable to the participants or even young people with VI as a population. They readily overlapped with

domains commonly included in prominent component models of wellbeing and QoL, including those identified among young people with and without disabilities (Bourke & Geldens, 2007; Fattore et al., 2009; Foley et al., 2012; Honey, Coniglio, & Hancock, 2015; McDougall et al., 2016; Scott et al., 2014). One prominent model of QoL – introduced in Chapter 2 – is the eight domain model proposed by Schalock and Verdugo (Schalock, 2004; Schalock et al., 2016). As illustrated in Figure 10.1, five of these eight domains were directly echoed by the current participants. While the three thematic domains of physical health, capability and control identified in the participants’ discussions had direct equivalents, their understanding of social connection as including both one-on-one relationships and their inclusion in larger communities matched the separate domains of ‘interpersonal relations’ and ‘social inclusion’ in Schalock and Verdugo’s model. Participants acknowledged both individual- and community-level relationships as impactful for wellbeing; however, for many participants the line between these levels seemed too blurry to present them as distinct domains.

**The Participants’
Important Life Domains**

**Schalock’s & Verdugo’s
Eight Domain Model of Quality of Life**

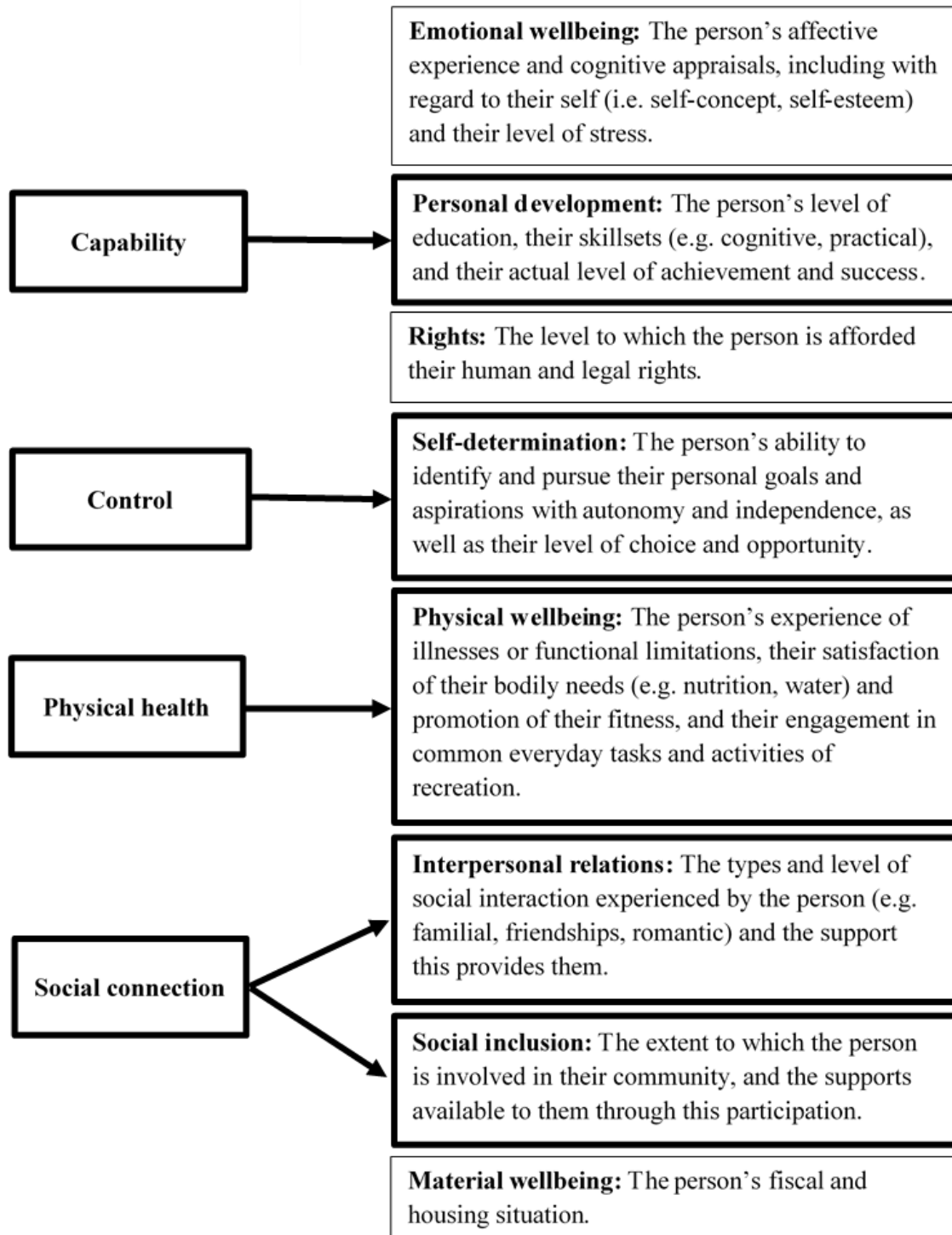


Figure 10.1. The fit of the important life domains identified by the participants with the well-cited eight domain model of quality of life outlined by Schalock and Verdugo (Schalock, 2004; Schalock et al., 2016).

The three domains of ‘emotional wellbeing’, ‘rights’ and ‘material wellbeing’ in Schalock and Verdugo’s model (Schalock, 2004; Schalock et al., 2016) were not explicitly reinforced by the current participants. This is not to say that they were not discussed at all. Indeed, participants discussed the importance of their positive and negative feelings (i.e. their affective experiences) and their own self-evaluations to how they were travelling: elements captured within the domain of ‘emotional wellbeing’ in Schalock and Verdugo’s model. As these elements were present in the participants’ discussions as arising as a result of their level of attainment of the important elements captured within each of the four thematic life domains presented in this thesis, they were not identified as a separate domain themselves. Similarly, captured within Schalock and Verdugo’s ‘material wellbeing’ domain, material resources were important to the current participants, insofar as some spoke about the value of money and their housing situation as means supporting other elements of life that they valued. Money, as discussed in Chapter 8, was perceived as a resource to facilitate their use of taxis for independent mobility (a key subtheme in the domains of control and capability) and thus their attendance of social events or physical activities (the social connection and physical health domains). Meanwhile, the importance of having stable and regular shelter was key to the participants in meeting a basic need of their body (the physical health domain).

The domain of ‘rights’ from Schalock and Verdugo’s model, which captures the level to which a person is afforded their entitlements as a human and under the law (e.g. dignity, respect, citizenship; Schalock, 2004; Schalock et al., 2016) was far less frequently discussed. Only a handful of explicit references to rights were made by older participants (>20 years of age). This discrepancy between the important life domains identified in the current study participants’ discussions and those proposed by Schalock and Verdugo, however, is one that is shared with the domains of wellbeing or QoL that

have been previously identified from the voices of youth with and without disabilities (Bourke & Geldens, 2007; Fattore et al., 2009; Honey et al., 2015; McDougall et al., 2016; Scott et al., 2014). Similar to my research findings, these researchers reported no explicit discussion of individual rights by their young participants. This suggests that when seeking to engage with and support young people directly – as those who provide VI services to them do – discussing the youths’ wellbeing with the youth themselves in terms of individual rights may not be appropriate or relevant.

The consistent emergence of the thematic domains of physical health, social connection, capability and control in the participants’ discussions of what is central to their life when they feel it is going well holds implications for VI services targeting the promotion of wellbeing among youth with VI. Each represents an important domain to consider and explicitly measure when working to promote their wellbeing. To date, most established self-report instruments intended and labelled as QoL measures for younger populations with VI or specific eye conditions, however, predominantly gauge the impact of VI on a young person’s functional performance of everyday visual tasks (Tadic et al., 2013). At best, these ‘QoL’ measures can be perceived as capturing the domain of control – grounded in practical independence – espoused by the current participants. The focus of these measures at this functional level is in line with the personal tragedy model of disability outlined in Chapter 2 (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000), and reflects the tendency for the ‘sameness’ of the wellbeing of youth with VI to be overlooked. The current youth stressed that they value the same broader set of important life elements as do all (sighted) youth, and yet these measures do not capture these more complete sets, instead focusing on those presumed to be impacted by their VI (i.e. their difference). Thus, continued work is required – such as that currently being done by Tadic and colleagues (Rahi et al., 2011) – to develop self-report measures of

wellbeing that directly tap into the broader lived experiences of youth with VI. In particular, such future development work should consider the inclusion of items/indicators of physical health. This thematic domain was identified as key to how the participants perceived the quality of their life and yet is rarely captured by existing QoL instruments for youth with VI (Tadic et al., 2013). VI services intended to promote the wellbeing of youth with VI should also include components directly targeting each domain, as I discuss later.

However, while it is important for this broader set of life domains (and thus the sameness of youths' wellbeing) to be reflected in these measures, the current participants' accounts also (paradoxically) indicated the need for these measures to be developed so as to be sensitive to the VI-specific factors important for each domain. That is, they should include specific indicators tapping into the VI-related experiences that commonly affect the lived quality that young people have in each of the important life domains (i.e. tapping into the difference of living with VI), alongside more general indicators related to these domains. For example, potential sensitive indicator items for a young person with VI's physical health, identified from the current participants' accounts, could include their subjectively-experienced levels of energy and physical safety; each representing a specific element of physical health for which they had distinct appreciation due to the difficulties associated with living with VI (see Table 10.1). Similarly, for their experiences of control and capability, measures should gauge the extent to which youth both feel able to make decisions and mobilize relevant support from others, on their terms, to aid their participation in activities and endeavours, and the extent to which they feel their capacities and successes are recognized by others (rather than undermined). Such indicators would help capture the subjective nuance of experiencing success associated with living with VI. They represent two VI-related factors key to participants'

evaluations of their capacities and accomplishments: their prioritization of “decision autonomy” (Cardol et al., 2002, p. 972) given their recognition of the incompatibility of their external supports with dominant ideals of practical independence, and the psycho-emotional disablism of others’ assumptions about their helplessness due to their VI and their use of external assistance.

The discrepancies between the important life domains identified by the participants and those outlined in Schalock and Verdugo’s model should also be considered in light of participants’ own reflections upon the four life domains in the project’s member-checking phase (Schalock, 2004; Schalock et al., 2016).

10.2.3 The situated nature of their wellbeing

Participants emphasized that physical health, social connection, capability and control represented key life domains important to all of them but were not exhaustive (outlined in Chapter 5). That is, they did not capture *all* life domains of importance to themselves or other youth with VI. This resonates with critiques made of objective theories and approaches to the measurement of wellbeing and QoL: that no list of domains or indicators is ever equally applicable to all people or wholly complete, and thus such proposed lists must be recognized as the imposition of one person’s or group’s conception of wellbeing upon others (Diener et al., 1998; Reinders, 2014; Wallander & Koot, 2016). Participants emphasized that – while the four important life domains offered guiding posts for factors to consider in service provision –VI services looking to promote the wellbeing of youth with VI need to be tailored to each individual young person. In short, they advocated for “person-centeredness” (Leplège et al., 2007, p. 1555) or “client-centred practice” (Gupta & Taff, 2015, p. 244).

Notions of person-centeredness are pervasive in healthcare and rehabilitation, and yet have been critiqued as poorly operationalized (Bright et al., 2012; Gupta & Taff, 2015; Leplège et al., 2007; Levack et al., 2011). However, participants' discussions offered some indication of how such practice could and should look with youth with VI. The situated and relational nature of their wellbeing was evident – such situated and relational conceptions challenge the perceptions of wellbeing as something simply possessed by an individual. Rather, an individual's wellbeing is experienced and maintained in particular situations due to the occurrence of certain interactions between the individual and (social) environment (S. Atkinson, 2013; White, 2017). Participants echoed these ideas in framing their evaluations of how they were travelling in their lives within their senses of identity. The shaping of participants' lived experiences by their personal characteristics and circumstances continuously (re)informed their senses of who they were and how they fit within the (social) world around them, which in turn dictated what it meant for the participants to be living well. They articulated their own unique images of the attainment or maintenance of the valuable elements captured across the four important life domains – e.g. their individual images of success in life of Max and Caelan presented in Chapter 5 over pages 173 and 174 – due to their perception of their own life circumstances, including their VI. In short, participants' understandings of wellbeing were imbued with their considerations of their particular situation and relationships to the world around them. Thus, VI service providers should be actively mindful of young people's own voices regarding their experiences, as well as the consideration of their broader personal characteristics and circumstances in delivering services. The policies and procedures of VI service organizations must also allow service providers longer timeframes to work collaboratively with youth with VI in examining these broader factors. These are consistent with the recommendations made by Bright et al. (2012) to

support the successful enactment of a client-centred approach. To aid this process, subjective indicators of a youth's global sense of wellbeing (e.g. life satisfaction) should be incorporated into the measurement of wellbeing in this population alongside any 'objective' domains that are being objectively or subjectively measured. Such a recommendation is well-established within larger literature regarding the measurement of wellbeing and QoL (Cummins, 2005; Schalock et al., 2016; Wallander & Koot, 2016). Cummins et al. (2005, p. 701) stresses that objective and subjective indicators of QoL should not be simply combined as though "these types of measures have a simple and a linear relationship to one another" because "they do not". Instead, it is asserted that when used in conjunction, subjective and objective approaches to QoL should be carefully considered as distinct but complementary sources of information regarding a person's QoL (Wallander & Koot, 2016). This is the case for VI services. A set of 'objective' domains derived from the contributions of youth with VI themselves (e.g. the four domains identified by the current participants) can prove invaluable in flagging major areas likely to be important for consideration and service provision. Nonetheless, simultaneous consideration of such global subjective indicators of wellbeing may highlight valuable information – regarding their personal prioritization of the objective domains or provide an indication that important features of wellbeing for the young person are being overlooked – useful to tailoring services to meet the needs of each young person. Reductively understanding wellbeing among youth with VI in terms of the four key life domains proposed by the current participants would also lead VI services to inadequately handle much of the complexity encapsulated within participants' overall experiences of their lives when they felt they were going well. Dodge et al. (2012) highlighted the need to develop the definition of wellbeing, and not just the description of its domains and indicators. In offering such a definition of 'living well with VI' within the

overarching themes of a personal sense of life in balance, a sense of identity, and situated sameness, current participants offered especially valuable insights for VI service provision. This builds upon the work of Tuttle and Tuttle (2004) around ‘adjusting with blindness’ introduced in Chapter 2.

10.2.4 The significance of personal balance

Tuttle and Tuttle (2004) outlined a staged model of adjustment through which they propose people with VI maintain a positive self-concept by adjusting to the difficulties of everyday life, including the additional impairment effects and psycho-emotional disablism of VI (Reeve, 2012; C. Thomas, 2007). Implicit within this model was the understanding, therefore, that if living well with VI, a person is successfully adjusting through this process and thus feel they are living their life in accordance with their conception of what they value, of what they wish to achieve and of what they are capable. The central importance of identity – which was the participants’ term for their self-concept – in participants’ conceptions of wellbeing echoed Tuttle and Tuttle (2004). In particular, participants felt their lives were going well when they felt that they had a balance among the multiple important life elements (across the four key domains) that aligned with their personal priorities informed by their sense of who they were. In explicitly emphasizing this balance between these elements, participants extended Tuttle and Tuttle’s (2004) work by introducing greater recognition of the complexity of living in line with one’s self-concept.

Tuttle and Tuttle (2004) acknowledged that people with VI (like all people) place greater or lesser importance within their self-concept on different aspects of their life. Given their primary focus on adjustment, however, their model lends itself to discussing how a person with VI responds to one particular difficulty at a time. In contrast, my participants highlighted that, in many cases, how they chose to respond to a difficulty

presented to one important life element had implications for other elements. Living well with VI for youth represented a process of balancing the elements of their lives that they found valuable – in response to the difficulties they encountered – in line with the personal value they placed upon each element. This was a process that involved trade-offs between elements, rather than a more straightforward adjustment process.

The participants' emphasis on personal balance across their lives aligned with an increasing body of literature complicating largely functional definitions of wellbeing commonly employed in rehabilitation or disability service provision, including VI services (Prilleltensky, 2009; Warren & Manderson, 2013). As I argue in Chapter 2, VI services are underpinned by a working model of wellbeing for youth with VI that is informed by the larger personal tragedy model of disability (M. Oliver, 1990; Prilleltensky, 2009; Swain & French, 2000). These services – and much of the research that surrounds them – approach the wellbeing of youth with VI in terms of the degree to which they overcome the functional difficulties their VI, itself, is perceived to produce, as well as any presumed negative psychological sequelae due to the restrictions placed on their life. Despite the existence of broader conceptualizations of wellbeing and QoL (e.g. Schalock, 2004; Schalock et al., 2016), a young person's VI is understood to inevitably inhibit their attainment of these domains, and thus the degree to which its direct impacts are addressed represent the key indicators of their wellbeing. This bias is specifically represented in the primary focus of VI services on the provision of assistive technologies and skill development for youth with VI in order to overcome the limitations of their VI, and the conflation of indicators of the performance of everyday tasks with the concept of QoL in instruments developed to measure this construct among youth with VI (Lewis et al., 2014; Tadic et al., 2013).

The current participants underlined a distinctly different understanding of what supported their experiences of wellbeing. This was grounded on their acknowledgement that the various elements that they perceived as enriching the quality of their lives were interconnected and mutually-perpetuating. Having a good group of close friends whom they trusted and with whom they could share a laugh (elements within the social connection domain), afforded the participants a place to relax and recuperate their sense of energy (elements within the physical health domain). This energy could then, in turn, be channelled into their own efforts (the domain of control) to overcome difficulties at work or study, thus supporting their experiences of success (the domain of capability). Maintaining a personal balance between these valuable life elements was central to ensuring such positive cycles and that, overall, they had a positive feeling about their life. Even in the face of momentary difficulties, this balance provided participants with a protective buffer and thus allowed them to maintain their wellbeing. This offered an alternative working model of wellbeing for youth with VI to the current personal tragedy model informing VI services in this population. VI services should, thus, target personal balance among such valuable domains of wellbeing when working with youth with VI, as opposed to primarily focusing on the promotion of their functioning and independence on the assumption that this will flow through to broader wellbeing benefits (Binns et al., 2012). The participants' accounts offer suggestions for how this can be achieved, as I now discuss.

Targeting personal balance through service provision. First, a crucial indicator of wellbeing for use among youth with VI should be the extent to which they are maintaining balance among the features of their life that they prize. Indicators reflecting the important life domains described by the current participants should be utilized and

considered together (as discussed earlier) to enable the ascertainment of their comparative fulfilment. More importantly, the emphasis in the participants' accounts on the personal nature of the balance between the valuable life elements indicates that subjective measures of a young person's sense of balance should also be considered alongside any such attempts of VI service providers to gauge this balance from considering a combination of other sources (Cummins, 2005; Wallander & Koot, 2016).

In order to promote their wellbeing, services provided to youth with VI should also include components intended to directly promote the fulfilment of each of the four important life domains identified by the current participants. Peer support and recreation programs represent one key form of intervention that, therefore, should be included alongside the provision of assistive technologies and specialist instruction in important skills. This latter technology and skill development leans toward promoting a young person's independence (the domain of control), and if provided alone, will not necessarily bolster the social participation or physical health of youth with VI. Participants found peer support and recreation programs run for (and, in some cases, by) people with VI valuable places in which they experienced positive social connection (Chapter 7), and through which they engaged in physical activity to support their physical fitness and feelings of energy (e.g. the VI-specialized sports discussed in Chapter 6). Running or actively endorsing a variety of regular peer group and recreation programs within VI services may also further support balance in the lives of youth with VI by assisting these young people in establishing a personal routine. As discussed in Chapter 5, having regular extracurricular activities and social groups enabled participants to build a routine in their

week regarding when they would, for example, spend time with friends, be physically active and rest, and work towards success in their activities and endeavours²⁷.

Such peer support and recreation programs are not novel recommendations. Previously research has also supported the benefits of such programs among youth with VI and other disabilities (e.g. Goodwin et al., 2011; Goodwin & Staples, 2005; Jessup et al., 2010; Qasim et al., 2014). Furthermore, as introduced in Chapter 1, the ECC – a set of nine skill categories that are deemed essential areas within which all young people with VI should receive instruction – includes the skill category of ‘recreation and leisure’ (see Figure 1.1 on page 23; Hatlen, 1996; Sapp & Hatlen, 2010). In order to promote these recreation and leisure skills in youth with VI, visiting teachers are discussed as introducing young people with VI to accessible opportunities for their engagement in recreation, including, for example, VI-specialized sports. Despite this recognition of their importance, the current participants’ accounts joined previous research findings in raising questions around the extent to which, in reality, such peer support and recreation programs are incorporated into VI services for youth.

Participants felt that VI-specialized sports needed greater resourcing and identified that a major barrier to their utilization of these programs was that they were not referred to them by VI service providers (Chapter 6). Instead, several who regularly participated in such events described coming across these initiatives by happenstance. Similar findings were also obtained in the UK, in which youth with VI indicated that VI services could be improved by providing greater information about avenues for peer support (R. Thomas, Crossland, & Dahmann-Noor, 2015). Meanwhile, research

²⁷ Such domain fulfilment did not necessarily happen separately, as I have highlighted throughout my thesis. Nonetheless, even if a particular extracurricular activity entailed participants simultaneously catching up with friends (social connection) and being physically active (physical health) – a combination that the VI-specialized sports leagues represented for several participants who played ‘socially’ – having this activity structured into their week still gave the participants the knowledge that at that set time those important elements of their lives would receive a boost.

examining the provision of ECC instruction suggests that, in practice, instruction in the skill categories less directly-related to a young person's participation at school – such as their recreation and leisure – is both more disorganized and less frequent (Agran et al., 2007; Lohmeier et al., 2009; Wolffe et al., 2002). Echoing the discussion of the person-centred approach above, insufficient time and competing demands have been identified as factors contributing to this. In response to these findings, Lieberman, Haegele, Columna, and Conroy (2014) propose that visiting teachers or other VI service providers should work with general education teachers in subjects such as physical education to incorporate instruction in all ECC categories – including recreation and leisure – into their general class experience. However, the current participants' accounts emphasize that, in doing so, efforts to provide peer support and recreation programs with their peers with VI as part of VI service provision should also be maintained for the benefits they present to directly supporting balance in the lives of youth with VI.

Promoting adaptability and self-reflection. Promoting the capacities of youth with VI to flexibly respond to VI-related difficulties and thus maintain their own balance across their valuable life domains should also be a focus of VI services. Participants highlighted two important mechanisms by which VI services should seek to achieve this in outlining the importance of their adaptability, and their engagement in self-reflection in managing and moving on from difficulties.

Possessing a balanced set of strategies and resources was identified as central in enabling the participants' adaptability. VI services, therefore, should focus on working with youth with VI to establish a broad set of strategies and resources upon which the youth can draw in responding to the difficulties they encounter. The need for this to include strategies and resources for the management of the negative self-evaluations

associated with frequent encounters with others' negative reactions to their VI is especially important. While the psychological health of youth with VI has been discussed (Augestad, 2017; Pinguart & Pfeiffer, 2012b; Sacks, 2010; Tuttle & Tuttle, 2004), research on vision rehabilitation and educational services for younger populations with VI has focused on interventions targeting the promotion of their individual functioning in terms of their practical task performance and participation (Barker et al., 2015; Chavda et al., 2014; Lewis et al., 2014). Less attention has been given to the psycho-emotional disablism encountered by these young people, even in its indirect form, in which negative feelings and thoughts arise as a result of practical difficulties (Reeve, 2006, 2012; C. Thomas, 2007). This is a significant gap that needs to be addressed in future work. The current participants' experiences in each of their important life domains – and thus the balance between the valuable life elements captured within them – were all directly impacted by such psychosocial difficulties, echoing consistent findings in previous research that others' reactions to their VI had significant implications for their levels of life satisfaction and symptoms of psychopathology (Hess, 2011; Pinguart & Pfeiffer, 2011, 2012a; Worth, 2013a)

Participants suggested certain ways in which VI services could support the management of such psychosocial difficulties by youth with VI. Providing and encouraging youth with VI to use avenues to vent negative feelings and thoughts (outlets), or temporarily distract themselves from them (escapes) represented two such strategies. In line with previous findings of the value of social support to the wellbeing of youth with VI (Chang & Schaller, 2000; Hadidi & Al Khateeb, 2014; Kef & Deković, 2004; Pinguart & Pfeiffer, 2013c), family and friends represented key outlets and escapes, as did regular recreational activities. In particular, others with VI presented a useful source of understanding, in line with previous findings regarding the value of shared

experience to emotional support (Suitor & Pillemer, 2000; Thoits, 2011). This, again, highlighted the importance of incorporating peer support and recreation programs into VI service provision for younger populations (as discussed above). Participants' accounts also stressed that VI service providers should be open to the different ways in which youth with VI can mobilize strategies in a given situation depending on the type of difficulty they wish to manage. For example, passing as non-disabled – concealing one's disability from others in order to blend in – is a “loaded term” (Worth, 2013b, p. 579) in literature regarding living with VI and disability. This is because it is positioned as an indicator of denial and shame, while disclosure of one's disability is perceived as the healthier option (Tuttle & Tuttle, 2004). The ongoing use of passing is thus positioned as maladaptive and reflective of a person's negative self-concept (Tuttle & Tuttle, 2004). In contrast to such accounts, however, the current participants described the instrumental value of socially concealing or performing their VI depending on what they wanted to achieve in a given social setting (e.g. connection with others, success in a task), and thus as invaluable in managing the balance across the various valuable elements in their life. They recognized the well-established negatives of passing (e.g. fatigue, risk of exposure; Lingsom, 2008; Uttermohlen, 1997), but considered the concealment of their VI through the use of technologies or through the use of their own voice as one of many ways they could choose to manage possible psycho-social difficulties.

VI services should also seek to promote the capacities of youth with VI to inform their management of difficulties by reflecting upon their own goals, priorities, current sense of wellbeing and the particularities of the situation in which they anticipate or actually face these difficulties. Engaging in self-reflection, in particular, enabled the current participants to determine what aspect of their life (e.g. social inclusion, independence) they wished or needed to promote in a given situation in order to work

towards or maintain a sense of balance and thus wellbeing. The importance of promoting these skills for monitoring and appraising their individual situation, and then using this information to make decisions about how they wish to respond to best meet their own ends has previously been recognized as an important goal for VI services. This was formalized in the early 2000's by the addition of the skill category of 'self-determination' into the ECC (Sapp & Hatlen, 2010). However, a recent review of interventions targeting the promotion of self-determination skills among children and young people with VI found limited research knowledge exists regarding optimal approaches for promoting these self-determination skills (Lewis et al., 2014). Furthermore, this translates, in turn, to gaps in service provision with a lack of knowledge and the absence of curricula/teaching materials listed by 34.4% and 38.3% of visiting teachers of students with visual impairment, respectively, as barriers to instruction around self-determination (Agran et al., 2007).

10.2.5 Combining individual-level services with a drive for social change

My focus in this thesis was to contribute to the theoretical development of how we think about what it means to live well with VI as a young person, and thus enable the development of more sensitive forms of individual-level VI service delivery targeting the wellbeing of youth with VI. This was important in order to begin the process of replacing the current implicit personal tragedy model that underpins these services (McGrath et al., 2017), given findings of the inconsistent effectiveness of these services at promoting indicators of psychological health and QoL (Binns et al., 2012; Rees et al., 2010). In light of the current participants' accounts, it is important to stress that, no matter how sensitively provided, individual-level services are only part of the picture of the promotion of wellbeing of youth with VI.

Continued efforts to drive social and cultural change around disabilities, such as VI, need to accompany the above-described move towards providing VI services to youth in a way that targets their personal sense of balance among the elements they consider important to the quality of their lives. The frequent encounters with powerful forms of psycho-emotional disablism of the current participants (Reeve, 2006; 2012; C. Thomas, 1999, 2007), and the direct impact that this had on their experience of possessing or attaining many of the life elements they prized in all four key life domains, highlights this need. Although providing participants with strategies and resources to manage or respond to such disablism is essential, many of the psychosocial difficulties that the participants reported went well beyond anything that could be addressed with such individual-level strategies alone. It would be insufficient, for instance, to seek to address the relentless and intense bullying several participants encountered at school due to their VI (discussed in Chapter 7) by improving their social and self-assertion skills and providing them regular escapes from such difficulties through peer support/recreation programs. Such strategies will not prevent the detrimental impacts upon wellbeing of persistent and wilful bullying; impacts which can be quite long-lasting, as shared by the current participants and found among sighted youth (Vessey et al., 2013; Wolke & Lereya, 2015).

The push for social change in how people with disabilities are perceived and treated, then, is paramount to reduce the frequency with which such negative encounters occur, in addition to equipping the youth with VI with means of managing such encounters. Importantly, this requires greater advocacy and education work among the non-disabled population that is focused not only on issues of material access and discrimination, but also on education regarding disability and the promotion of a greater cultural respect for people who live with it. The need for this social change has been well-recognized with regard to disability more generally, yet despite the high profile of VI

services in Australia, limited attention has been given to young people with VI in this way. It is only by advocating for an engaged and responsive construction of wellbeing that such social changes will benefit the long-term life outcomes of youth with VI.

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Appendices

Appendix A. Project Recruitment Flyers

This first appendix contains the following:

Document	Page
Written content of initial project recruitment flyer: prior to amendment of the project's age range of inclusion	435
Written content of amended project recruitment flyer: following amendment of the project's age range of inclusion	437

Adolescent Vision Impairment Needs Focus!

Are you or do you know an adolescent with vision impairment? We are conducting a study to help service providers improve the services available to these adolescents. We want to work with them to learn more about vision impairment's effect on their psychological wellbeing: how they feel, think and spend their time. We want to know:

- ❖ what makes up and should be looked at when assessing their psychological wellbeing;
- ❖ how their vision impairment gets in the way of their psychological wellbeing; and,
- ❖ how they handle their vision impairment when it gets in the way.

Can you or the adolescent you know be involved?

We are looking for adolescents who feel they have significant vision impairment:

- ❖ who are between 12 and 18 years old;
- ❖ who do not have a cognitive impairment or any other impairment of their senses; and,
- ❖ who are comfortable conversing in English in a group setting.

What is involved?

This study has two phases. In phase one, adolescents will:

- ❖ attend a 1-hour training session on respectfully recording environmental sounds;
- ❖ record and reflect on sounds in their own time to respond to research questions; and,
- ❖ attend two 2-hour group sessions where their recordings will be played and discussed.

In phase two they will:

- ❖ complete activities to identify common themes in the recordings and discussions; and,
- ❖ then come up with suggestions for service providers and other stakeholders.

Adolescents can choose to take part in phase one or both one and two, and will be given two \$10 Coles-Myer gift cards per phase as reimbursement for their time.

If you are interested please contact Ross Anderson at [REDACTED] or by phone between 9.30am-5pm on Monday-Friday on [REDACTED] If you are under 16 years of age please contact Ross with your parent or guardian.

Adolescent Vision Impairment Needs Focus!

You may have heard about the project being run by Ross Anderson from Monash University to learn more about how the psychological wellbeing of adolescents (aged 12-18 years of age) is affected by vision impairment to help service providers improve their services. He is now also looking to work with older adolescents moving into their young adulthood (19-25 years of age) to learn more about how vision impairment affects their psychological wellbeing: how they feel, think and spend their time. He wants to know:

- ❖ what makes up and should be looked at when assessing their psychological wellbeing;
- ❖ how their vision impairment gets in the way of their psychological wellbeing; and,
- ❖ how they handle their vision impairment when it gets in the way.

Can you or the young person you know be involved?

We are looking for young people who feel they have significant vision impairment:

- ❖ who are between 12 and 25 years old;
- ❖ who do not have a cognitive impairment or any other impairment of their senses; and,
- ❖ who are comfortable conversing in English in a group setting.

What is involved?

This study has two phases. In phase one, those taking part will:

- ❖ attend a 1-hour training session on respectfully recording environmental sounds;
- ❖ record and reflect on sounds in their own time to respond to research questions; and,
- ❖ attend two 2-hour group sessions where their recordings will be played and discussed.

In phase two they will:

- ❖ complete activities to identify common themes in the recordings and discussions; and,
- ❖ then come up with suggestions for service providers and other stakeholders.

Young people can choose to take part in phase one or both one and two, and will be given two \$10 Coles-Myer gift cards per phase as reimbursement for their time.

If you are interested please contact Ross Anderson by phone between 9.30am-5pm on Monday-Friday on [REDACTED] or at [REDACTED] to arrange a time that suits you. If you are under 16 years of age please contact Ross with your parent or guardian.

Appendix B. Facilitation Guides for Sessions in the First Phase of the Project

This second appendix contains the following:

Document	Page
Facilitation guide for initial training session	441
Facilitation guide for first interview/focus group session	443
Facilitation guide for second interview/focus group session	445

Facilitation Guide for Initial Training Session

This guide outlines the points to be covered in each stage of the initial training session.

Welcome

- This is a 1-hour session.
- It is confidential.
- Can ask questions at any time.
- *For focus group:* Brief “ice-breaking” activity to allow everyone to get to know each other and feel comfortable to share experiences. Ask each participant to share an experience related to some of the following statements:
 - I have had or do have a pet;
 - I play a musical instrument or sing;
 - I have been to the snow;
 - I can speak a language other than English;
 - I play a sport outside of school;
 - I have been overseas;
 - I have been to a football game; and,
 - I have been to a concert.

Introduction to Project

- Ask participants what they think of when they hear the term “psychological wellbeing”.
- Offer deliberately broad definition of psychological wellbeing to guide participants thinking: how well someone is feeling/doing.
 - It can involve talking about: feelings, thoughts, plans, goals, activities and how you spend your time.
- Emphasize project’s objectives: The questions I want to answer with you:
 - How you define psychological wellbeing?
 - How does your vision get in the way of your psychological wellbeing?
 - How do you handle your vision when it gets in the way?
- Begin introducing audio-recording task: highlight that we also want participants to record and talk about sounds in their life to answer these questions.

Recording Sound Instructions

- Think about above questions.
- Questions will be provided on two handouts.
- Record sounds that:
 - Stand out to you;
 - Show your experiences; and,

- Help answer/explain answers to questions.
- Record sound of about a minute long.
- Examples:
 - What psychological wellbeing means to them? Friends talking about movies.
 - How does their vision impairment affect their psychological wellbeing? Car sounds to reflect inability to drive.
 - How do they handle their vision impairment's effects? Mum talking.

Recording Reflections: Instructions

- Can also record your thoughts on the sounds you record, including:
 - Why you recorded it;
 - What it means to you; and,
 - How it helps answer the question.
- Record reflections of about a minute long.

Bringing Recordings to Next Session

- We will collect as many recordings as you want to share.
- Group sessions at end of each week approximately.
- Due to time constraints, think about two sounds and reflections you want to play aloud in each session: pick most important sounds.

Recording Respectfully

- Talk through the need to get consent to record other people.

Practice Using Recorders

- Have participants demonstrate the use of their selected recording device (i.e. their phone, or provided recorder).
- For provided recorders, run through how to:
 - Change batteries;
 - Turn on and off;
 - Record;
 - Pause and stop;
 - Volume, between tracks;
 - Move between different storage folders;
 - Highlight that can be plugged into computer to label recordings; and,
 - Erase.

Conclude Session

- Run through first audio-recording task handout.

Facilitation Guide for Week 1

Note: If being used for an interview, ignore the questions intended for the “group as a whole”, and focus instead on exploring interviewee’s account.

Point in session	Questions
Start	Does anyone want to start today’s session by sharing one of the sounds they recorded and any thoughts that they recorded about it over the last week?
Following sound or reflection	<p>To adolescent who recorded sound/reflection:</p> <ul style="list-style-type: none"> • <i>(if need further elaboration on reflection)</i> Tell us a little bit more about why you recorded this sound. <ul style="list-style-type: none"> ○ What does this sound mean to you? ○ How important is this to you? ○ Why is this important to you? • <i>(if considerable detail in their reflection)</i> Do you have anything to add to what you said in your recording? <p>To group as a whole:</p> <ul style="list-style-type: none"> • What did everyone think when listening to ____’s sound and explanation of why he/she recorded it? <ul style="list-style-type: none"> ○ Is <i>*insert description of what the sound was representing*</i> an important part of your life when you are doing well? <ul style="list-style-type: none"> ▪ How important is it to you? ▪ Why is it important to you? Or why not? ○ What did the sound make you think about? <ul style="list-style-type: none"> ▪ Does it mean the same thing to you as it does to ____? Or something different? ▪ Is this an important part of your life when you are doing well? ▪ How important is it to you? ▪ Why is this important to you? ○ Did hearing ____’s recordings make you notice something important in your life when it is going well that you hadn’t thought about before? <ul style="list-style-type: none"> ▪ What was this? ▪ How important is it to you? ▪ Why is it important to you? • Does anyone have another sound that they recorded which touches on the same kind of thing or a related idea? • <i>(if no-one has any similar or related sounds/reflections)</i> What other sounds has everyone recorded?

Point in session	Questions
No sounds or reflections are volunteered	<p>Pick or adapt the most appropriate question depending on what has already been discussed in the session:</p> <ul style="list-style-type: none"> • What activities do you spend time on when you are doing well? <ul style="list-style-type: none"> ○ How important are these activities to you? ○ Why are these activities important? What is it about them? • Other than things you do, what other things do you have in your life when you are doing well? <ul style="list-style-type: none"> ○ How important are these activities to you? ○ Why are these things important? What is it about them? • What kinds of thoughts do you have when you are doing well? <ul style="list-style-type: none"> ○ (<i>Re-phrase if necessary</i>) What do you think about when you are well? • What is your mood like when you are doing well? <ul style="list-style-type: none"> ○ (<i>Re-phrase if necessary</i>) What feelings do you have when you are well?

Facilitation Guide for Week 2

Note: If being used for an interview, ignore the questions intended for the “group as a whole”, and focus instead on exploring interviewee’s account.

Point in session	Questions
Start	Does anyone want to start today’s session by sharing a sound and their thoughts that they recorded over the last week about how their vision impairment gets in the way of how well they are doing?
Following sound or reflection regarding effects of vision impairment	<p>To adolescent who recorded sound/reflection:</p> <ul style="list-style-type: none"> • <i>(if need further elaboration on reflection)</i> Tell us a little bit more about why you recorded this sound. <ul style="list-style-type: none"> ○ What does this sound mean to you? ○ Does this happen because of your vision impairment? If so, why? ○ How does this affect how well you are doing? • <i>(if considerable detail in their reflection)</i> Do you have anything to add to what you said in your recording? <p>To group as a whole:</p> <ul style="list-style-type: none"> • What did everyone think when listening to ____’s sound and explanation of why he/she recorded it? <ul style="list-style-type: none"> ○ Does everyone else feel that their vision impairment gets in the way of how well they are doing because it <i>*insert description of what the sound was representing*</i>? <ul style="list-style-type: none"> ▪ Why? or Why not? ▪ How does <i>*insert description of what the sound was representing*</i> affect how well you are doing?

Point in session	Questions
Following sound or reflection regarding effects of vision impairment (continued)	<ul style="list-style-type: none"> ○ What did the sound make you think about? <ul style="list-style-type: none"> ▪ Does it mean the same thing to you as it does to ____? Or something different? ▪ Is this something that happens in your life because of your vision impairment? ▪ Why does this happen because of your vision impairment? ▪ How does it affect how well you are doing? ○ Did hearing _____'s recordings make you notice some way that your vision impairment gets in the way that you hadn't thought about before? <ul style="list-style-type: none"> ▪ What was this? ▪ How does this affect how well you are doing?
Following sound or reflection regarding effects of vision impairment (continued)	<ul style="list-style-type: none"> ● Does anyone have another sound that they recorded which touches on the same kind of thing or a related idea? ● <i>(if no-one has any similar or related sounds/reflections)</i> What other sounds has everyone recorded to show how their vision impairment gets in the way of how well they are doing? ● <i>(After sufficient conversation about the effects of vision impairment on psychological wellbeing)</i> Does anyone want to move the session along now by sharing a sound and their thoughts that they recorded over the last week about what helps them handle their vision impairment when it gets in the way?

Point in session	Questions
Following sound or reflection regarding handling effects of vision impairment	<p>To adolescent who recorded sound/reflection:</p> <ul style="list-style-type: none"> • <i>(if need further elaboration on reflection)</i> Tell us a little bit more about why you recorded this sound. <ul style="list-style-type: none"> ○ What does this sound mean to you? ○ What effects of your vision impairment does this help you handle? ○ How does this help you handle these effects? • <i>(if considerable detail in their reflection)</i> Do you have anything to add to what you said in your recording? <p>To group as a whole:</p> <ul style="list-style-type: none"> • What did everyone think when listening to ____'s sound and explanation of why he/she recorded it? <ul style="list-style-type: none"> ○ Does everyone else feel that <i>*insert description of what the sound was representing*</i> helps them handle their vision impairment when it gets in the way? <ul style="list-style-type: none"> ▪ Why? <i>or</i> Why not? ▪ What effects of your vision impairment does it help you handle? ▪ How does it help you handle these effects? ○ What did the sound make you think about? <ul style="list-style-type: none"> ▪ Does it mean the same thing to you as it does to ____? Or something different? ▪ Is this something in your life that helps you handle your vision impairment when it gets in the way? ▪ What does it help you handle? ▪ How does it help you handle it?
Following sound reflection regarding handling effects of vision impairment (continued)	<ul style="list-style-type: none"> ○ Did hearing ____'s recordings make you notice something in your life that helps you handle your vision impairment that you hadn't thought about before? <ul style="list-style-type: none"> ▪ What was this? ▪ What does it help you handle? ▪ How does it help you handle it? • Does anyone have another sound that they recorded which touches on the same kind of thing or a related idea? • <i>(if no-one has any similar or related sounds/reflections)</i> What other sounds has everyone recorded about things that help them handle their vision impairment when it gets in the way?

Point in session	Questions
No sounds or reflections are volunteered	<p data-bbox="488 241 1305 315">Pick or adapt the most appropriate question depending on what has already been discussed in the session:</p> <ul style="list-style-type: none"> <li data-bbox="539 327 1315 405">• How does your vision impairment get in the way of how well you are doing? <ul style="list-style-type: none"> <li data-bbox="635 416 1289 490">○ How does it get in the way of activities that are important to you? <li data-bbox="635 501 1337 575">○ Other than activities, how does it get in the way of you having other things that you want in your life? <li data-bbox="539 586 1315 665">• How does your vision impairment affect your mood and your thoughts? <ul style="list-style-type: none"> <li data-bbox="635 676 1321 750">○ What happens because of your vision impairment to make you feel or think this way? <li data-bbox="539 761 1193 840">• What do you find helps you handle your vision impairment when it gets in the way? <ul style="list-style-type: none"> <li data-bbox="635 851 1225 925">○ What helps you when it gets in the way of activities that are important to you? <li data-bbox="635 936 1283 1010">○ What helps you when it gets in the way of you having something that you want? <li data-bbox="635 1021 1342 1095">○ What do you do that helps you? What steps do you take? <li data-bbox="635 1106 1123 1131">○ What do you have that helps you? <li data-bbox="539 1142 1337 1220">• What do you find helps you when your vision impairment effects your mood or your thoughts? <ul style="list-style-type: none"> <li data-bbox="635 1232 1342 1305">○ What do you do that helps you? What steps do you take? <li data-bbox="635 1317 1123 1341">○ What do you have that helps you?

Appendix C. Audio-recording Task Handouts for the First Phase of the Project

This final appendix contains the following:

Document	Page
Audio-recording task handout for between initial training session and first interview/focus group session	450
Audio-recording task handout for between first and second interview/focus group session	451

Your Task for the First Week

Follow this handout to complete this week's sound-recording activity. If you have any trouble recording sounds or using your sound-recorder please contact Ross on [REDACTED] or at [REDACTED]. If you are going to record any other people as part of the activity please contact Ross by the same number or email address so that you can be sent a form to get their written consent.

Over the next week please record some sounds which are up to one minute long that help you answer the following question.

What is going on in your life when you are doing well?

Here are some examples about how you might answer this question:

Example 1: Jenny records the sound of herself typing and her screen-reading software reading her homework to her. She says that she is doing well when she is on top of her homework because it makes her feel proud and like she is achieving things.

Example 2: Mitchell records the sound of his friends talking about movies. He says that he is doing well when he can spend time with his friends including going to the movies with them as they make him laugh and help him have fun.

To help answer the question above, you can choose to record yourself talking for up to a minute about why you chose to record each sound. Below are some ideas about what you could talk about:

- "This sound helps show why I feel ____ when I ____ because ____"
- "This sound helps show why I think ____ when I ____ because ____"
- "What is important about this sound is ____"
- "I recorded this sound because ____"

Your Task for the Second Week

Does your vision impairment affect how well you are doing? If YES, please follow the “INSTRUCTIONS FOR YES” section below. If NO, please follow the “INSTRUCTIONS FOR NO” section below. If you have any trouble recording sounds or using your sound-recorder please contact Ross on [REDACTED] or at [REDACTED]. If you are going to record any other people as part of the activity please contact Ross by the same number or email address so that you can be sent a form to get their written consent.

To help answer the questions, when you record each sound by following the instructions below you can choose to record yourself talking for up to a minute about why you chose to record them. You could talk about:

- “This sound helps show how ____”
- “I recorded this sound because ____”
- “What is important about this sound is ____”

INSTRUCTIONS FOR YES

Please record sounds which are up to one minute long that will help you answer the following two questions

1. In what ways does your vision impairment get in the way of you doing well?

Example: Tim recorded the sound of a car. He says that he would like to be able to drive but can't because of his vision impairment which makes him feel different from his friends; AND,

2. What helps you to deal with your vision impairment when it gets in the way of you doing well?

Example: Pamela recorded the sound of her mum talking to her about a problem. She says that her mum's support helps her handle her vision impairment as it helps solve problems.

INSTRUCTIONS FOR NO

Please record sounds which are up to one minute long that will help you answer the following question:

What helps you to stop your vision impairment from getting in the way of how well you are doing?

Example: Rick recorded himself playing the piano. He says that his vision impairment does not affect how well he is doing as it cannot stop him from playing his piano which always cheers him up.

