Immured, Suspended, Provisioned: The Meaning of Home for People with Complex Communication (Access) Needs

By

Betty-Jean Dee-Price
(M.Ed., BA.Soc/Wk, B.Ed, GradDipSo/Sc)

Submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy

Flinders University

8th June 2018

Declaration

I am the author of the thesis entitled Immured, Suspended, Provisioned: The Meaning of Home for People with Complex Communication (Access) Needs for the degree of Doctor of Philosophy.

I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any university; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

I certify that I am the student named below and that the information provided is correct.

Betty-Jean Dee-Price

Acknowledgements

I wish to express my gratitude and appreciation for the support of my supervisors Associate Professor Kathy Arthurson and Associate Professor Lorna Hallahan during my time as a PhD candidate. With oversight of Active, the establishment of my scholarship (through A/Prof Kathy Arthurson's ARC Future Fellowship research group at the Southgate Institute of Health, Society and Equity) Associate Professor Kathy Arthurson was Principal Supervisor for most of the candidature but sadly was unable to complete the journey with me. This role was continued under the expert guidance of Associate Professor Lorna Hallahan. The learning I have gained under their guidance has enabled me to use my knowledge with immediate effect.

I also wish to acknowledge the generous support of the Southgate Institute for Health, Society and Equity for the provision of a full PhD scholarship. In addition to the financial backing of a scholarship, the Southgate Institute provided a rich and supportive research environment. Thank you also to Associate Professor Pammi Raghavendra (Flinders University) and lecturer Sophie Diamandi (UniSA) who supported my application for a scholarship.

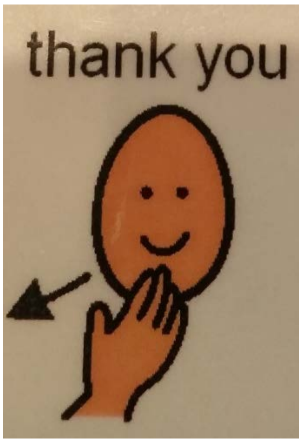
I am particularly grateful to the participants who shared their stories and expertise, giving me an insight into the diversity and humanity of communication that I am unlikely to ever forget and hope to honour in future work. Their patience and creativity in telling and re-telling their stories so I could understand was especially appreciated.

The methods developed for the study required expert input from a variety of people. Special thanks to the young man who pilot tested the study and to the numerous friends, family, fellow PhD students and staff from the Southgate Institute who assisted in a variety of ways including appearing in photographs used in the study, and in undertaking the role of test participants. Staff of the Medical Illustration & Media Centre of Flinders Medical Centre, South Australia assisted in the creation of the photographs used for the study, for which their time and expertise is appreciated.

Finally, I wish to acknowledge and thank my family. I am very appreciative of my patient and supportive husband Tim and beautiful sons Max and Quinlan who understood the importance of the thesis and allowed it, at times, to take priority in our home life.

Family brings forth a simple reality about this thesis. Without my son Max the thesis would never have been. He, alongside his brother Quin, have been enormous teachers of many things but Max's teaching about what it means to be human with impairments, particularly CCAN, is unique.

> *I can't wait until you are old enough to take on formal teaching in your own right. Your thoughtfulness, patience and willingness to share with others makes us all so proud …*



Abstract

Textured layers of communication are critical to basic survival and to achievement of the things that make a good life. These include meeting everyday needs, forming an identity, affiliation with others, making decisions, defending oneself from harm, having control over one's lifestyle, earning a living, connection with the public sphere, and having a say in the social and political world. From these things one can establish a home. Yet it is not simply communication, on face value, that serves to achieve these social goods. Rather it is socially sanctioned communication in the form of speech and written word which has this power; not guttural vocalisations or staring down at a picture on the tray of one's wheelchair or purposely swinging one's arms if one has complex communication needs (CCN).

The purpose of this study was to render as close as possible a picture of what home means to the participants of the study – people with CCN. Yet creating this image required another, preliminary, purpose, and that was to find the required materials and methods that would help capture this picture. Finding or creating new methods suitable for research with people with CCN was a necessary component of the research because, as indicated in the literature, much of it old and sporadic, people with CCN have largely been overlooked as research participants.

Understanding the nature of CCN, and how the experience of CCN might be experienced by the world, formed the early parts of this study. The concept of 'communicative competence' emerges early in the thesis through the works of sociologist and critical theorist Jurgen Habermas and in the writings from the field of Augmentative and Alternative Communication (AAC). It is from this position that one begins to learn what counts as communication in society. This in turn, presented a twofold dilemma for the study. Firstly there was little prior research undertaken specific to the sociological understanding of CCN culminating in descriptions of persons with CCN as presenting challenges for efficacious research, and without background information it was difficult to locate CCN within the broader field of disability in which it was imbedded. There was no clear indication of the numbers of persons with CCN in Australia, let alone where they might live. The second dilemma, related to the first, demonstrates there currently exists very little to guide research practice when interviewing people with CCN. This meant that, in order for the study to ensue, a suitable methodology and the development of reliable methods would be required. The

study, as such, was founded on two parts. The ‘how’ of doing research with people with CCN, as well as the ‘what’ – the meaning of home.

The study explores the nexus between disability and housing in general, particularly as it has come to be known in Australia. An outline of the history as well as current social policy changes to the Australian landscape of disability and housing provides background colour for this work. Onto this background the typology of home and housing, the listing of capabilities developed by Martha Nussbaum (2006), the notion of status enhancement (Jonathan Wolff, 2009), theoretical challenges to traditional linguistics, and the emerging methodological innovations of sensory ethnography, particularly that of anthropologist Sarah Pink, is painted.

From here pieces of information not available in the literature are merged to support knowledge gaps, including the findings of a quantitative analysis of secondary Australian Bureau of Statistics reports revealing early evidence of a relationship between CCN and home being in residential care settings. Spurred by the influence and flexibility of sensory ethnography, new methods (combining AAC with such tools as photo elicitation) were developed and tested for the study, which reduced the need for participants to provide spoken or written responses. Furthermore, processes of obtaining consent and providing feedback were developed that welcomed participants with cognitive impairments.

The thesis includes dabblings of self-portrait – reflexive, embodied, and invested with my own experience of CCN. This personal insight was helpful when it came to crossing the thresholds of ten different homes and meeting the people whose stories, alongside my emplaced experience, would provide the ‘what’ of the meaning of home with many illustrations of home experience. The uniqueness of each participant is described, yet these stories bear strong themes shaping the themes Immured, Suspended and Provisioned. The ‘how’ of doing research with participants with CCN resulted in participant feedback that was combined with feedback received during the method testing phase.

The study offers rich and unique insights into what home means, not just for people with CCN, but also for all people, with or without impairment(s). Much of this is detailed in what access to communication means and how many of us take it for granted. Communication remained at the forefront of the study; its unfolding dynamic was observed with ever-growing interest. From the beginnings of the study, the concept of the ‘architecture of communication’ emerged as connected to the many types of communication-promoting features which surround us (or not), influencing the extent to which we can live quality lives.

Communication is faceted and layered; it includes the types of conversation starters in or around one’s home, internet and social media use, prayer, access to a communication support worker, how furniture is placed to support face-to-face interaction, snowballing into something that could be captured as data and analysed. Alongside the ‘what’ of the meaning of home and ‘how’ methods might work, an appreciation of communication access as both encompassing and measurable is also described. Even more compelling is the finding that communication access forms the foundation from which notions of the good life such as Nussbaum’s (2006) capabilities are able to flourish. Without good architecture of communication, capabilities are thwarted and home exists as little more than a ‘venue’, an ‘accommodation’ that fails to accommodate ‘home’.

TABLE OF CONTENTS

CHAPTER SEVEN – Analysing Methodology and Architecture of Communication

List of Tables

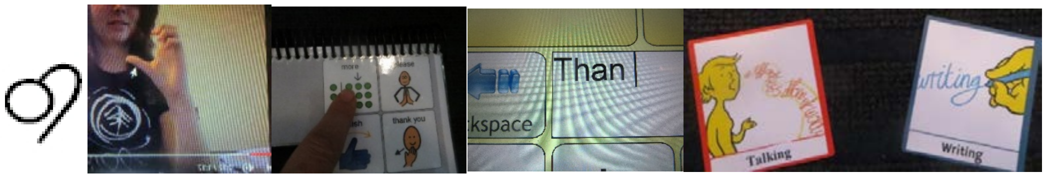
List of Figures

List of Abbreviations

AIS	Adapted image selection
ASHA	American Speech-Language-Hearing Association
ADHD	Attention deficit hyperactivity disorder
AAC	Augmentative and alternative communication
ABS	Australian Bureau of Statistics
AGOSCI	Australian Chapter for ISAAC
AHURI	Australian Housing and Urban Research Institute
AIHW	Australian Institute of Health and Welfare
ANUHD	Australian Network for Universal Housing Design.
APO	Australian Policy Online
CCN	Complex communication needs
CURF	Confidentialised Unit Record File
DHS	Department of Human Services
FaHCSIA	Department for Families, Housing, Community Services and Indigenous Affairs
FC	Facilitated communication
HCSCC	Health and Community Services Complaints Commissioner
ICF	International Classification of Functioning
ID	Intellectual disability
IDPD	International Day of Persons with Disabilities
ISAAC	International Society for Augmentative and Alternative Communication
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
NHMRC	National Health and Medical Research Council
PGSS	Participant-generated sensory selection
PODD	Pragmatic Organised Dynamic Display
PSW	Personal support worker
PWD	People with disabilities
SPA	Speech Pathology Australia
SPSS	Statistical Package for the Social Sciences
TGPE	Theory-generated photo elicitation

UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

CHAPTER ONE – STARTING A CONVERSATION: CCN, HOME AND ART



Language is more than talking / writing.

Figure 1. Statement by study participant 2014

1.1 *Through the Doorway of CCN*

This study advances the sociological and philosophical exploration of complex communication needs (CCN) in an investigation of the meaning of home as revealed by people who live with severe communication impairment. Herein, it aims to understand the relationship between home, communication, and the building of quality lives. Given the participant cohort, the study required an innovative methodology throughout the design process including testing and application of new data collection methods.

There are significant pockets of literature relating to the functional assessment, treatment, and rehabilitation of people with CCN, as described in the journals of medical and allied health professions such as the *Journal of Communication Disorders, Journal of Speech, Language and Hearing Research, Communication Disorders Quarterly,* and so forth. As such, these publications reflect the critical role of intervention and care of people with communication impairment. The current study finds its niche in the less explored sociological experiences and meanings attributed to (and by) people with CCN. "Scant information is available to guide the selection and modification of methods for doing research with people with communication impairments." (Teachman et al, 2018, p.1) It also raises a second important consideration in relation to methodology and the gaps in research which presents an additional niche. People with CCN are usually not included as research participants (Cascella, 2014; Ison, 2009; Hodge 2007; Lloyd, 2006; Paterson, 2002), as little is known about the day-to-day lives of people with CCN (Hodge, 2007; Duchan, 2006). This suggests an absence of research methodology in relation to participants with CCN, and as such, this study takes the position of engaging with scientific methodology in conjunction with (or adjunct to) the topic of investigation.

This study involves a complex arrangement of themes which places it at the nexus of disability, housing, research, and Australian policy. For this reason, Chapter One is dedicated to providing a background and introduction to these broad topics, which are separated into Parts A and B. Part A, which introduces the theme of CCN, provides an outline of the thesis followed by a description of the fundamental themes relevant to the intended cohort. Part B, which introduces disability and home and housing issues in Australia, presents an outline of the disability and housing context in which the study is imbedded. This section is partly theoretical, as the intent here is to lay out the context of policy, practices and justice debates occurring in Australia today. Towards this end, Part B reveals the present-day national contexts and the relationship between CCN and disability housing.

In Chapter Two, the thesis moves into a phase of theoretical exploration wherein the values and tensions of the role communication plays in socio-political theory are brought to the fore. Habermasian ideologies (Habermas, 1983, 1981; McCarthy 1984) of communicative rationality, communicative action and discourse ethics are explored, critiqued and interwoven with Nussbaum's (2006) interpretation of capabilities as well as Wolff's (2009) idea of a status enhancement approach to disability. These theories enable the possibility of reviewing or transcending some of the socio-political friction and justice shortfalls as described in Chapter One by providing an alternative viewpoint from which the justice issues of people with CCN might be better understood.

The subsequent chapters take these theories and roll them into methodological and analytical practice, which encompasses the investigation's preparation, development, testing and application of methods suitable for the inclusion of participants with severe barriers to normative language processes. Less conventional mechanisms of communicating the experiences of others are explored, such as art and visual research, together with the incorporation of alternative communication strategies, including AAC and sensory inquiry techniques. The study also seeks to learn new ways to adapt inquiry techniques to transcend traditional research barriers faced by potential participants with CCN. This includes strategies such as asking participants directly for their ideas and suggestions as part of the process of evaluating the methodology of the study. An interest in finding authentic and meaningful ways to understand the perspectives, ideas, thoughts, experiences and imaginings that might benefit all people, not necessarily only those with CCN, was also critically important for successful outcomes. Ethnography, sensory ethnography, in particular, forms the methodological bedrock for the study.

The study is intent on detailing the processes it enlisted to learn from people with CCN, including any problems it encountered in doing so, and concludes with a discussion of the implications drawn from the findings, which reflect both aspects of the study – the meaning of home, and the methodology from which this understanding might be drawn. Implications of the findings are predominantly related to the sectors of housing and disability, with attention given to theoretical significance as well as practical operations within the socio-political mechanism of present-day Australian policy, particularly regarding communication diversity and AAC.

The beginning chapters, one to three, are written in the present tense, reflecting the thinking and decision making of the study as it was occurring. The intent here is to enable the reader to appreciate some of the thinking and decision making propelling the study. The following chapters four and five are written in the past tense, with the final chapters seven to nine returning to a present tense discussion. The first person singular pronoun 'I' is used throughout the text to denote my position as the author of the thesis, and to indicate my experiential role in the research process.

1.2 *A Conversation on Canvas*

The thesis can be aligned with the painting of a canvas; this is not to say it is a work of art, but, as its white pages are like a canvas, many tubes of paint represent the various theories and models. There are mixers and blending tools which layer on each other and hold ideas together. The artist manipulates these tools, blending in pieces of herself with the colours and hatchings of embodiment and auto-ethnography – and there is the frame that emplaces the image in context with its environment. The frame that might ordinarily come last, after the art work is completed, is, instead, built first to ensure the boundaries and the dimensions of the work; therefore, the work itself becomes part of the art.

Chapter One, **introducing the frame**, aims to do precisely what is described in the metaphor: it reveals the boundaries and dimensions of the thesis. It provides the reader with the answer to the questions of *who* the people are (those being investigated), *what* the various themes of the study are, *why* the study is important, *who* the researcher is and *what motivates her*, and *where* the study is located in place and time. Against a backdrop of Australian disability policy and housing debate, critical truths about CCN are introduced and explored.

Chapter Two opens the art box to reveal all the various tubes of theory – there are nuanced colours, a few are old and dried, but others are notably revived with the oils and thinners of fresh debate. In this chapter, housing and disability theories are applied and critiqued, and then re-applied, to deliver a theoretical platform for an investigation of CCN and housing. The ideologies of Jürgen Habermas and the relatively new theories of Martha Nussbaum's (2006) approach to capabilities and Jonathan Wolff's (2009) description of status enhancement are discussed here too. Applied in partnership, they emerge as the dominant theoretical underpinnings of this study.

Chapter Three is the priming of the canvas. Before laying down media, it is important to ensure the foundation is prepared. In understanding the power and limitations of materials, the rules and directions which must be considered when using such materials also form part of this chapter. At the core of this chapter are the questions: Who are people with CCN to sociological research? How are they typically 'experienced and supported' through the research process? What must the researcher do, or know, or pursue to ensure best practice in undertaking a study such as this? With this background in place, the artist-researcher is then ready to collect and experiment with the materials.

Chapter Four accounts for the method and the media used. Just as an image can be captured in many forms – oils, water colours, mixed media – methodology can also be. This chapter outlines a process of mixed and experimental methods as well as the underlying reasons why such approaches have been adopted. This, however, is not limited to metaphor; there is a clear overlapping of methodology with visual and other art processes which underline the combined and experimental use of AAC, photo elicitation and sensory ethnography in this study.

Chapter Five is about making the art work with a dynamic connection between the subject (as both topic and participant) the artist-researcher and the media, and data collection tools. Here too there is an exchange of roles: at times the subject becomes artist, and the artist experiences and merges with the emplacement of a subject. It is here that the genre, the style, the stories and content is shaped and decided by what both the participant and the researcher bring to the work. The artist's primary role is to capture the essence, the closest truth, the integrity of what she is taught by the subject and what she sees/hears/senses before her. This chapter tells the stories of how these embodied experiences of sensory ethnography and the other methods used in the research evolved and were experienced in the study. It was here that the artist realised there were three powerful themes which could not easily be reflected in one painting. This chapter of ‘doing research’ moves from a single image to the creation of a triptych.

Chapter Six reveals the paintings: the layered stories and what they mean as a whole. The voices of participants are painted into this chapter. These stories and experiences are reflected with some messages especially highlighted to illustrate the conceptual framework. Other parts retreat into a background that, in combination with the researcher’s own embodied experience, help paint the ‘knowing’ of what home means.

Chapter Seven explores, discovers and describes creative new approaches used by the artist to create these works. It describes additional important findings, particularly in the discovery and analysis of the architecture of communication. Just as art can reveal the unexpected, the unanticipated colours of communication architecture spill onto the canvas.

Chapter Eight interprets and discusses the implications of the work. It provides a conclusion. In some sense, it is like the artist who steps back from the canvas for the last time, drops the brush into the water, and declares the work finished. Perhaps there is relief, satisfaction, and a sense of completeness. Alternatively, the work may be left *non finito* – an unfinished work unresolved and open-ended. The study is both – there are some clear findings, but there is also a strong sense of the ‘unresolved’, or ‘continuation’, with important considerations for future work raised in this final chapter. As is the case with an exhibited painting, it is hoped the thesis generates critique and contributes to the ideas and creative work of others.

Part A. Framing the Picture (CCN and its Major Themes)

1.3.1 *The Textured Framework of Communication*

Chapter One (Parts A and B) frames, supports and delineates the boundaries of the study. It does this by drawing upon a variety of literature sources spanning the current academic debate as well as the recurrent, everyday socio-political face of grey literature. In consideration of the aforementioned gaps in research specific to people with CCN, the study relies upon the inclusion of material such as government reports, conference papers and fiction. It is also motivated by the time delay between research and publication, and the potential that some important research may never be published; hence, access to innovative information can be challenging. Grey literature can fill this void (Pappas and Williams, 2011).

In this chapter CCN is defined and described with brief reference to the meaning and function of communication. Some experiences of CCN are illustrated in stories of people from different corridors of life, offering illustrations of the diverse and contextualised 'living with' experiences of CCN. Furthermore, the varying nuances of each of these stories, such as where this person is positioned in time, the nature and type of additional impairments, associated health conditions, age and gender, and orientation to agency, provide insight into layered facets of advantage and disadvantage embedded in the overall tensions of disability.

Part A of Chapter One also introduces the reflexive experiences of the researcher as entrenched in the lived experience of CCN, and hence reveals the motivation for the study. Thereafter, the topics of communicative competence, agency, communication access and alternative processes for communication (AAC in particular) are briefly introduced. Due to their close relation to the study, these topics help shape the underlying theory and methodology used in the research.

1.3.2 *Complex Communication Needs (CCN)*

According to ISAAC (2009) and Beaukelman and Mirenda (1998), CCN can be congenital or acquired and can be due to such conditions as cerebral palsy, stroke, motor neurone disease and autism, which can mean diminished or absent ability to speak and write. This ultimately can impede one's access to communication. The term 'complex communication needs' is frequently used to refer to individuals for whom verbal and written communication is difficult. This has led to the formal development of augmentative and alternative communication (AAC) approaches developed with or for people with CCN. For some people, CCN may have been present from birth in conditions such as cerebral palsy. For others, it may evolve later in life through events or injuries such as strokes, acquired brain injuries, or the onset of motor neurone disease or muscular dystrophy.

To appreciate the experience of CCN, it is helpful to briefly acknowledge the function of communication. The *Penguin Dictionary of Sociology* (2006, p. 69) defines *communication* as the transfer of messages from one party to another, and *semiotics* as the study of signs which take on meaning through the construction of codes: 'encoded by the sender and decoded by the receiver’ (2006, p. 69). Communication has two different but equally important parts: receptive language and expressive language. The International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY, 2017) describes it this way: a person transmits a message by speech (expressive communication) and receives a message by means of spoken and written language (receptive communication). To clarify, receptive language is what one hears and understands; expressive language is what one says to others, and perhaps also to oneself.

Alongside CCN, a variety of terms exist to describe communication impairment, revealing interests across medical and allied health and social science fields. Communication impairments, in themselves, are diverse with various terminologies used in the literature. For example, in addition to CCN, Beaukelman and Mirenda (2012) refer to various terms such as ‘communication disorders’, ‘communication impairment’, ‘speech and language disorder’, ‘aphasia’, and ‘dyspraxia’. Complex communication needs (CCN) is currently the overarching terminology used by the International Association of Augmentative and Alternative Communication (ISAAC) to encompass the range of more severe forms of communication impairment. According to Balandin (2002), people with complex communication needs have communication problems associated with a wide range of physical, sensory, cognitive and environmental causes which restrict/limit their ability to participate independently in society, and may benefit from using AAC methods either temporarily or permanently.

According to the American Speech-Language-Hearing Association (ASHA) website (http://www.asha.org/about/history/), the year 1925 was the beginning of formal assessment and remediation of speech-related problems in the United States. ‘Communication’ (as different from speech assessments) emerged much later, with the Communication Function Classification System (CFCS) following the World Health Organization’s (WHO’s) International Classification of Functioning (ICF). This is a five-level communication assessment system developed by Hidecker et al. (2011) initially designed for use with people with cerebral palsy but now utilised as a generalised communication functioning assessment. The terminology of ‘CCN’ is not used within this classification system; however, Balandin’s (2002) definition of the term CCN is the most widely used in the literature and by speech pathologists and is therefore employed in this study.

There is little quantitative research knowledge about the lives of people with CCN. (McDonald et al. 2017). As explained by Ison (2009), when information has been gathered it has often been conducted through of proxy interviews with caregivers or healthcare service providers instead of exploring the lived experiences of people. Ison, in reference to Carlsson et al., (2007) and Lloyd et al. (2006), suggests that proxies often have a different perspective from the person with a disability; indeed, they are likely to provide more information about their own experiences than those of the person they are representing. This study therefore relies upon some less conventional means to introduce people with lived experience of CCN.

A young Leeds University Masters graduate who uses a wheelchair for mobility introduced a conference paper with this defining statement: ‘I am Kate Caryer and I am a dumb spaz!!![1] In other words I have athetoid cerebral palsy and this affects my mouth so I can’t speak with it, but I can speak through a communication aid’ (Caryer, 2012). Real-life and fictional narratives in text and film offer a corridor into understanding ‘home’ lives and lived experience of CCN. For example *My Left Foot* (Brown, 1954) is an autobiography that was later adapted as a film based upon the life of author Christie Brown. This is an exceptional story of someone who, despite great odds, was able to find a way to connect to conventional communication and language by, for example, drawing and typing with his foot.

Novels and films as fiction ultimately offer valuable insight into the complex features of housing life, attitudes, experiences and interpretations from a wide cultural milieu (Manzi, 2005). Heather Rose, a woman with cerebral palsy and CCN, who co-wrote and acted the role of Julia in Rolf de Heer’s movie *Dance Me to My Song* (1998) is fictional, although there are elements that are based on Rose’s personal story. Not only does Rose’s portrayal offer a relevant and poignant illustration of life and CCN, it brings forth themes of home and place which are central to this thesis.

The film centres on the lives of two women: Julia, who has severe cerebral palsy and requires personal assistance in daily tasks such as getting in and out of bed, positioning herself into a wheelchair, showering, dressing, eating, setting up and turning on a communication device, and Julia’s support worker, Madeleine (played by Joey Kennedy). Madeleine resents caring for Julia and cruelly places Julia under a cold shower, reminding her: ‘If it wasn’t for people like me, you’d be back in a home’ (meaning institutional care rather than living in the

---

[1] The word spaz is used here as a reappropriation (reclaimed word) or, as Foucault (1976) describes it, ‘reverse discourse’.

community). The abuse continues throughout the film as does the dilemma: Julia either continues to face abuse at the hands of a resentful support worker, or risks going back to a residential care setting. Julia chokes on food that is forced too quickly into her mouth, she is hit, and she is admonished, yet she chooses the abuse rather than be forced back into residential care.

There are themes raised here which connect with other topics raised in the literature, for instance, the reality of abuse in care settings is pertinent, which is evident by current targeted government projects such as 'Less Silence More Safety' of the South Australian Health and Community Services Complaints Commissioner (HCSCC) Disability and Abuse Project launched in 2012. Government projects such as these suggest that home may not always be, as Dovey (1978) suggests, *a place of safety or security*.

In *Dance Me to My Song*, the harsh reality of limited choice is despairingly played out. If Julia is unable to make her 'in-home care' viable, then she must return to residential care. The lack of available 'carers' to provide the type of care Julia requires, and the fact that the person currently doing this role is being abusive, presents a harsh dilemma. Both living arrangements are untenable. In her own home, she faces brutal physical, psychological and financial abuse from her personal attendant 'carer', but she declares she would rather die than return to the institution. In 2002, Heather Rose passed away aged 36; in her obituary, an excerpt from her diary was read: 'People see me as a person who has to be controlled. But let me tell you something, people. I am not! And I am going to make something real special of my life! I am going to go out there and grab life with both hands!! I am going to make the most sexy and honest film about disability that has ever been made!!' (quoted in Starrs, 2008).

Australian author and disability advocate Anne McDonald is co-author of her own story *Annie's Coming Out* (Crossley and McDonald 1980). The limitations of her home in institutional care as well as the legal battle to enable (the then 18-year-old) Annie to leave it, are central themes raising the question of how closely these stories align with current-day experiences. How close to real lived experience is Julia's or Annie's situation? Since the onset of de-institutionalisation, do people with CCN still live with the coercive pressures of residential care?

> Home is a place of security within an insecure world, a place of certainty within doubt, a familiar place in a strange world, a sacred place in a profane world. It is a

> place of autonomy and power in an increasingly heteronomous world where others make the rules. (Dovey, 1978, p. 46)

When reflecting on these stories, and the exceptional expressions of agency within them, questions arose of whether strong expressions of agency might feature in the lives of the participants of this study.

The following anecdote exposes the tension between vulnerability, struggle and agency, voice and voicelessness. My friend, Ann, is the mother of Stella, who had an undiagnosed syndrome involving physical and sensory (hearing and vision) impairments. During a visit Stella, then three years old, was shuffling across the space between her mother and me, tapping everything before her with her hands and head. Stella stopped when she came near to me. I tapped the ground in front of her. She tapped the ground and then slid closer to me, tapping my leg. I tapped her knee twice. She tapped my leg twice and then vocalised with loud shrieks, neither laughter or screams, and went into a wild flurry of tapping and knocking her head. Two years later at a picnic, Ann explained her daughter raises her arms in the air to show ‘yes’. I asked Stella if she would like to come out of her wheelchair and onto the grass. Her arms shot up into the air, accompanied by the same shrieks as I lifted her to the ground. In the years before Stella’s health declined, I witnessed Ann’s struggle to find a place for Stella in a mainstream public school, rather than a ‘special school’. Ann explained to me that her daughter was not welcome in mainstream schooling because *they say Stella can’t communicate.*

The theme of agency emerging in the literature extends sometimes to those closest to the person with CCN. Returning to the autobiography titled *My Left Foot,* Brown (1954) describes a scene from his childhood:

> There was Mother, on her knees on the grass, a bucket of cement on one side of her and a jug of water on the other. She held a trowel in her right hand. She was looking proudly at the line of blocks she had already set out before her? That evening when she had served dinner and tea, she went quietly back to her work in the back garden. A few minutes later, father, happening to go into the yard for something saw her. He stood stock still, then slowly he approached the growing wall.
>
> He touched it with his foot. ‘What’s this?’ he asked. ‘What do you think you’re doing?’ Mother looked up. ‘I’m building Christy’s house,’ she said, setting in another block. (p. 117)

Faced with the unacceptable option of institutional care, the dilemma of how to provide a home for the now adult Christy was resolved by his mother and the eventual support of his father and four of his brothers, all bricklayers. A small home was built for him in the rear garden of their Irish, working-class home. Without the options before her that her other adult children had of leaving home to marry or live independently, Christy's mother finds another means, however onerous.

1.3.3 *Reflexing the Entrenched Researcher*

Unlike research where there can be scope to choose a perspective, or a position on a debate, I have learned a lens can be forced upon you without your knowledge or agreement. I, like Bridget Brown (Christie's mother), am the mother of a child with severe cerebral palsy, and share a similar compulsion to lay the foundations for home for our child. Yet to acknowledge this awakens shame and fear. Having a 'motive' not entirely rooted in an impartial tradition of science coupled with the gendered and often stigmatised role of 'mother' evokes a fear of being perceived as a 'woolly' researcher, or a 'mother on a crusade'.

Yet more than the 'parent' propels the study. Social work, art education and an interest in sociology influences much of the theoretical direction of this study. For instance, the study of critical theory led me to visit the Wolfgang Goethe Universität Frankfurt in 1992, and the work of Jurgen Habermas, sociologist and creator of the influential theories of communicative rationality and communicative action inspired me. Back then, these theories promised a fair and democratic society enlightened by discourses of society members – discussing, debating and rationalising the good. My learning of Habermasian theories occurred at a time *equal opportunity* was a lexicon or buzzword of national social policy. In the years of social work (and related workplace research) that followed, I adopted this into my psyche, and practice, as with other Australian social policy terminology trends which have seen the language of 'social justice' evolve to 'social inclusion' and in recent years 'inclusion' as popular words in the toolkit of the Australian justice debate. These terms have found expression in pieces of Australian social policy and I consider them now, as I did back in the 1990s, as lexicons or signifiers connecting Habermas' theories about the obligation of leaders and governments to make adjustments to ensure a rational, democratic society.

Over a night of traumatic labour, I descended from the 'helping professional' to the 'helped', but also from the 'in' to the 'mother of the out'; descended because that is how it felt – my child and I were suddenly pulled down into a world of others – the lesser, the poorer, the pitied. A doorway was flung open, exposing a ‘knowing’ of disability as ‘lesser’, as ‘misfit’ and as ‘charity’. It spurned an acute attitudinal change in me and carved a motivation for learning stretching beyond all previous passions. Hence, I have a lived experience of knowing that these lexicons of democratic society fall short of their signified objective. Through re-visiting the theories of Habermas, a new understanding of communicative rationality and communicative action emerged as it might be perceived and recognised as effective through the homes of people with CCN.

I bring to this study my learning and living of disability and the struggle to make life work for my child. On his behalf, I have experienced exclusion and pity but also curiosity, creativity, enthusiasm and a way of thinking about the world that has encompassed richer facets, and for this, I am grateful. Evoked too is the power to learn and make sense of this experience of CCN, to make comment, and to discover opportunities for progressive change.

Yet deep appreciation of the diversity of human communication has emerged from this experience. ‘The one thing a child does is make a philosopher out of a parent’ (Cohen, 1982, , quoted by Kittay, 2009). This statement quoted by Eva Kittay, who is herself the mother of a child with severe impairment, holds resonance for me, as philosophy is simultaneously my haven, my protest, and my mind-home to escape, as Dovey (1978) describes, ‘a profane world where others make the rules’ (p. 46). The tacit rules of citizenship that govern if, how and when my son gets to participate in society have elicited my ponderings and questioning of justice.

The need to understand the landscape of ‘home’ and to find safe passage in an uncertain future for my (now 12-year-old) child propels this inquiry. As might be expected, this concern has fostered a connection with other families and people with cerebral palsy, and the subsequent absorption of storytelling of others and where they have ‘ended up’. There are common and disturbing reports about isolation and abuse which are also sadly reflected in the Australian national reports *Shut Out: The Experience of People with Disabilities and their Families in Australia* (Commonwealth of Australia. National People with Disabilities and Carers Council, 2009) and the Productivity Commission report *Disability Care and Support*, Report No. 54 (2011).

The title of a philosophical paper by Kittay (2009), ‘The personal is philosophical is political: a philosopher and mother of a cognitively disabled person sends notes from the battlefield’, speaks to my situation. Being a mother of a child with severe impairment pushes one into arenas beyond that of a parent. Like my child, I live a life governed by the nuanced rhythms and interpretations of community beliefs and social policy. There is a need to carve out a way of living for my child, and a way to be a mother when the many unspoken rules of normalisation and citizenship have been turned on their heads; it requires the careful search for footholds at every height of the problem. ‘Embattled’ is a word I often use to describe my own position in the world as I navigate similar minefields (another metaphor used by Kittay) to negotiate and remediate the needs of my child. The battlefield is littered with mines which must be identified, understood, carefully traversed and, as with soldiers, psychological safety is at risk.

Yet I am *currently* a person without embodied impairments. Despite the closeness to my son and the bonds formed with others with CCN, there is a limit to my understanding of what it actually feels like to traverse life with CCN. I can wield language in support of my interests. On one hand, this study takes a critical approach to written and spoken language in research, yet on the other, it conforms to it. With the exception of the methodology I intend to implement, it is fully invested in written language. Sensory ethnography supports the researcher’s use of alternative methods of presenting the knowledge, or findings, gained from research such as video and other art forms. Yet, as pointed out by Pink (2009), ‘there are good reasons for writing. The written word is the most embedded and developed form of ethnographic representation, and a sophisticated technique for scholarly communication’ (p 135). From the perspective of CCN, these same reasons highlighted by Pink ironically concur with the status of written communication – as most developed, sophisticated and scholarly. These too form reasons for pursuing this approach, but likewise, I sense they are founded on conservative, unimaginative and ‘safe’ assumptions.

In addition to being a mother, there are other aspects of personhood shaping this study which both offer creative opportunities for the study and bring potential risks. My first degree in secondary art education, combined with a background in counselling work, are pockets of personal history woven into the project. Art, visual art in particular, is a natural communicator for me. Art is liberating and, in relation to this study, it offers the possibility of transcending written and spoken word, yet it can also be complex and confusing and, as such, there is the risk it may misrepresent meaning. I intend to use it with great care.

Non-reflexive social work too raises an element of risk. Personal motives for undertaking this study are spurred not just by lived experience of CCN, but are fuelled by the pursuit of social justice as strongly connected to the ethos of social work. In the tacit blend of the personal and professional lies the possibility of the study becoming influenced by unhelpful perceptions. For instance, Gleeson (2008) states that ‘wanting to contribute to the improvement of disabled people’s lives may be a noble enough sentiment, but it immediately raises some confronting political-ethical doubts centring on the dangers of paternalism and unconscious domination’ (p. 66).

Gleeson, in this comment, questions motives and reminds of the importance of reflexivity in research. In preparation for a study such as this, there is also a clear risk that the stories of others might be muddied (or even hijacked) by researcher agenda(s). I recognise a significant risk factor at play – a social worker attuned to being and much preferring the power, and feelings of satisfaction, in being the ‘helper’ rather than being the ‘helped’, coupled with experience of CCN and a personal need to ‘fix justice gaps’ that may risk the flourishing of the fully immersed learner this study requires me to be.

At a recent disability workshop one of the presenters suggested that a comment I had made bordered on paternalism – I was aiming to ‘fix things’ for others that they may not need or want fixing. The feedback was confronting and correct, and as such I enter this study aware of the risk Gleeson describes: championing and unwittingly undermining, which is an affronting approach to this study, particularly in my role as a researcher, which is to simply investigate, learn and understand.

This study also traverses the fine edge between competence to undertake the investigation, and the possibility of failure. Can I assume that my experience of CCN will be enough to manipulate methodology so as to discover answers to the questions of the study? Is there some arrogance in believing this could be possible, and am I at risk of overlooking possible alternatives? Furthermore, this investigation may involve the vicarious traverse of new battlefields, including those from an adult world not yet fully considered. These too might impact the study. There are many reasons to keep reflexivity at the forefront in this study. Reflexive practice highlights an imperative to remain mindful of this risk and to establish mechanisms of self-evaluation so as not to diminish, overlook or assume the thoughts, agency and interests of others. A journal will accompany this study with reflexive notes and descriptions of the embodied experiences of time spent with participants.

1.3.4 *Communicative Competence*

Sociologist and philosopher Jurgen Habermas states that

> symbolically pre-structured reality forms a universe that is hermetically sealed to the view of observers incapable of communicating .... The life world is open only to subjects who make use of their competence to speak and act. They gain access to it by participating, at least virtually, in the communications of members and thus becoming at least potential members themselves. (1984, p. 112)

As though in response to the gatekeeping notion that Habermas describes, the endeavour (and challenge) to help people become communicatively competent is fostered by the *International Society of Augmentative and Alternative Communication Journal*. Augmentative and alternative communication is underpinned by the notion of communicative competence, a term coined by Hymes (1966) but also broadly used by others such as Light and McNaughton (2015), Light (1989), and Todman and Rzepecka (2003).

The concept maintains a strong hold within ISAAC and journal contributions including the development of numerous forms of AAC and scientific research papers. At ISACC conferences, people with CCN and their families are welcomed alongside professional allied health service providers, with their voices contributing to the ‘consumer stream’ of these conferences.

The following excerpt from Light and McNaughton (who up until recently were editors of the ISAAC Journal) provides an account of the meaning of communicative competence:

> In 1989, Light defined communicative competence for individuals with complex communication needs who require augmentative and alternative communication (AAC) as a dynamic interpersonal construct based on functionality of communication; adequacy of communication; and sufficiency of knowledge, judgment, and skills. Specifically, Light argued that, in order to demonstrate communicative competence, individuals who required AAC had to develop and integrate knowledge, judgment, and skills in four interrelated domains: linguistic, operational, social, and strategic. In 2003, Light expanded this definition and argued that the attainment of communicative

> competence is influenced by not just linguistic, operational, social, and strategic competencies but also a variety of psychosocial factors (e.g., motivation, attitude, confidence, resilience) as well as barriers and supports in the environment. (2014, p. 1)

From this account, there appears to be a considerable onus on the individual with CCN, working with the AAC therapist, to bridge the communication gulf between themselves and the community, with little expectation of society, in whole or part, to become AAC competent. The linguistic, operational, social and strategic competencies are primarily aimed at bringing the skills of the person with CCN as close as possible to the conventional use of spoken and written language. The responsibility is located largely with the individual to demonstrate the outcome of communicative competence.

The work of allied health professionals in ameliorating the impact of communication impairment is essential. They work to close communication gaps by maximising the skills of individual and key communication partners (families) in using AAC. Yet the concept of communicative competence, as it currently stands, does not fit with strategies more attuned to a social theory of disability. The construct of ‘disability as personal tragedy’ has been challenged over the last 40 years (Oliver, 1990) with disable-ism, oppression and exclusion re-defined by focusing the problem of disability away from the medical perception of the individual (needing to be treated) to society itself as the main contributory feature of disablement (Oliver, 1990). ‘One of the most oppressive features of the prejudice which disabled people experience is the assumption that we want to be other than we are: that is, we want to be normal’ (Morris, 1991, p. 34). Arising from this is the question of how participants of this study might consider themselves placed on the journey to communicative competence.

Disability is not a characteristic of a person, nor an inevitable consequence of particular health conditions. It is a socially determined outcome resulting from the operation of disabling and discriminatory cultural, social and environmental conditions (Emerson et al., 2010). This means it is important to be alert to the potential relationship between the experience of CCN and the social constructs surrounding the person with CCN and their use of AAC. From this perspective, the communicative competence of others, including the wider community, in relation to AAC might also be placed under scrutiny. The South Australian Curriculum Standards and Accountability Framework (2009) outlines the learning of languages other than English, including Indigenous languages – *but why not AAC?*

1.3.5 *Augmentative and Alternative Communication (AAC)*

AAC is the lynchpin of communicative competence, so it is useful to examine it further. AAC refers to techniques or approaches which support or replace spoken language including all forms of communication (other than oral speech) that are used to express thoughts, needs, wants and ideas. People with significant speech or language problems rely on AAC to supplement existing speech or replace speech that is not functional. Special augmentative aids, such as picture and symbol communication boards and electronic devices, are used to help people express themselves. AAC intervention can either focus directly on the person using the communication system, teaching them to use communication skills with the aim of increasing participation, and/or focus on their communication partners (Pennington, 2007).

Augmentative and alternative communication (AAC) systems include signs, symbol charts or books, and voice output communications aids (VOCA), otherwise known as speech generating devices, which are often prescribed and introduced by speech pathologists to people who have difficulties producing understandable speech, gestures and/or writing (Pennington, 2007). Supporting this practice is a solid body of evidence documenting the effectiveness of AAC intervention (Baker et al., 2011; Dietz et al., 2009; Beukelman et al., 2007).

When considering the function and purpose of AAC, there is an inherent binary. Is AAC a treatment (an intervention) for the individual to gain as close as possible access to communicative normality, or is it a language with a rationale related to broader (non-impaired) social adaptation and utilisation? In relation to this study sits a core question – can we expect the sociological researcher to use AAC? Furthermore, there appears to be little available research distinguishing natural (or informal) AAC, and that which is introduced more formally by a speech pathologist or AAC specialist. Studies have tended to focus on the development and efficacy of professional intervention rather than on the more organic types of AAC engineered by individuals and families in their attempt to improve communication.

My direct experience of CCN has taught me that multiple forms of natural or organic AAC exist; that communication inroads can be formed by the individual and those in intimate relationships with them (rather than structured through the intervention of a therapist), enabling ways to get their message across. One evening in 2014, a friend who was working at the time in the Department of Linguistics at Adelaide University observed the family communicative interactions with our son. In describing what he saw us do (head tapping, eye-pointing, timed stares, nasal vocal sounds) he declared it a unique form of language. This observation encouraged me to look more closely at the concept of language to include AAC.

Adjunct to this observation is the tension between formalised AAC and the valuing of communication diversity. In reference to speech and language therapy, and the social model of disability, Earle (2003) poses the question: is it always appropriate to treat disability? Is it important that everyone communicates the same way? Looking at this issue in another way: is it plausible to anticipate a society capable of embracing diverse forms of organic communication?

1.3.6 *Facilitated Communication*

Facilitated communication, ostensibly a form of mediated communication (Stock, 2011), is described by the Anne McDonald Centre (an Australian organisation devoted to the needs of people with little or no understandable speech)

> as a hands-on training technique which aims to give people the skills they need to use communication aids effectively with their hands … the degree of facilitation needed varies from person to person, ranging from an encouraging hand on the shoulder (to boost confidence) to full support and shaping of the communicator’s hand (to enable them to isolate and extend of an index finger so they can point). (Anne McDonald Centre 2016)

Facilitated communication techniques, however, are controversial, for instance, if facilitated communication is used to report abuse, there is a lack of certainty about whether the facilitating partner might be influencing the content of the message (Mostert and Kavale, 2001) and for this reason, although it is referred to at times in the study, it is not used as a data collection method.

1.3.7 *Communication Access*

Emerging from pockets of AAC discourse, communication access is highlighted by Blackstone (2008) as a broad concept within disability. ‘Access today means having ways to participate actively and equally alongside others in the community. This requires an ability to communicate in authentic and meaningful ways’ (2008, p. 2). It differs to the notion of communicative competence in that the concept of access focuses on adaptations to the environment to accommodate communication needs and methods. Anne McDonald, a disability advocate and a person with lived experience of CCN, provides an illustration of gaps in communication access:

> For people without speech, talking is often dependent on the generosity of others, either in providing interpretation or facilitation or in giving up time to listen. While this is inevitable, there needs to be an irreducible right to make one’s opinions known on issues concerning your future well-being.
>
> At the moment social conversation and medical consent are equal in the sight of the law, both depending on the accidental availability of communication partners with the necessary skills and commitment.
>
> There is no right to be heard. There is no right to an interpreter. There is no obligation to listen. (McDonald, A. Anne McDonald Centre)

Communication access rights of people with CCN has recently emerged as a fundamental rights issue. For example, the implementation of the South Australian Disability Justice Strategy (2014–2017) has seen the state government commence a process of introducing justice legislation to assist people with CCN. For example, the Justice Strategy Plan 2014–2017 (SA) outlines more than 40 priority actions, two of which are listed below:

> 2.1. Amend the *Evidence Act 1929* to give people with complex communication needs a general entitlement to have a specially trained Communication Assistant present for any contact with the criminal justice system.
>
> 2.2. Establish a service in the non-government sector which provides a pool of trained independent Communication Assistants to facilitate communication between witnesses or defendants and an investigative interviewer. The Communication Assistants would be available throughout the criminal justice process.

As suggested by these recent recommendations, access to communication has not received the same acknowledgement as other forms of access in the field of disability. The arguments for communication access are as valid as those for parking spaces, curb cuts and ramps (Collier et al., 2012) but they have been slow in gaining ground. For example, the recommendation of the South Australian Disability Justice Strategy (2014–2017) of the use of Communication Assistants is supported by research which suggests the provision of trained communication assistants significantly increases the ability to communicate and participate in their communities for people with CCN (Collier et al., 2010) yet, unlike the right to a language interpreter as suggested by McDonald (1992), the Justice Strategy described above sits in isolation in its recommendation for rights to such assistance.

1.3.8 *CCN and Agency*

> Contentment is not the only thing that matters in a human life; active striving matters too. (Nussbaum, 2006, p. 73)

While CCN and agency were introduced earlier in the stories of Christy Brown and Heather Rose, agency needs to be conceptualised further to account for the nuanced experiences of agency and self-determination as they might be expressed by (or denied to) persons with CCN. According to the *Penguin Dictionary of Sociology* (2006), an agent is an individual engaging with the social structure. Wehmeyer and Schwartz (1997) refer to an earlier definition of self-determination as ‘acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference’ (p. 22).

Various understandings of agency and self-determination have emerged in recent years, reflected in phrases such as ‘self-advocacy’, ‘self-directed care’ and the concept of ‘user-led service delivery’ described by Barnes and Mercer (2006). There is also agency specific to CCN and AAC, as reflected in the earlier stories of the utility of both formal AAC and organic methods of getting their message across developed by people with CCN in connection to those closest to them. There is an important debate about the extent (or the limits to which) the social structure determines what individuals do. It reveals the existence of disparate thinking in relation to the extent that social structures might impact upon the person, with some sociologists placing more, less or very little responsibility on the individual.

This is a particularly interesting concept when considering CCN. As described earlier, communication is paramount to human agency – without it, it is difficult to accommodate a notion of agency at all. Secondly, the compelling pressures (as described earlier) for individuals to become communicatively competent in socially sanctioned language run counter to the acknowledgement of the agency behind the individual's natural, or informal, AAC, referring to types of communication the individual has created for themselves. For example, a soft growl (to say 'no') also risks social misunderstanding such as a possible perception of aggression.

Multiple illustrations of agency will likely be revealed when conducting research with participants in their homes. For now it is useful to consider some more general examples of how agency might be enacted by people with CCN.

When returning to the story of Stella and her less conventional ways of communicating or her 'unique language', it may be easy to acknowledge her agency from an informed position. Yet when considering the output of this agency, for example, would Stella have been lifted from her wheelchair onto the grass by someone who did not recognise that her arm movements were her voice? Agency in this context requires the informed agency of others to bring about outputs or desired affects. These types of questions may prove useful when reflecting upon the types of communication experiences participants might share in the study.

In an article titled 'Enabling the Auteurial Voice in *Dance Me to My Song*', Starrs (2008) provides a description of Julia's agency:

> he treats her to an over-priced ice-cream the shop assistant says 'Poor little thing … She'll enjoy this, won't she?' Julia types the words 'Fuck me' and promptly drops the ice-cream on the floor. Eddie laughs supportively. 'I'll just get her another one,' says the flustered shop assistant, 'and then get her out of here, please'. With striking eloquence, Julia wheels herself out of the shop, her voice machine announcing 'Fuck me, fuck me, fuck me, fuck me', as she departs exultantly. With this bold statement of independence and defiance in the face of patronising condescension, the audience sees Rose's burgeoning strength of character and agency reflected in the onscreen character she has created.

While not all expressions of agency in this scenario are reliant upon the VOCA (voice output communications aid), there is an undeniable theme that runs through Starr's (2008) account of (and indeed my own interpretation) of the movie. VOCA, the substitute voice, becomes the conduit of agency. ‘The callous Madelaine soon realizes Julia’s strength is in her voice machine and withholds access to the device as punishment’ writes Starr (2008). Agency, here, is dependent on the voice she transmits from the machine, which evokes the question: *without the communication device, which reproduces normalised, albeit robotic, human language, is there still room for agency*?

1.3.9 *CCN and Justice*

The agency described in the fictitious Julia, and in the real life Heather Rose, belies a strong relationship between verbal and written communication and power. Chapter Two is dedicated to theories of justice as related to people with CCN. However, before entering a discussion about disability in Australia it is worthwhile highlighting the notion of ‘voice ‘and its connection to individual or group agency, advocacy and protest. As already indicated, justice arises as a major theme within the available literature as there is compelling evidence of CCN being inadequately understood and accounted for within the socio-political field of disability. ‘Voice’ has become an important tool in struggles for recognition of disability (Thil, 2015), yet discourses of communication disability, likely due to dominant research and language constructs, appear thwarted from the outset. ‘Arguments about access, for instance, are prominent in the disability field, yet communication access is given short shrift’ (Duchan, 2006).

People with communication impairments are largely excluded from disability politics. As in all other forms of politics, arguments are dominated by people who communicate well and fluently (Levin, 2013). Without vehicle(s) to realise the agency of people with CCN, such as processes of incorporating and normalising AAC, the literal and metaphorical activation of ‘voice’ for such individuals is stymied. The person with CCN, regardless of how well she or he might communicate in other ways, is overlooked, resulting in the loss of their social contribution as well as diminished citizenship.

It is not sufficient to argue the interests of people with CCN are encapsulated within broader disability debates. There are common concerns, however, that people with CCN have unique experiences, resulting in more communication-specific needs and interests. As outlined earlier, literature from the field of AAC highlights communication access needs and barriers of people with CCN (Caron and Light, 2016; Collier et al., 2012; Bryen et al., 2004).

Herein, despite the development of increasingly sophisticated communication aids, as well as recent policy initiatives (such as the United Kingdom’s current policy) aimed at improving access to them, some major obstacles stand in the way of the potential of AAC being realised to any significant degree (Hodge, 2007). Many individuals continue to experience serious challenges participating in educational, vocational, healthcare and community environments (Light, 2015).

Part B. Introducing the Frame (Disability and Housing in Australia)

1.4 *The Structural Framework of Disability, Housing and CCN*

Part A explored the meaning of CCN. Part B is centred on the exploration of home and the meaning it has for people with CCN. To place the study in context, the related topics of disability and housing are introduced, to inquire how these are experienced across the Australian socio-political landscape, particularly for people with CCN.

A statistical account of disability in Australia is outlined, followed by a more detailed exploration of its relationship to housing described in research and policy. Crucially related issues such as care provision, universal housing and inclusion paradigms are also examined. Throughout this part of Chapter One the recurrent theoretical and socio-political elements underpinning these themes are explicated and blended, leading to a purely theoretical examination of the topic in Chapter Two.

By introducing the shifting ideologies and practices of disability in Australia, the realm between the ‘theoretical’ and the ‘real-life’ lived political world of disability is laid out. Drawing upon the limited available literature, and combining it with a secondary analysis of data sought from the Australian Bureau of Statistics (ABS), the demographic context of home for people with CCN is located.

1.5 *Disability in Australia*

The ABS calculates that 18.5 per cent of the total population have a disability (ABS, 2012). According to Wiesel et al. (2015) about a third of that percentage (or 1.4 million) have profound or severe core activity limitation or restriction (ABS, 2012). In 2012, the disability rate among 15–24-year-olds was 7.9 per cent, becoming successively higher in older age groups; for example, it is 29.0 per cent for 55–64-year-olds. At the time of the study there was not a clear indication of the percentage of Australians with CCN, so I carried out a secondary analysis of ABS data to calculate an estimation of the population affected. The process and findings of this prevalence study are presented in more detail at the close of this chapter.

Disability policy in Australia is currently undergoing significant change. In 2009, the National People with Disability and Carers Council released the findings of a national consultation project titled *Shut Out: The Experience of People with Disabilities and their Families in Australia.*

> For many years, people with disabilities found themselves shut in – hidden away in large institutions. Now many people with disabilities find themselves shut out – shut out of buildings, homes, schools, businesses, sports and community groups. They find themselves shut out of our way of life. (Commonwealth of Australia. National People with Disabilities and Carers Council, 2009, p. vi)

The report paved the way for the Australian Government Department of Social Services National Disability Strategy 2010–2020 and in 2011 the Productivity Commission released its own report, *Disability Care and Support*, describing Australia’s approach to disability as ‘underfunded, unfair, fragmented and inefficient’ (p. 5). Since this time, the landscape of disability policy in service provision in Australia has undergone significant change. This has most notably involved the introduction of the National Disability Insurance Scheme. Launched in 2013, it is expected to be fully implemented by 2019 (NDIS, 2015). The NDIS states that its purpose is supporting people with a permanent and significant disability towards achieving life goals including independence, involvement in community, education, employment and health and wellbeing.

While this initiative fosters a commitment to better, more individualised support for people and their families, Australia continues to face problems in establishing a governance model of disability capable of alleviating the ongoing poor outcomes for people with disabilities (Henman and Foster, 2015). This is not surprising when considering the limited role of the NDIS as an agency of resource allocation, primarily in the purchasing of needed services such as care, rehabilitation and equipment. Although the NDIS states its purpose is to assist participation within the community, with education and employment highlighted as examples of this, it is clear that it does not include direct access to other social goods such as education and employment (*National Disability Insurance Scheme Act 2013*).

‘While the NDIS is clearly positioned as only part of the response to the social exclusion pictured within both documents [National People with Disabilities and Carers Council, 2009 and Productivity Commission, 2011], I ask whether its implementation overshadows a wider reform agenda focused on community inclusion and economic participation’ (Hallahan, 2016, p. 193). Reinforcing this questioning of the NDIS in relation to economic participation is a study by Hemphill and Kulik (2016) who report a decline of employers hiring people with disabilities, post the introduction of the NDIS. Furthermore the NDIS is divorced from education as recently illustrated in a Senate report on the education of students with disabilities in Australia. The NDIS does not fund the resources needed to access an education but nor does Australian public education as was declared by report of the Australian Senate Employment and Education Reference Committee in 2016. ‘Access to education is a basic human right, but for many students with disability in Australia, it is a right which they are prevented from accessing’ These critical and ongoing elements of being *shut out of schools, businesses and employment* are yet to be afforded the social planning and policy rigour required to address such exclusion. This suggests that, although this study was carried out at a time of progressive social policy change, significant inroads are still required.

The profile of CCN concealed in this landscape of evolving disability justice ideologies and discourses has required an attendance to literature spanning multiple fields of academia as well as the initiatives of social policy. Furthermore, at this transformational time in Australian history, a continuous stream of grey literature has accompanied and informed the development of this project, flavouring it with a sense of ‘evolution’, a work in a collective chain of progress. This grey literature includes social media and the continuous flow of petitioning from citizens seeking a political voice through vehicles such as Change.org[2] and Getup,[3] and their campaigns in relation to disability and housing issues in Australia. Illustrations of the ongoing need for change exist throughout disability rhetoric, having become more relevant with the introduction of the NDIS. The People with Disabilities

---

[2] Change.org is a petitioning application developed by B Corp certification, USA.

[3] Getup is an Australian independent movement of lobbying on campaigns for social justice, economic fairness and environmental sustainability.

website (PWD) provides a list of citizen advocacy services which include government, non-government and self-help organisations, covering a vast number of topics.

The significance of this form of grey literature is illustrated in the alignment between the varying types of advocacy. For instance, a Change.org campaign initiated by Connor S. (2015) titled *To urgently launch a national inquiry into violence, neglect and abuse against people with disability in residential and institutional settings* was built upon the recommendations of the Office of the Public Advocate (OPA) report (2015) into violence and abuse against people with disability in Victoria. This information is further supported by the findings of the *Senate report into the violence, abuse and neglect against people with disability in institutional and residential settings, including gender and age-related dimensions, and the particular situations of Aboriginal and Torres Strait Islander people with disabilities, and culturally and linguistically diverse people with disabilities* (Parliament of Australia, 2015):

> Violence against people with disability in institutional and residential settings is Australia's hidden shame ... The evidence of this national epidemic is extensive and compelling. It is a deeply shameful blight on our society and can no longer remain ignored and unaddressed. (p. 1)

As illustrated in the grey literature, there is a reality of abuse, particularly located in residential settings, and this has implications for this study. In addition to the ethical concerns likely to be raised as part of a research endeavour with vulnerable adults, the potential to discover the existence of abuse in the lives of participants appears to be significant.

1.6 *Disability Housing in Australia*

> Many people with disability in Australia experience housing and living arrangements which are markedly different to the rest of the population. A large proportion of people over 25 years old live with parents, in group homes or in large congregate or institutional settings. People with disability are more likely to experience housing stress, are over-represented in housing assistance programs and in the homelessness population, and are under-represented in owner-occupation. (Wiesel et al., 2015, p. 1)

As part of a broad welfare structure which encompasses other aspects of disadvantage, not just disability, Australia provides some low-cost housing options for people who experience difficulty accessing the private rental market. This includes housing provided and managed by both government and non-government community agencies, with these agencies operating as the social landlords owning and manage social housing. In South Australia, the largest social landlord is Housing SA – South Australia's public housing provider or state housing authority – with a range of other social landlords operating within the community housing sector providing housing specifically for target groups, such as people living with disability (McLoughlin and Tually, 2012).

In relation to disability, Australia is a party to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) wherein article 19 bears specific relevance to housing. It states people with disabilities have equal rights to all persons to live in the community. This includes the opportunity to choose their place of residence and in doing so have access to a range of in-home supports to support living and inclusion in the community (UNCRPD, 2016, Article 19). Yet a submission to the previously cited *Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings* by the Australian Cross Disability Alliance, which is a joint committee of Australian legal, advocacy and human rights organisations, indicates a significant disconnect between the rights of people described by the UNCRPD and the reality of everyday lives:

> People with disability in Australia are restricted in their right to live independently and be included in the community, including the right to choose freely where and with whom they will live. The inaccessible design of social and private housing options and the lack of appropriate and portable support services are key barriers. The predominant 'supported accommodation' framework used by Australia within the specialist disability service system also plays a key role … The 'supported accommodation' framework does not separate housing needs from support needs, and results in many people with disability, particularly those with high and complex support needs, being compelled to live in residential institutions and other specific purpose arrangements in order to receive the supports they need. Article 19 is derived from the traditional civil and political rights of liberty and security of the person (see also Article 14), and it makes clear that institutional accommodation is an explicit violation of rights to liberty, and that Australia has an immediate responsibility to prevent and remedy this violation. (2012, p. 127)

This submission points to a significant gulf between the United Nations convention and Australian public housing provision. Together with the transition in disability policy through the introduction of the NDIS, Australia appears to be grappling with a cascade of unfettered legal, social and moral obligations such as how to meet the residential needs of people in an NDIS policy context. These themes will be explored a little further on; however, at this point it is useful to examine some of the concrete themes surrounding Australia's response to housing and disability. These topics are discussed under subheadings within this section: 'Housing and Care', 'Universal Housing' and so forth.

Historically, many Australians with significant impairments have resided in institutional care. According to Goggin and Newell (2005), institutions since colonial times have met a stark need. For children with disabilities, for instance, 'the only facilities and access to care were often to be found in institutionalised care established by the state and religiously auspiced organisations' (p. 127). The *Disability Services Act 1986* (Cth) details within its principles and objectives the rights of people with disabilities to live within communities rather than in segregated settings. The research literature appears to point to varying interpretations of 'live within the community'.

As outlined below, this can vary considerably in the day-to-day living arrangements of people with impairments, and is greatly affected by resources. Research in Australia highlights ongoing deficiencies in appropriate and affordable housing for people with disabilities (Bleasdale 2006; Beer et al., 2006). Bridge (2002) highlights severity of disability as the single greatest influence on the proportion of people living in care accommodation. Furthermore, the housing experiences of people with disabilities in Australia are shaped by the type of disability they have (Beer et al., 2009). This raises the question of how CCN might shape the nature of housing choice and home experience.

This report, amongst others, reveals the broad scope of disadvantage of Australians living with disability. However, in line with the interests of this study, issues of housing are particularly highlighted. Once physically segregated in institutions, many Australians now find themselves socially, culturally and politically isolated in so-called community settings only to be re-institutionalised into clustered group homes with a continuance of smaller-scale institutional practices. Congregating people is designed to support fiscal objectives but can result in quasi-institutions where residents are often excluded from the local community (Goggin and Newell, 2005).

Wiesel and Bigby (2015), in examining the process of de-institutionalisation (1974–2014) for people with intellectual impairment, highlight shaping factors such as shifting policy frameworks from ‘normalisation’ to ‘choice’, urban development policy and the re-use of large-plot institutional lands, and the opposing voices of families of people with intellectual impairment.

Gaps in sufficient reporting of the quality of homes and housing post-institutionalisation continues to prevail, as noted by Bigby and Beadle-Brown (2016). They state that, since the 1980s and de-institutionalisation, group homes have been the most common alternative to institutional care, but evidence concerning factors that affect the quality of group homes is limited. Bigby et al. (2016) and Bigby and Beadle-Brown (2016) have explored the quality of culture within group homes for people with intellectual impairments at severe or profound levels. They have examined some of the qualities of ‘underperforming group homes’ where Bigby et al. (2016) discovered staff-centred orientation, staff viewing residents as ‘not like us’ and the misalignment of power holder values and organisations’ espoused values. In ‘better group homes’ there was better alignment between the vision and mission of the service and staff values, as there was a person-centred approach, flexibility in practice and stronger leadership (Bigby and Beadle-Brown, 2016).

AHURI have published a handful of reports specific to people with disabilities in recent years including Wiesel and Habibis’ report (2015), which refers to the debate surrounding cluster housing, another alternative to institutionalisation (where two or more houses/units are located on one site):

> A major argument in favour of certain cluster housing models, such as ‘intentional communities’, is the advantage of living close to other people with disability, creating opportunities for friendships that can be more easily sustained over time (Randell & Cumella 2009). Indeed, people with disability experience significant benefits from housing that facilitates opportunities for friendships and meaningful relationships with other people with disability leaving nearby. However, this could be achieved in non-congregated housing where there is a more balanced mix of people with and without disability. (p. 25)

This final report outlines the findings of research addressing two conceptual and policy challenges: 1.What impact does housing assistance have on social inclusion for people with disabilities? 2. How can governments ensure that they maximise the social inclusion benefits from the housing assistance they provide now and into the future? In concluding, the report makes it clear that:

> people with a disability and their households remain one of the most disadvantaged groups within society. Housing assistance, and especially access to social housing, is one measure that governments can take to substantially improve their wellbeing and degree of social inclusion within broader society. People with a disability should remain a priority group in the housing allocation processes of social housing providers and more attention needs to be paid to the interface between health services and housing. (p. 68)

1.6.1 *Housing and Care*

The Australian Bureau of Statistics' Disability Ageing and Carers surveys (2015, 2012) reveal that communication, particularly for people with severe or profound disability, determines daily care needs. Care provision is a major factor in housing for people with disabilities (McLoughlin and Tually, 2012; Bleasdale, 2006), hence some exploration of its meaning is warranted. Like inclusion, the term 'care' can evoke nuanced interpretations. The ability to give and receive care is essential and rewarding to society (Noddings, 2012; Kittay, 2011) in that it addresses needs but also fosters and strengthens our human capacity for social relatedness and empathy with others. Noddings (2012) illustrates concepts of everyday experiences of care by referring to a student who energetically pursues a topic after the educator's encouragement, a patient who breathes a sigh of relief under the nurse's gentle touch, and a library user who works effectively with new technology under the librarian's direction. These notions of care can be extended more broadly to include the continuous care relations expressed through human empathy, reciprocity and receptivity. Concepts of charity, friendships and familial expectations are woven into the subject of care; so too is the notion that care, given and received, is universal.

Human beings are naturally subject to periods of dependency, and people without disabilities are only 'temporarily abled' (Kittay, 2011). In this sense, we all fit on a shifting continuum of vulnerability, as supported by Nussbaum (2006), who states: 'we are needy temporal animal beings who begin as babies and end, often, in other forms of dependency' (p. 160). The experience of disability, too, places people on a continuum of care with a relationship existing between the severity of impairment(s) and the level of care required (Bleasdale, 2006). It is important to consider that level of care can also be influenced by inaccessible environments. On a personal level, without my glasses I am unable to read, and my dependence would greatly increase as a result. Davis (1989) writes:

> If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would not be an inconvenience. (p. 19).

Shakespeare (2006, pp. 165–166) argues social relationships, charity (as known through love and solidarity), care and friendships must play a part in the support of people with disability. However, there is a tense line to be traversed between notions such as care and charity and oppression. Assumptions that care will be provided ‘out of love’ still places enormous burdens on women, traditionally allocated this role, which ‘diminishes their productivity and contribution to civic and political life’ (Nussbaum, 2006, p. 102). This gendered nature of care translates into a realm of industrial ambiguity between paid and unpaid ‘carers’. In Australia, for instance, multiple terms are used to describe paid care including ‘support workers’, ‘carers’ and ‘personal attendants’. There is no delineation of different levels of ‘care’. For example, preparing a meal, assisting with showering, and loading and programming a sophisticated technological communication device are care needs that might also be allocated to the role of the care attendant.

The complexities within the philosophy, structure and delivery of care, including the ongoing risks that come with not receiving ‘good care’, span all eras in the provision of disability services. Fine (2005) emphasises the intimate nature of care, but also highlights the extent to which this sensitive work has been de-humanised in some hospital and nursing home settings, with low status and reward attached to it, and with confusion/blurring with other roles.

Care work is not highly paid due to its association with women’s unpaid care work (McDonald, 2016). As Fine (2005) suggests, ‘a potential workforce of low-paid care staff suggests a future of McDonaldized care, workers who might be thought of as providing cheap and affordable labour at short-term notice, ready to be laid off if and when it is convenient’ (p. 262).

Disability housing research (Winker, 2015; Bridge, 2002) demonstrates a link between increasing complexity in care needs and the escalation of care in residential establishments. Situations of control and uniformity indicated by Barnes (1999) continue to be evident in residential care settings years later. The autobiography of a young South Australian man with cerebral palsy without CCN living in an aged care facility provides a recent example of how such uniformity of living might be experienced: ‘Changes at Flora are ongoing and new rules and regulations sometimes seem never ending. It can be difficult to keep up with them all and to get used to the constant changes in staff’ (Afford, 2009, p. 183). For a resident with CCN, this likely inhibits communication as communication partnering skills learnt and offered by staff might be lost due to this constant staff turnover.

While Afford (2009) describes positive aspects of his aged care home, there are several parts of his narrative which flag concerns such as a description of self-harm and the loss of autonomy:

> Maria, a volunteer at Flora who gives me hand massages and manicures, has become a very good friend. One day she noticed a bite mark on my hand and she suggested that I use a teething ring instead of my hand to take out my frustrations. (2009, p. 183)

An inter-relationship exists between home, care and autonomy.

> The ability to be in control of care tasks is critical to people with disability and needs to be considered explicitly in this research when the issue of support, and the delivery of services, is studied in its relationship to the provision of housing. (Bleasdale, 2006 p. 21)

Being able to manage and control one’s own care is made difficult for a range of reasons which include Bleasdale’s (2006) observation that care work is de-valued and its status is diminishing. This holds ramifications for choice making, such as the ability to choose who does the caring. Thus, the question remains: how can people with CCN control care tasks? Furthermore, how effectively are support workers trained in the use of AAC?

This situation includes many young people. In 2005, the Australian organisation Youngcare was established in response to the large number of young people residing in nursing homes. According to its website (Youngcare.com.au) in reference to a report from the Australian Institute of Health and Welfare (AIHW, 2007), more than 6,500 young Australians with a severe or profound disability live in aged care due to lack of choice, with a further 600,000 being cared for by family or friends. The National Aged Care Data Clearinghouse (2014) highlights the statistic that 54 per cent of young people in residential aged care receive a visit from friends annually and even fewer will leave an aged care facility to visit a friend (YoungCare website 2014).

In response to this problem in Australia, some apartment-style housing alternatives have emerged. For example, the YoungCare Project, as described by Muenchberger et al. (2012), refers to the establishment of a contemporary, purpose-built supportive accommodation solution for young adults with access to 24-hour attendant care that commenced in Queensland. In some other states, similar models of accommodation are emerging with much of the evaluation still forthcoming at the time of this study. Since this time, despite a National Senate Inquiry announced in 2014, and the sporadic establishment of housing initiatives such as YoungCare, little appears to have changed. ‘More than 7,000 young Australians with disabilities are forced to live in nursing homes because they’re unable to find suitable accommodation that meets their needs’ (Winkler, 2015).

The delivery of care in relation to housing is the fiscal grouping together of people based upon the commonality of their ‘care’ needs. This streamlined sharing of care amongst a group rather than a process of designated support to people living in their own homes of choice offers an apparent fiscal benefit. It is cheaper to offer ‘care’ in this way; however, there are other costs to be borne. In recent years, a scattering of disability research projects and reports (Johnson et al., 2010; Bostock, 2001) have addressed the question of housing, often premised by themes such as deinstitutionalisation and community care. Research and planning into housing needs was neglected prior to deinstitutionalisation, only to emerge ‘once the horse has bolted’ (Bleasdale, 2006; Goggin and Newell, 2005). The question of how to ensure the care required for people with significant disabilities, whilst enabling equitable residential choice, has only received attention in recent years (Bleasdale, 2006; AHURI, 2007; Youngcare website).

With the arrival of the NDIS, new opportunities for housing discussion have emerged. David Bowen, the CEO of NDIA, states:

> The current system of accommodation support is failing people with disability in Australia. There are thousands of Australians with disability who are forced to live in unsuitable housing because there are no alternatives. Often that means accommodation where people are segregated from the broader community. (National Disability Insurance Scheme, 2016)

In April 2016, the NDIS showcased some of the nation’s most innovative housing projects. Two of these projects are displayed in video format on the NDIS website (2016). The final statements of each video reflect, at least, the intention to improve the way housing is experienced for people with care needs:

> Supported accommodation can really look any way and be any makeup and any model it needs to be. (National Disability Insurance Scheme, 2016, Chilvell Project)
>
> It’s important because people should be able to choose where they live not based on how much money they receive or what needs they have. It’s about what they want out of life and they should have the right to choose that. (National Disability Insurance Scheme, 2016, Abbotsford Project)

These are encouraging statements, but they represent small fragments of progress amidst great fiscal and social challenges. Housing shortfalls, in the context of the NDIS, are evident, as demonstrated by Wiesel (2015) and Winker (2015). ‘The National Disability Insurance Scheme (NDIS) faces a huge shortfall in disability housing when it is fully rolled out in 2020’ (Hermant, 2016).

As with all other pockets of disability housing research, people with CCN or communication issues are not a focus of the discussion of housing needs in Australia. The extent to which CCN impacts upon the experience of home, and how this might be understood, supported and improved, is unknown. CCN in relation to housing is likely to be entrenched in notions of care, and in the new era of the NDIS the who, how and where of care are important topics for policy and emerging practice.

These are practical issues which underlie a significant philosophical tension between goodwill and rights. The fact that we are all on a continuum of care is an important point, as is the value of caring. ‘The good of others is not just a constraint on this person’s pursuit of her own good; it is part of her good’ (Nussbaum, 2006, p. 158).

For the recipient of care, particularly at the more complex end of the continuum, there are other issues such as freedom and choice.

> Until the concept of disability disappears and is replaced by a society that is structured to support everyone’s life relatedness and contribution – until that day my life and opportunities and the lives of every other person who carries the label ‘disabled’ depends on the goodwill of people in the human service system. Goodwill is no

> substitute for freedom. (National People with Disabilities and Carers Council, 2009. p. 1)

So far the discussion about care has been premised by communal behaviour constructs such as ‘goodwill’, ‘charity’, ‘love’, and ‘friendship’, revealing tensions with qualities such as ‘rights’ and ‘freedoms’, implying a human rights perspective. Furthermore, there is a less discussed aspect to the notion of care. Shakespeare (2006) highlights a point made by Sevenhuijsen: ‘Caring for others can also stem from less noble motives, such as the urge to meddle or to control others’ (p. 145). This notion opens the study to the possibility that care may not always be delivered free from other agendas and interests.

1.6.2 *Inclusion and Housing*

The term ‘inclusion’ features in the title of many published works centred upon the topic of disability and housing (see Gooding and Anderson, 2017; Merrells et al., 2017; Taleporos and Winkler, 2017; Tually et al., 2011). The concept of inclusion is widely used, as it bears power in its popularity and its symbiosis with government housing policy, yet it is punctured with multiple meanings that undermine its impact and reveal that it does not bring tangible social change. An examination of the topic of ‘inclusion’ in relation to the notion of home and the various housing debates in Australia provides insight into the bedrock from which housing research and social policy is grounded.

On the face of it, the notion of social inclusion appears laudable; as it is aimed at bringing excluded people into the mainstream population. Clapton (2009) points out that it often does not take into consideration the processes of exclusion which created the situation of ‘outside’ in the first place, stating: ‘I contend that addressing structural exclusion is not merely about attending to “absence” or the state of “being left out”, it involves the intentional deconstruction of processes of active exclusion configured with existing relationships of power, orthodoxy, and hegemony’ (Clapton, 2009, p. 2). It also unwittingly collaborates with the concept of assimilation. The person on the outer must come into the fold to be ‘fitted’. It is never the other way around. Inclusion Press, a Canadian organisation that collaborates with people with disabilities and their families, explains this point:

> Much more needs to be done including a search for an acceptable definition and practice of inclusion. Across this country a definition of inclusion is offered. It is

> generally accepted that ‘Inclusion’ means inviting those who have been historically locked out to ‘come in’. This well-intentioned meaning must be strengthened. A weakness of this definition is evident. Who has the authority or right to ‘invite’ others in? And how did the ‘inviters’ get in? Finally, who is doing the excluding? It is time we both recognize and accept that we are all born ‘in’! (Inclusion Press 2016)

Yet justice in Australian policy appears bounded to the idea of inclusion, to the extent that it is difficult to find literature on the topic of disability and social housing that is not underpinned by this one-way exclusion–inclusion paradigm. The words inclusion and/or exclusion often feature in titles (Tually, 2011; Tually and Beer 2010; Beer, 2008; Bostock and Gleeson 2004; Sommerville 1998). Yet the concept of social inclusion ‘lacks a coherent, theoretical base’ (Morrison, 2010, p.4). Morrison (2010), referring to Levitas (1998), describes social inclusion discourses as potentially stigmatising, creating a sense of ‘other’ in relation to an idea of ‘centre’. The role of stigma in social inclusion is further critiqued by Clapton (2009), who explores the concept and its relationship to intellectual disability. According to Clapton (2009), the inclusion paradigm serves many masters and presents wide-ranging conceptual and practical implications. Clapton (2009) describes inclusion as a metaconcept ‘which can be metaphorically conceptualised as a position, a belief, an aspiration, a policy, a practice, an action, a sense of being, and an ideal’ (p. 2).

Inclusion is utilises processes of assimilation wherein there is a political commitment to ‘include people with intellectual disability into social institutions’ (Clapton, 2009, p. 1). In relation to housing policy, the concept of deinstitutionalisation provides an example of the ideology of inclusion enacted through policy. Since the 1970s the concept of deinstitutionalisation has gained momentum (Goggin and Newell, 2005), emerging in recent years through the practice of moving people out of segregated settings of institutional care to be included in so-called community settings.

In light of these critiques, the overt reliance upon the word ‘inclusion’ in housing literature raises questions about its efficacy as a tool for propelling justice in Australian housing. Some authors appear to have found ways to circumvent this problem. Writers such as Jackson (2014), Arthurson (2007), and Bleasdale (2006) couch inclusion within their arguments by specifying what inclusion actually means as well as detailing the actions required to actually implement such meanings. This is noted by Arthurson (2007):

> Five key ‘musts’ need to be applied in order to ensure the imperative of freedom to choose.
>
> - Accommodation options for persons with disabilities must reflect what is available to other Australians.
> - Governments must be prepared to take the lead in funding disability specific accommodation, as well as mixed models.
> - National legislation that includes the freedom to choose, as a stated right must be established.
> - Regulations must be framed so as to enable, rather than restrict the freedom to choose.
> - Families must have the right to choose whether to provide accommodation and support for their family member with a disability. (p. 45)

Others have attempted to overcome the inherent problems by adjusting the term through the use of prefixes. For example, Chris Glennen, CEO of Active Community Housing, uses the prefix ‘valid’ in his conference presentation entitled ‘Valid States of Inclusion’ (2014). This suggests that states of inclusion can be invalid, or perhaps meaningless. Overall, the discourse surrounding ‘inclusion’ suggests the use of this word can be problematic and it needs to be appreciated in this light.

1.6.3 *Universal Housing*

In theory, the concept of universal housing has garnished support from within the housing field. ‘Many people are disabled at some point in their lives and many of the specific layout requirements such as barrier-free access and wide internal circulation spaces are as useful for others such as adults with young children in pushchairs’ (Clapham, 2005 pp. 134–135). Yet the Australian Network for Universal Housing Design (ANUHD) notes this is not being realised in Australia. Current housing designs are short-sighted, and do not accommodate the changing needs of people across the life span (ANUHD 2016). For example, the Australian Network for Universal Housing Design and Rights and Inclusion Australia recommend including minimum access features in the National Construction Code for all new and extensively modified housing.

> Current housing designs do not work for many people including older people, people recovering from illness or injury, mothers with prams and people who have mobility difficulties. Universal housing refers to homes that are practical and flexible, and which meet the needs of people of different ages and abilities over time. A universally designed home generally avoids barriers that may discriminate against people living in or visiting the home. (ANUHD 2016)

Bleasdale (2006) supports the argument for universal housing to go beyond merely making housing accessible or adaptable for people with impairments, but rather suggests all housing should be accessible. Herein, adjustments and adaptations might be avoided if houses were not inaccessible in the first place. While this is an important consideration it also highlights, once again, conceptualisation of access centred on *physical* access. Communication access is yet to find its place within the universal housing debate.

Universality is also a key principle of the National Disability Strategy (2010–2020). Yet despite these inroads, rigorous legislative and policy changes have not, to date, appeared on the Australian housing landscape.

Hon. Kelly Vincent MLC, in a budget analysis speech at the Annual Scientific Meeting for the Australian and New Zealand Spinal Cord Society on 16 November 2016, referred to a Renewal SA initiative to build ‘1,000 homes in 1,000 days’. ‘To Dignity for Disability, this represents a disappointing failure of a truly great initiative. Because only 100 of these homes will be accessible’ (Vincent 2016). Vincent extended this further by stating:

> We are calling for just four simple design features in new housing to make all of these new dwellings accessible.
>
> 1. We need every new house to have a step free entry, with a continuous path of travel from the street.
> 2. There needs to be a toilet on the ground floor.
> 3. The bathroom walls need to be reinforced in order to simplify the retro-fitting of safety grab rails in the future, and
> 4. All the doorways need to be a little wider than the old standard doors.
>
> That’s it, four very simple measures.

> And, really, any accessible home is a dream home, because everything is easier with wider doorways: from unpacking the shopping, wheeling a bike inside, getting a pram or moving a wheelchair through, it all becomes simpler when living in a well-designed home, instead of a continual struggle. (Vincent 2016)

This study is underpinned by the notion that all new housing needs to be designed with the access of the total population in mind. As mentioned, what a universally accessible home might entail in relation to communication access has yet to be considered. At this point in the study, another question arises. To what extent might a home in both its physical and symbolic structures enable, support and promote communication access both within its confines and in connection to the outside world?

1.6.4 *The Changing Landscape of Disability Housing in Australia*

The website of the Australian Housing and Urban Research Unit (AHURI), a government and privately funded national body, provides an indication of housing research interests in Australia. Disability, being one such topic, has received increased focus in recent years. As the Australian Housing and Urban Research Institute (AHURI, 2002) summarises, following the processes of deinstitutionalisation, four main models of housing and care packages were established (and continuing to exist) for people with disabilities in Australia:

1) formal care (e.g. residential care group homes, cluster housing)
2) privatisation (e.g. boarding houses, aged care units)
3) informal care (e.g. Community Disability Housing Program)
4) adaptable homes.

In addition to reports outlining the structure of housing, some studies have included descriptions of what is needed to support a good home. For example, in 2007, Arthurson et al. (2007, pp. 969–970) outlined a list of housing qualities required for tenants living with disability:

- Independence with choice of personal supports: Living independently, but with desired supports available and ability to exercise choice in support services;
- Interdependence and mutual social connections in housing are also important to many;

- Choice and control over housing and where to live;
- Preference for living alone/being able to choose who to live with, especially friends and family;
- The need to address issues of stigma or discrimination from the community generally and neighbourhoods when living in independent and community-based housing; and
- The need to address social isolation and exclusion, especially for people living with disability in low income neighbourhoods.

When comparing this list with recent reports related to the extensive gaps in the housing of people living with disability (Wiesel et al., 2015; Tually et al., 2011) it appears that this list of needs, published in 2007, has resulted in little progressive change, and as such, remains on the table alongside the further complexity of housing issues soon to arise when adults eligible for the NDIS are enrolled onto the scheme. This holds significant implications for the NDIS (Wiesel, 2015).

> While the recent introduction of the National Disability Insurance Scheme (NDIS) means that people can get funding for support and equipment, without more accessible and affordable housing options, few will move out of residential aged care. (Ryan and Reynolds, 2015, p. 6)

In 2002, the AHURI *Research & Policy Bulletin* outlined what it perceived as the key barriers to appropriate housing and care for people with disabilities in Australia:

> Reform has been impeded by a lack of research knowledge about the best way to package services, the complexity and piecemeal nature of the current system and the plethora of bureaucracies funding housing and support. The current policy emphasis on ‘user pays’ care packages, along with decreasing support for public housing, limits options for community integration and flexible responses to care needs.

The ongoing limitations in the amount of research required to support justice initiatives, together with the gaps just described, appear to be reflected in recent studies (Wiesel, 2015; Ryan and Reynolds, 2015; Winkler, 2015). Since 2002, gaps in research have been highlighted across recent AHURI disability-related publications (Tually et al., 2011; Beer and Faulkner, 2008; Bleasdale 2006) and herein there are solid claims that housing is not working well for people with disabilities; nor have the causes of these gaps been understood, particularly in relation to seeking knowledge directly from people living with disabilities themselves. ‘Most housing research in Britain is commissioned by government departments concerned to evaluate the impact of specific government policies, it is oriented to practical and policy issues and adopts an atheoretical, empiricist approach’ (Clapham, 2005, p. 7). Australia appears to be in much the same situation, with few studies directly engaging the involvement of people experiencing disability in research and decision making at the time of undertaking this study.

Wiesel’s (2015) reinforces the impression that the recommendations outlined in previous research remain unmet. There is a stark contrast between the list of recommendations made by Arthurson et al. (2007), for example, and the present-day description of the housing for people with disabilities by Wiesel (2015). While this may be an example of barriers to transferring research to policy/practice, it also highlights how unmet needs contribute to a cycle of compounding social problems. For instance, Saugeres (2010) suggests that a shortage of affordable and adequate housing, together with inadequate social care, may have contributed to the marginalisation of people with disabilities and their reinforced dependency on welfare. She argues this reinforced dependency due to inadequate housing diminishes access to employment. Furthermore, a remediation of these shortfalls does not appear imminent, with suggestions that the introduction of the NDIS may create even greater demand for scarce resources.

> Detailed housing policies and strategies are necessary to prepare for the NDIS. Most NDIS participants will have low incomes, and private rental will not be affordable for many. Existing social housing stock falls far short of meeting existing levels of demand, let alone the growth in demand expected with the national rollout of the NDIS. (Wiesel et al., 2015, p. 3)

Again, the same message of research gaps and low resources appears in this report, as in its predecessors: ‘The implications of the NDIS for housing policy are immense, yet existing research is scarce’ (Wiesel et al., 2015, p. 90).

As in all previous housing studies related to disability, the specific interests of people with CCN are not highlighted, either in housing research or NDIS documentation. These reports do not refer to the needs of people with CCN, and are often generalised or limited to three or four basic categories such as psychiatric, mobility and sensory/cognitive disabilities. This presents a problem because ‘disability is not uniform and the impacts upon housing career vary significantly according to its source, nature and severity’ (Beer and Faulkner, 2009, p.

3). In the few Australian studies that explore disability housing patterns and differing housing histories and trajectories, the nominated categories of ‘disability’ do not extend beyond psychiatric, mobility and sensory disabilities (Tually et al., 2011; Beer and Faulkner, 2009; Bleasdale 2006).

1.6.5 *Urban Planning and the Built Environment*

Clapham (2009) claims that a weakness of housing research is that it relegates the built environment to the role of ‘sleeping partner’ in the relationship with housing. This study includes awareness of the significance of urban planning and the built environment within the experience of home. Focusing on the built environment, understood as the social spaces used beyond home such as places visited (or not), is important when exploring connections between home and the dynamism of surrounding neighbourhoods. But research needs to go further and deeper to examine communication infrastructure as part of urban and social planning.

1.7 Housing, Homes and CCN

1.7.1 *Finding the Residential Demography of People with CCN*

There has been a growing interest in the topic of housing and disability with a range of generalist (Ryan and Reynolds, 2015; Tually et al., 2011; Beer and Faulkner 2008; Bleasdale 2006) as well as impairment-specific reports (Robinson, 2003; Bostock et al., 2001) yet, as earlier indicated, finding a background specific to CCN has been difficult. This study is located within that gap. At the time of the study, knowledge of where and how people with CCN live in Australia was not available. To gain at least a rudimentary understanding, a preliminary investigation based upon the analysis of ABS data was undertaken. These findings provide some demographic insight into how people with CCN might live compared to those who have what the ABS describes as a disability (but without CCN).

1.7.2 *Existing Research on CCN and Housing in Australia*

A rare exception to the lack of published research on CCN and housing is a study centred on service access data across four Victorian regions. Perry et al. (2004) provide some statistical analysis of the residence of people with CCN. In this dated study, the percentage of adults with CCN residing in their own home was 22 per cent compared to 42 per cent of people with CCN who were either living in community residential care or a nursing home. According to this study, the majority of people with CCN were residing in formalised care. This provides an overall indicator of the high number of people with CCN living in residential care settings, rather than in their own homes. While this study is confined to Victoria, and there is considerable disability policy variability across Australian states, there is no reason to suggest that the link between complexity of needs, seriousness of impairment and residential care models is not operating in other parts of the country.

Unfortunately, there are several limitations to the data. The study is dated and the purpose of the study was largely driven by service delivery assessment, and, as such, the cohort was limited to persons accessing this specific government service within one state of Australia. It does, however, provide a unique first insight into a relationship between CCN and the type of housing, and potentially 'home', people with CCN might experience.

1.7.3 *CCN and Residential Status: Examining ABS Data*

It is not possible to indicate, with accuracy, the number of people with CCN in Australia, their ages, where and with whom they live, and how they are supported. A secondary investigation of Australian Bureau of Statistics (ABS) survey data was undertaken and provides some insight into the absence of housing and other demographic data in relation to people with CCN. This part of the study is aimed at obtaining a more up-to-date national estimation of Australians with CCN, including identifying the proportion who reside in residential care settings. This data was sought to provide a quantitative context for this investigation into the home experiences of people with CCN.

This investigation involved using Statistical Package for the Social Sciences (SPSS) and Stata 13.0 (Statacorp, Texas, USA) in the analysis of Confidentialised Unit Record File (CURF) microdata produced by the ABS in the most recent Disability Ageing and Carers Surveys 2012, 2009 and 2003 (ABS, 2015). From the many variables within the original ABS analysis, those which could be compared and further analysed were identified for the purpose of obtaining secondary data (based upon three specific questions central to the background data sought by the study). What are complex communication needs? How many people in Australia have complex communication needs? Is there a significant difference in the percentages of people living in residential care settings who have CCN, and those with disabilities but without CCN?

As the study focused on analysing the prevalence of CCN and general residential patterns, additional demographic data such as employment, gender and Aboriginal status was not incorporated. Members of the deaf community who communicate by signing and persons with minor communication impairments were also excluded. The population of interest were people with experience of more severe communication impairment, most of whom indicate multiple impairments which often included differing levels and/or differing combinations of physical, intellectual and sensory capacity or impairment. For example, some of the group were indicated as having vision or hearing impairment and/or intellectual impairment, while others were not.

1.7.4 *Method*

Following the initial analysis, a qualified statistician employed by the university tested the results for accuracy and synthesised three initial frequency tables into one table.

In accordance with the Australian *Census and Statistics Act 1905*, the ABS is subject to strict confidentiality guidelines before releasing data. To access this data, after the study had received university ethics committee approval, I was required to undergo a formal process of application to the ABS in order to access the confidential ABS data. Statistical data from the three most recent ABS surveys on Disability, Ageing and Carers taking place in 2003, 2009 and 2012 was sought.

Residential status was analysed using the ABS's definitions of 'household' and 'establishment', wherein household is defined as

> a group of two or more related or unrelated people who usually reside in the same dwelling and who make common provision for food and other essentials for living; or a person living in a dwelling who makes provision for his or her own food and other essentials for living without combining with any other person. (ABS, 2009b, p.40)

Establishment is described by the ABS as ‘hospitals, homes for the aged such as nursing homes and aged care hostels, cared components of retirement villages, and other “homes” (disability), such as children’s homes’ (ABS, 2009b, p. 36).

The ABS used a sampling technique and collected the original data through the use of trained interviewers attending homes (‘households’) and accommodation settings (‘establishments’) (ABS, 2009b, p. 36) to conduct the survey in person. From the hundreds of data variables used by the ABS, I selected those with direct relevance to CCN and housing. Data indicating the percentage of people living in ‘care’ establishments with CCN was sought across the adult lifespan, and compared with that of persons with disability but without CCN. This involved identifying and creating frequency tables for a number of the ABS variables, for example, the abbreviated *Ability to be understood by someone does not know.*

Although all three surveys were designed for longitudinal comparison, the age of the person was not recorded consistently across these surveys. Age was recorded at five-yearly increments (i.e. 0–4, 5–9, and so on) for the 2003 survey, but for the 2009 and 2012 surveys it was recorded differently for people who dwell in establishments and for people living in households. For people in households, the age was recorded at yearly increments up until the age of 15 years, then at five-yearly increments thereafter. For people residing in establishments, the age was only recorded as one large group for participants under 40 (i.e. 0–39), then at five-year increment levels from 40 (i.e. 40–44, 45–49, and so on). All three surveys recorded people who were 85 years and over as one group. For analysis using age, we followed the age group defined as the age of person in establishment records by adding up the number of people whose ages fall between 0 and 39.

Statistical analysis was conducted using SPSS and later tested by the faculty statistician who used Stata 13.0. All data was survey weighted using the JackKnife Method (Quenouille 1949). Survey-weighted proportions were compared among the three surveys. P-values were considered to be statistically significant if they were less than 0.05.

1.7.5 *Results*

The proportion of people needing assistance to communicate because of disability (CCN) and the proportion of people who could not be readily understood by someone they do not know were similar. For example, the ABS-estimated population of Australia was just fewer than 22 million in 2009. The survey weighted number (%) of CCN was 306,648 (1.4%) according to the responses to the question ‘Whether needs assistance with communication disability’ and it was 285,455 (1.3%) according to the question ‘Ability to be understood by someone does not know’. This was consistent across all three surveys, although the prevalence was slightly higher for 2003 and 2012. Thus an overall 1.5 per cent of the population of Australia, which is equivalent to 0.3 million people, can be estimated to have CCN.

The percentage of people living in establishments with CCN is significantly higher in all age groups across all three surveys compared to those with other disabilities (i.e., disability excluding CCN) ($P < 0.05$, see Figure 1). As age increases, the percentage of people living in an establishment with CCN steadily and significantly increased ($P < 0.05$), while the percentage of people living in an establishment with a disability excluding CCN only significantly increased for people who are 60 years and older for the 2003 and 2012 surveys, and 65 years and older for the 2009 survey (both with $P < 0.05$). The gap between the percentage of people living in an establishment with and without CCN is consistent in all three surveys, although the gap decreased for the age groups younger than 60 in 2012. Between 20 to 30 per cent of people with CCN aged between 40 and 44 were living in residential care settings in the 2003 and 2009 surveys. This compares to 5 per cent of 40 to 44-year-olds with CCN in the 2012 survey. This is a significant reduction over a relatively short period of time.

As might be expected, with ageing comes an increased likelihood of dependency due to health and/or impairments; however the gap between the number of people in establishments with CCN who are over 60 years of age and other aged people with disabilities is extensive. Close to 80 per cent of people with CCN in the 80-year-old age group are living in care establishments, compared to less than 20 per cent of people with disabilities but without CCN. Unfortunately the scope of the study did not encompass an investigation into the nuances between the two groups that may have contributed to this disparity, such as the type of condition. Nor was there much detail available on the nuanced experience of communication. Qualitative studies may provide finer grained understandings of the day-to-day lives and experiences of people with CCN.

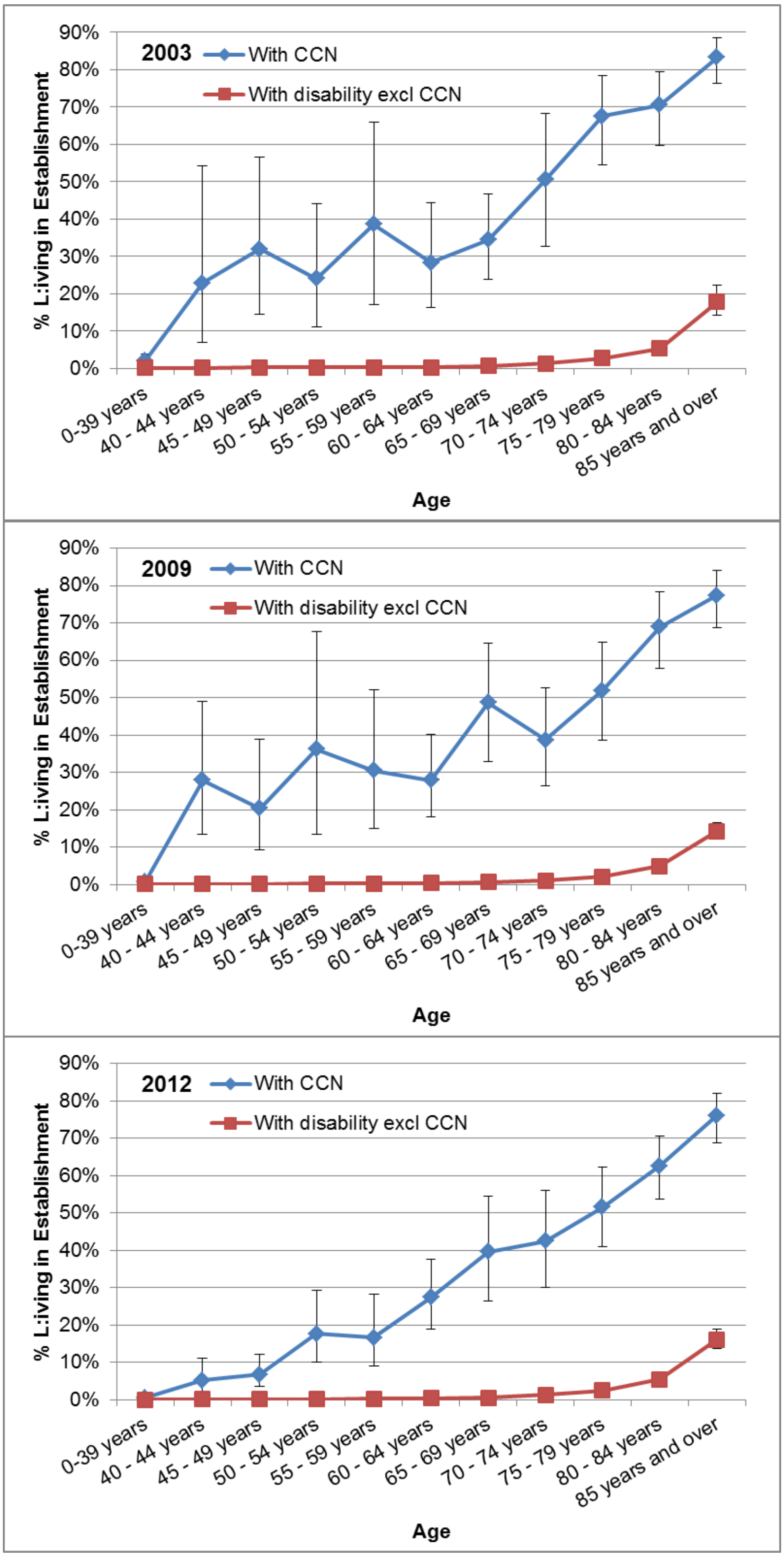


Figure 2. *Percentage of people with disability, with and without CCN, living in establishments in 2003, 2009 and 2012 by age group. Produced by Dr Susan Kim, Statistician*

1.8 *Chapter Summary*

The meaning of home for people with CCN entails an understanding of a complex arrangement of themes related to CCN and understandings of home. This thesis begins with an introduction to CCN, what it is, the types of people who live with CCN, as well as the various understandings attributed to disability services, professionals and the wider community. At a nexus with CCN are the fields of disability and housing, and the way in which they are experienced across the Australian socio-political landscape.

This chapter has sourced perspectives from a variety of areas including narratives, film, dated studies and conference papers. This opening part of the study includes a preparatory quantitative investigation to determine the Australian prevalence of CCN. Viewed together, these perspectives and data suggest three main starting points:

1. CCN appears to be sequestered (or hidden) within the broad field of disability, with an evidenced gap in CCN literature in general, and in relation to home in particular.
2. The literature reveals important social justice issues. People with CCN have, in general, been denied opportunities for a social and political voice, which includes input into the shaping of policy, as well as views and opinions about day-to-day life. This and other evidence of marginalisation highlights the significance of justice as an underlying issue in relation to a study of people with CCN. Furthermore, people with CCN are likely to be impacted by the same significant shortfalls as described in relation to broader disability housing; perhaps even more so, when considering that the notion of ‘communication access’ has received less attention than other forms of access.
3. The study is positioned at a time of social policy change and subsequent development in Australia. The introduction of the NDIS and its impact on an already problematic disability housing landscape in Australia with significant shortfalls in housing stock, appropriate responses to care needs, research and policy, raises key points for consideration in relation to the context of the study. This includes the findings of the preliminary quantitative investigation which identified that 1.5 per cent of Australians

have CCN, as well as evidence suggesting that CCN may be correlated with people living in residential care settings.

The potential gap in research methods regarding the involvement of people with CCN as research participants presents something of a double-edged sword. On one side is the lack of available data, but on the other lies it is also the reason for the gap. Communication barriers affect access to research as it is traditionally understood. This conclusion points to two vital areas for further investigation:

1. How can we understand the significance and meaning of home as a determinant of life quality?
2. How can participant and researcher communicate in a relationship where CCN exists?

It is evident that the development of new methods that are suitable for use with people with CCN will be required for the study to continue.

CHAPTER TWO – SELECTING AND BLENDING THEORIES OF HOME AND DISABILITY

2.1 *Introduction*

Drawn from the material in the previous chapter is a background of core issues and themes concerning disability and housing. Where possible in this study, CCN is aligned within the context of the Australian landscape of disability and housing, including past and present housing research, policy, social debates and theory combined with the newly introduced National Disability Insurance Scheme (NDIS). As a preliminary to the theoretical exploration of the study, this background information shapes the following justice philosophy framework. This chapter aims to maximise a multi-faceted understanding of some underlying factors of the problems outlined in the first chapter. More importantly, in combination with Chapter One, the justice framework chosen for the study sheds new light on how problems such as those described in Chapter One might be philosophically addressed.

This chapter begins with an outline of housing theory before turning to an exploration of disability as related to broader understandings of justice which have a bearing on life both within and outside notions of home. The theories of sociologist and philosopher Jurgen Habermas on communicative rationality and communicative action (Habermas, 1981, 1983, 1991) and discourse ethics (1993) are introduced, critiqued, reinterpreted and applied to support the concept of equal participation of people with CCN in social and political life. The inclusion of people with severe communication impairment into Habermasian ideologies is assisted by the application of political philosopher Martha Nussbaum's description of *flourishing* (2006) and *capability approach* (2010) as applied specifically to disability, and in particular to severe communication impairment. A re-thinking of disability frameworks by philosopher Jonathan Wolff transcends the dichotomy of the impairment model of disability versus the social model, providing instead a description of a renewed social contract of 'resource allocation', 'personal enhancement' and, more significantly, 'status enhancement' in support of the lives and 'home living' of people with CCN.

2.2 *Housing Theory*

This study takes on a theoretical understanding of what home means, appreciating its significance when pondering the more general paradigms of justice philosophy, discussed further in this chapter. For this study home becomes the locus where justice and life quality issues are experienced, examined and understood. This is because home is the private world where social affiliations, discourses and pathways to equitable democracy can be shaped if persons are afforded the opportunity to flourish. Alternatively, home can also be a place of exclusion. As Hulse et al. (2011) indicate, people can be excluded from society through housing processes such as living in poor housing, or in areas with few job prospects.

Housing theory is a relatively new field, with journals such as *Housing Theory and Society* emerging around 1984. Since then, a proliferation of descriptions of the meaning of home have emerged in the fields of sociology, anthropology, psychology, human geography, history, architecture and philosophy, with variations in meaning according to disciplines (Mallet, 2004). Across all disciplines there appears to be a unified acceptance of the importance and significance of home to human beings. This section provides a brief overview of the multi-layering of concepts of place, house, home and neighbourhood to illustrate the significance that home has come to convey.

On a broad scale, the type of neighbourhood, where people are located, and proximity to resources such as employment and transport, have sociological and geographical significance. This is a relationship between social capital and health as embedded in local geographical contexts. Mohnen et al. (2011) suggest that neighbourhood social capital is increasingly considered to be an important determinant of a person’s health, revealing a complex relationship between housing and health, with poor housing frequently associated with poorer health (Baum, 1999; Labonte, 1999).

The fields of psychology and anthropology refer to strong social, psychological and emotional attachments that derive from the home. Reinders (2008) describes the home as the centre of a complex web of social networks, where ‘[p]laces not only “are”, so to speak, they “happen” and “gather” (p. 7), with home, as a physical structure, with associated qualities such as safety, security and protection (Fox, 2007). This is evident in a 2010 Department of Disability, Housing and Community Services (DHCS) report which asserts that ‘[a] home, rather than a house, residential facility, or accommodation, is a key foundation in life that helps sustain and uphold much of what is personal, private and intimate about ourselves and reflects our deep identity, values and preferences' (DHCS, 2010, p. 8).

In this statement there is a delineation between a house and a home. The house, as defined by Laurence (1987), is a physical unit defining and delimiting space for household members. It provides shelter and protection for domestic activities. This sense of a physical shelter contrasts with the description of home in Goyen's (1950) novel *The House of Breath*:

> That people could come into the world in a place they could not at first even name and had never known before; and that out of a nameless and unknown place they could grow and move around in it until its name they knew and called with love, and call it HOME, and put roots there and love others there; so that whenever they left this place they would sing homesick songs about it and write poems of yearning for it, like a lover.

Hulse et al. (2011) acknowledge this creation of a place to nurture intimate relationships and describe home as the base for daily routines for socialising, schooling, shopping and working, but also as important to self-identity, attachment and a sense of belonging. Home is also sensory, with Howes (2005) arguing that there is a need to move beyond notions of embodiment and toward a thinking 'where there is a sensuous interrelationship of body, mind and environment' (p. 7).

The field of human geography too provides an associated understanding of the connection between human beings and the meaning they give to home and place. Humanistic geography emerged in the 1970s as a qualitative approach to understanding the relationship between human behaviour, feeling and ideas in relation to space and place (Pater, 1996). In this sphere, the terms 'place' and 'space' are often used interchangeably. Topophilia, as defined by Yuan (1974), is described as the 'human love for a place, the affective bond between people and place' (Pater, 1996, p. v).

Proshansky, Fabian and Kaminoff define home as a 'potpourri of memories, conceptions, interpretations, ideas and related feelings about specific physical settings' (1983, p. 60). Place-identity is a sub-structure of self-identity, much like gender and social class (Hauge, 2007).

Furthermore, housing and the built environment have the potential to shape positive lives and influence wellbeing (Bostock and Gleeson, 2004), with concepts of home and housing playing a major role in the health and wellbeing of Australians, and thereby enabling positive health, education, employment and community safety. The existence of government departments dedicated to housing issues such as Housing SA, federal and state Ministers for Housing, and organisations such as Australian Housing and Urban Research Institute (AHURI) demonstrate the public and policy significance of housing, but also an appreciation of the meaning of ‘home’.

There is also a counter-argument in need of consideration. Shakespeare, while acknowledging the problems in residential institutions, suggests that they ‘were often places of security and friendship for disabled people’ (2006, p. 175) and as such, it is important to consider the value that people might experience in all forms of housing arrangements. This notion is not confined to disability. Described in a chapter titled ‘A Bed, Some Food and Other Benefits of Prison’, Hauschild (1999) outlines the reality of prison life for some South Australian prisoners as offering a better ‘home option’ to the lack of alternatives offered in the community. Herein, prison, like the residential institutions described by Shakespeare above, can afford positive meaning such as access to friendships and security.

Yet this thinking has its limitations. Miles (2011) extends this view further by building upon Shakespeare’s suggestion that ‘hidden subcultures in institutions emphasise sociability, harmony and self-esteem’, adding that this is a different matter from having the ‘right’ to die of loneliness and boredom from living independently in one’s own rented room. What appears to be suggested here is that the act of claiming one’s rights (pursuing article 19 of the United Nations Convention on the Rights of Persons with Disabilities) to have one’s own home can lead to the loss of security, friendship and self-esteem, instead having the right to die of loneliness and boredom. Added to this is the tension related to abuse as revealed in the previous chapter, and the findings of the Australian 2015 Parliamentary Report *Abuse of people with disabilities in residential settings*, in particular.

As a final facet to the various theories of home, a socio-political aspect to the notion of home is noted. Home and house distinguish the private sphere (Laurence, 1987) and are the foundation for participation in social, economic, cultural and political life (Hulse et al., 2011). This aspect of home is particularly relevant to the next section wherein the function of the private world of home is identified as having a significant role in the shaping of moral and political norms of broader society.

2.3 *Communication as Rationality and a Pathway to a Just Society*

Home is the private sphere that supports the connections to the public realm and ultimately the rationality of democratic society, locating communication itself in tandem with these private and public spheres. Habermas (1989) asserts that social normative and moral phenomena can be examined by analysing communicative action founded on speech or linguistic structures of communication, which forms and shapes such norms. Supporting this perspective is the concept of communicative rationality, which is the assumption that public and private everyday communication discourses provide a kind of clearing house of rational ideas and arguments which collectively help form rational democracy. Language use becomes the basis for reasoning, for coming to an understanding and consensus on matters large and small (Thomas, 2011). Habermas argues that the life-world is based on communication, agreement and consensus (Krey, 2002). In a 2005 interview, Habermas described the phenomenon in the following way: ‘Everyday communicative life is a kind of push to give reasons to be more or less reasonable, to give answers to the questions – why did you say that? Why did you do that?’ (Davidmeme, 2007).

These everyday discourses, occurring in locations such as home and work, become larger and more organised and merge to form what Habermas describes as the public sphere, representing ‘a highly complex network that branches out into a multitude of overlapping, international, national, regional, local and subcultural arenas’ (1996, p. 374). It is here that the notion of ‘home’ takes on another meaning. It is the arena from which private matters can be recognised, generated into public opinion, translated to authorities (such as government bodies) and incorporated into social norms. If there is communication access within, and connected ‘to and from’, the home, then it follows that opportunities to influence the broader world of public discourse are greater. If home assists in the connection to the public sphere then access to the qualities that enable quality of life lead to greater opportunity, such as Nussbaum’s (2006) capability of control over one’s environment, and of participation in political choices.

In relation to the present day, how big a public sphere needs to be before being considered *public* is a question raised by Thijssen et al. (2016). They answered this question by referring to Keane (1998), who proposed three levels of public sphere: *macro* (global), *meso* (territorially bound) and *micro* (smaller groups consisting of dozens through to thousands of people, for example, intellectual groups and religious bodies).

From this, the theory of communicative action emerges as central to Habermas' perception of morality and democracy, a phenomenon reliant upon a process of consensus building. As described by McCarthy (1984), it is founded on the notion that human action is underpinned by linguistic structures, with each utterance relying upon the anticipation of freedom from unnecessary domination. McCarthy (1984) outlined three interrelated features of this theory:

1) rationality is not limited to the subjective premise of modern philosophy and system theory.
2) that this concept of society involves two levels – the lifeworld (private everyday individual) and the system paradigms, and
3) From analysis of this, a critical theory of modernity is manifested. Communication derived actions are affected by other entities which Habermas defines as 'steering media' (such as money and power) which can bypass consensus-oriented communication (Habermas, 1987). In a simplified sense, social and moral outcomes are affected by how effectively the influence of steering media, in conjunction with the communicatively valid processes (discourse ethics), are managed towards the achievement of interpretive consensus. There is a complex relationship between Habermas' notion of discourse ethics and Theory of Communicative Action (Heath, 2014). In essence, the concept of discourse ethics emerges with the reality of argumentation across differing cultural and political positions. It refers to a set of criterion through which the validity of 'contested' norms can be judged (Khan, 2012).

2.4 Language, Habermasian Theories and CCN

It appears herein that, in order to engage in a process of shared understandings (whether at the broad social level or simply for everyday purposes), theoretical research discussions of CCN require a contextualised appreciation of language and an understanding of the role AAC plays in language. While it is understood that Habermasian ideologies are founded on discourse rather than the nature of discourse itself, one cannot exist without the other. It is from this symbiotic position that the exploration of language, AAC and communicative rationality is required, and that a critique of Habermas's failure to account for the gulf in communication access is valid. For this reason, this section introduces the background meaning and structure of language, with further discussion of Habermasian ideas, the role of

AAC and the thwarted access not only to a 'public voice' but to the Habermasian notion of democracy itself.

For linguists, the term 'language' is used broadly to encompass all the possible varieties of human communication, with the capacity to communicate as innate to both humans and other species of animal (Winkler, 2007). In contrast to this, language is defined by Beukelman and Mirenda as

> what allows us to talk, read, write and learn about the world. … Regardless of the cultural, cognitive, social and other factors that influence language development, all languages are composed of six domains: speech acts[4], pragmatics[5], phonology, semantics,[6] morphology[7] and syntax.[8] (Beukelman and Mirenda, 1998, p. 332)

Different again are the perspectives of a group of international research academics who have formed a website titled *The Interest Group on The Intersection of Linguistic Research and Augmentative and Alternative Communication (AAC).* They describe the phenomenon of AAC in this way:

> We do not ask what they can teach us about disabled language, or about the language of disabled speakers. We ask what these very abled AAC-speakers can teach us about human language, because we do not consider them linguistically disabled. (2015)

This contrasts with the earlier statement from Beukelman and Mirenda (1998) where a definition of language lies within the domain of the function(s) of speech.

This concept is shared by Tenny and Hill (2011) who, in reference to AAC, use the terms 'Voice Speakers' to describe people who use standard speech and 'Voice Articulation' to define their mode or production of language. For people with CCN the term 'AAC Users' is given and terms such as 'Single-Digit Manual Articulation' are adopted for the particular AAC being used. In doing so, the authors essentially use AAC processes as language; AAC, not words, becomes lexicon. This is an unusual approach taken by the authors as there appear to be few other sources that present AAC in this way. As indicated in Chapter One, there appears to be little to indicate that AAC is shared, normative or even understood by the

---

[4] Speech acts are communicative functions.

[5] Pragmatics describes the contextual rules for using language.

[6] Semantics refers to understanding words and how they relate to one another.

[7] Morphology refers to the rules for building and changing words, e.g. changing tense.

[8] Syntax refers to the rules for putting words into sentences (Beukelman and Mirenda, 1998).

general community; rather it appears as segregated, isolated to the realm of the individual, or within the specialist domain of professional and service agency foci. This, as explained in Chapter One, is not because people with CCN cannot communicate; rather the agency of the person with CCN, despite how well they might communicate in other ways, has yet to gain the type of social recognition that might enable social familiarisation, public acceptance and greater social participation.

Generally speaking, AAC is not accepted or utilised as language. This is evident in the ongoing debates surrounding sign language, which is arguably more recognised by the community than other forms of AAC. Yet deaf people continue to assert their rights as a minority linguistic community (Batterbury, 2012, 2007).

It is difficult to forge these integrative inroads amid the pervasive dominance of spoken language, reflected by theorists such as Habermas who have built influential theoretical infrastructure from these foundations. The communication paradigms of Habermas have been critiqued by other groups who have noted the dominant position of spoken and written language. For example, feminists have highlighted the gendered nature of the public sphere, but also critiqued the emphasis upon language. Irigaray (2004) states that Habermas considers verbal and written language to be society's beacon of universality and truth, yet there are many shortfalls within language that deliver many nuanced disadvantages, whether it be in its gendered nature or ultimately in its own hegemonic speech-acts existence.

Habermas, in referring to speech acts, outlines three types: locutionary, meaning the act of saying, causing no action on his listeners; perlocutionary, referring to the effect that the 'illocutionary act' has upon the listener; and vocalise, referring to the act of verbal utterance. Herein, society members are encouraged, or compelled, to comply with social norms through the existing illocutionary effect on the speech of others (Habermas, 1989).

In revealing his own personal experience of a cleft palette in childhood and the consequential 'failures' he experienced in verbal communication, Habermas (2004) suggests that without linguistic communication we could not exist as individuals. This reflection is further summarised by Clifford (2012, p. 12): 'Failure at linguistic competence threatens to result in "denied reciprocity", in which a person is no longer recognised as a free and equal citizen'. This sentiment dovetails with the tensions within the notion of communicative competence described by Light and McNaughton (2015).

Linguistic competence is aligned to discourse. The powers of discourse are also noted by other theories in slightly different ways. Michel Foucault (1970), with a focus on the social construction of ‘madness’ and ‘punishment’, examines how discourses have shaped and developed meanings that have gained validation as ‘truth’, dominating how we perceive and construct ourselves and our social world, with alternative discourses marginalised or negated. Fairclough et al. (2001) refer to the socially influential powers of discourse, whereby through a linguistic conceptualisation we name and conceptualise our world. These reflections on discourse are helpful in that they provide a study such as this with a reminder that the taken-for-granted existence of communication and language is also constructed and reliant upon conceptualised meanings.

On face value, Habermas’ theory of (and use of the term) ‘discourse ethics’ suggests a moral code, or a set of principles to which people with communication access barriers might appeal for justice. However the paradigm of modern discourse ethics, as originating from and discussed by Habermas (1990) and Apel (1999), holds little political and philosophical relevance for people with CCN. It fails to accommodate the type of communicative diversity of people with CCN, and arguably reinforces existing communication barriers. For instance, Habermas uses a set of criteria referred to as ‘presuppositions’ to shape the notion of discourse ethics, one of which states that participants in communicative exchange must be using the same linguistic expressions in the same way (Habermas, 1990). Inherent, again, is the assumption that all persons must speak and/or write to participate. The absence of an accommodation of AAC prevents people with CCN from appealing for justice using the sociological paradigm of discourse ethics as it currently stands.

Before exploring the possibilities of adapting Habermasian theories to AAC, it is helpful to take some precursory steps towards unveiling the cause of these problems within these theories. Clifford (2012 p. 213) states: ‘according to Habermas’ communicative theory of deliberative democracy, all persons who are affected by the outcome of a policy should be able to participate in deliberations. Yet he permits only subjects who are communicatively competent to participate.’ Without recourse, these theories appear to overlook diversity in communication, thereby missing the investment that might be otherwise made by conceptualising alternatives or at least shaping pathways to accessible communication. Imbedded in this argument is a question about responsibility. Is it the theory, or the status quo on which the theory is based, that propels the exclusion of members of society? Do we reject the notions of Habermas on the basis of points such as those made by Clifford (2012), who attributes his theories with the power to ‘permit’ or ‘exclude’ voices, saying that these theories initiate and perpetrate exclusion? Or do we acknowledge the powerful element of the public sphere and the already existing communicative processes that Habermas simply identifies? Further still, and more closely related to the interests of this study, is the invitation to *draw upon* other theories, which, in combination with the theory of communicative action, might help alleviate the limited appreciation of language and capabilities of people with CCN inherent in both Habermasian theory and the reality of the public sphere, as evidenced in Chapter One.

The communication-based theories of Habermas outlined in this section, despite failing to acknowledge the dilemma they present, have not caused the omission of people with CCN from the social and rationality-shaping public sphere. Instead they simply describe, and philosophically define, the phenomenon of a society confined by a normative understanding and use of language, created by its own consensus-building rational process communicative action; a process inadvertently leaving some people by the wayside.

Habermasian theories provide an explanatory function by shedding light on why, as revealed in Chapter One (Part A), people with CCN are missing from social and epistemological discourses. The assumptions that can be drawn from these theories of rationality, morality and democracy is that people with CCN are unable to participate in such processes because they require an ability to perform an elementary act precursive to being a player in this communicative success: utterances or speech acts. Revealed here too, as outlined in Chapter One and again in Chapter Three, is an assumed relationship between rationality, cognitive capacity and communication. In this sense, the ability to wield socially sanctioned language acts as a gateway; as a ‘criterion’ for inclusion in the cognitive, normative, objective and subjective world of individuals. Arising here is the potential of people with CCN being perceived as not cognitive (or assumed to be cognitively impaired in such a way that prevents their normative, objective and subjective world contributions). Without such participation, people with CCN sit outside the living processes of democracy, rationality and morality.

In highlighting the hegemonic functioning of written and spoken language, these theories inherently suggest that what is needed is *access to public discourse.* They also describe the problem(s) preventing this from happening: *language diversity gaps.*

From this discussion of language, three significant issues arise in relation to CCN. First, discourse has a pervasive power to shape, define and validate meaning. Secondly, discourse is validated through linguistic conceptualisations but, as revealed earlier, the alternative languages of people with CCN are subjugated. Thirdly, people whose bodies do not accommodate normative speech or writing face severe impediments to entry into the public sphere. Similar to all members of society, people with CCN require corridors into public platforms where the voices of communicative public discourse are manifest. Part of this solution lies in the adoption of theories and strategies aimed at improving opportunities for people with disabilities, and those with CCN in particular.

The problems people with CCN face in relation to access to the consensus-led functioning of the public sphere provoke questions about how these theories might be shaped to address these shortfalls. Sella and Muller (2011) pose the following question: ‘Is Habermas’ discourse ethics possible for people with disabilities?’ They conclude that it is possible to include people who do not use spoken and written communication within the notion of discourse ethics that Habermas describes; however, for this to occur it would need to rely upon an appreciation of human diversity, and a commitment towards plurality and human dignity (Sella and Muller, 2011). Sella and Muller’s question is salient for this section as it explores drawbacks in Habermas’ work, as well as locating the possibilities for inserting the appreciation of human diversity, plurality and dignity which they advocate.

When applying Habermasian theories, the following question arises: what are the public spheres of CCN? Moreover, when following Habermas’ (1981) assertion that, through the examination of communicative action, social norms and moral phenomena can be examined, one wonders how people with CCN might participate in this process of building and shaping social norms. These questions give rise to a series of assumptions about communication and language which are important to name as they form the lintel to the doorway of Habermasian ideologies.

The question of whether there is a public sphere for people with CCN arises. Bodies such as the aforementioned International Society for Augmentative and Alternative Communication (ISAAC) and the Anne McDonald Centre exist in the public sphere and in various ways contribute to discourse about CCN and AAC.

> Largely the professional domain of speech and language therapy, AAC has developed into a specialized area of research and provision over the last 30 years (Schlosser, 2003), with its own international society (the International Society of Augmentative and Alternative Communication) that is part professional organization, part social

> movement, drawing together clinicians, academics, manufacturers, AAC users and their relatives. (Hodge, 2007, p. 458)

This coming together of various groups of people with interest and expertise in the field of AAC provides a doorway to access to the public sphere. People with CCN have an opportunity to present lectures and workshops at the ISAAC conferences, and to vie for an ‘Outstanding Consumer Lecture Award’ (ISAAC, 2015). However, the notion of consumer clearly demonstrates that the main thrust of bodies such as ISAAC is therapeutic intervention geared towards progressing the communication ability of people with CCN. It is helpful to, once again, return to the points raised by Thil (2015) about ‘voice’ being an important tool in struggles for the recognition of disability. Further, Duchan (2006) highlights that access is prominent in the disability field, yet communication access is afforded little attention. His view is echoed by Levin (2013), who notes that people with communication impairments are largely excluded from disability politics, as, similar to all other politics, arguments are dominated by people who communicate well and fluently. Levin’s point brings to mind ‘the importance of articulation – the process through which tacit skills and knowledge are made explicit’ (Hakhanson, 2007, p. 51) and its critical significance for politics as interwoven with morality, democracy and the law. The challenge undertaken by bodies such as ISAAC is to increase the ‘articulation’ capacity of the individual, which assists access to the public sphere. However, as reflected earlier, pockets of the AAC community and authors such as Battersbury (2012) and Tenny and Hill (2011) seek a broader acceptance of language diversity.

Drawing from the insights gained in Chapter One, it possible to posit that language barriers are a likely contributor to these gaps in access to the public sphere. From here a reworking of an earlier question emerges which connects these ideas with the topic of home. The original question asked to what extent might a home in both its physical and symbolic structures enable, support and promote communication access both within its confines and in connection to the outside world. The re-worked question asks: do people with CCN participate in this notion of the public sphere and social norm building? Further still, do the homes of people with CCN support access (or not) to the public sphere, and if so, how does it achieve this access (or not)?

What is clear, however, is a body of evidence, such as that revealed in a statement by Kala (2011), which illuminates a major dilemma between language, Habermasian theories and CCN.

> To speak a language, therefore, is to inhabit a world of shared understandings, which of course are necessarily mediated through common historical experiences. In other words the text has to be understood in and through historically mediated contexts. Habermas is fairly clear on this. In order to carry on normal, undistorted communication we must share the same language, as well as the same cognitive, the same normative and the same objective and the subjective worlds … When these conditions are missing, communication becomes impossible because understanding becomes impossible. (pp. 333–334)

In addition to the assumption that language is spoken, and written, further barriers are thrown into the mix and must be surmounted before entry to the rational discourse of democratic society is possible. For the person with CCN, her cognitive, normative, objective and subjective world must align with, and be understood by, others. When reflecting upon this world of shared understandings, particularly in light of this study, the evidence thus far suggests the possibility of meanings and values of home existing outside the social norm, a consensus-driven phenomenon drawn from communicative action. This elicits the further question of whether the purported theoretical understandings of home fully encapsulate those left out of the rational consensus-building process. This, and earlier questions raised in this section, provide important food for thought for the ensuing study.

2.5 *Status Enhancement and a ‘Society of Equals’*

In responding to the theoretical gaps in communication access exposed in Habermasian ideologies, the philosophical workings of Wolff (2009, 2002) and Nussbaum (2010, 2006) offer ways to conceptualise remedies to segregation and exclusion so necessary for making the commitment to diversity, plurality and dignity effective. Though not speaking specifically of CCN, these theories provide a position from which society might engender a commitment to the type of plurality capable of enabling all citizens to reach the public platform. The notion of affiliation is central to understanding communication viewed in this way.

British philosopher Jonathan Wolff pursues notions of the attainment of a good life. He outlines three key variables which determine how well a person gets along in life:

1) Natural or internal resources of individuals, including intelligence, talents, physical appearance.

2) External resources such as money, property etc. as well as the social structure from which one lives such as laws, customs, level of technology.

3) The society in which one lives and interacts. (Wolff, 2002)

In relation to disability, Wolff (2009) proposes four considerations for addressing the disadvantage of people with disabilities: 1) cash compensation whereby an amount of money is provided for the person with a disability to use in whichever way they choose; 2) personal enhancement whereby action is taken to address the impairment itself through, for example, medical or therapeutic intervention; 3) targeted resource enhancement, referring to the issuing of resources to persons such as equipment and personal support workers.

The fourth is status enhancement, which is heavily reliant upon the social model of disability ‘in which social, material and cultural structures are made in order to modify the structural mediating factors between impairment and adverse consequences’ (Wolff, 2009, p. 51). Wolff argues for status enhancement as the preferred means to addressed disadvantage because it is non-stigmatising due to its universal social and cultural change initiatives. It is welcoming of differences and benefits everyone by reducing the risks of exclusion in the first place (Wolff, 2009).

Wolff (2009) describes the centrality of affiliation in both status enhancement and personal enhancement. Status enhancement supports affiliation by encouraging a ‘society of equals’ and personal enhancement by making everyone more similar. Underlying these two types of enhancement is a value position ‘sending a message of acceptance of people as they are, rather than how we need them to be’ (Wolff, 2009).

When applying these notions to the field of AAC and the roles of bodies such as ISAAC, the ‘living’ of these various strategies for addressing disadvantage can be noted. Resource allocation may be levelled at the purchase of speech therapy and communication devices. From the perspective of ‘personal enhancement’, the person with CCN is most likely to ‘fit in’ if they communicate as closely as possible to how the rest of community communicates; becoming ‘communicatively competent’. ‘Status enhancement’ suggests a reduced emphasis upon fitting in because the person, otherwise deemed as having ‘CCN’, automatically is in because society expands its communication access boundaries enough to recognise the universal structure from which AAC communication might be normalised.

> No wheelchair user should feel grateful that the architects have produced a building which he or she can enter just as easily as other people. These forms of accommodation encourage the idea of a society of equals, even if much else remains to be done. Ultimately there may be no perception of a distinction between a group needing help and a group that does not. (Wolff, 2009)

Using this analogy, the current research supposes that 'the wheelchair user' has CCN. It poses the question, who or what are the architects of communication? It returns to the earlier question of how the home promotes, builds and nurtures affiliation between this individual and the community. Despite the development of increasingly sophisticated communication aids, as well as recent British initiatives such as the introduction of AAC Service Standards (Communication Matters, 2012) aimed at improving access to them, some major obstacles stand in the way of AAC being realised to any significant degree (Hodge, 2007). Many individuals with CCN continue to experience serious challenges to participating in educational, vocational, healthcare and community environments (Light, 2015).

Making a case for status enhancement sustains the critical role of personal enhancement and targeted resource enhancement. The notion of status enhancement adopted by this study is the 'preferred' model amid a range of other relevant co-existing models. 'If a medical approach promises little benefit, but social and cultural change could significantly improve the lives of disabled people, then the balance conclusively shifts towards status enhancement' (Wolff 2009, p. 52). This notion is supported by speech and language scholar Sarah Earle (2003), who refers to Finkelstein's (1993) phrase a 'cure and care approach', which can inadvertently contribute to the process of disablement.

While Wolff takes a more social model of disability approach where disability is viewed as potentially ameliorated by societal actions, authors such as Morris (1991) and Shakespeare (2006) highlight an embodied experience of impairment, suggesting it is not always possible to adapt society to impairment. In preparation for this study, one wonders whether Wolff's notion of 'status enhancement' might be expanded to include an individualised notion of impairment. For instance, by an increased awareness of the embodied experiences of individuals with CCN and a cultural appreciation of diverse communication (AAC) as told in the stories of people who use AAC, might the ‘status’ of people with unique communication needs be improved.

Remediating the effects of impairment and improving opportunities for communication can be life changing, yet the effects of these initiatives are limited. For example, personal enhancement can only go as far as the individual *can agree to be* ‘enhanced’. Questions of individual choice and agency are relevant here. As outlined in Chapter One, accessible communication may not be delivered in a conventional way. For example, a groan, growl or grimace may be more available to people with severe CCN than a normative head shake to indicate ‘no’. In tying this back to Habermas, it raises the question of how unconventional utterances might be understood, thereby gaining their users entry to rational discourse and the public sphere.

When considering the possibility of future policy for people with disabilities, and for CCN in particular, it is helpful to note the tensions between efforts to treat and change, and the acceptance of difference. When the person with CCN, despite the AAC technology, training and devices available to her, remains outside the realm of the communicatively competent, should society accept this and expect the individual to accept their fate? Or, instead, should some of its focus shift toward cultivating familiarity with such things as AAC? Who bears the responsibility for pursuing this pathway? Speech pathologists and other allied health professionals such as occupational therapists are arguably trained to ‘person enhance’ not ‘status enhance’.

The notion of ‘personal enhancement’ implies the social requirement or goal of fitting the social norm. In the context of speech and language therapy, Earle (2003) raises the question of whether it is always appropriate to treat disability. Earle (2003) refers to the ‘relegation of people with impairments to objects of intervention, therapy and rehabilitation in the quest for normalcy’ (p. 3). The theoretical positions of status enhancement and capabilities are not concerned with such notions as ‘normalcy’. Both approaches are heavily invested in the concept and attainment of the type of lives people, subjectively, have reason to value (Sen, 1993).

The concept of status enhancement deviates from the more familiar roles of personal enhancement and targeted resource enhancement within AAC. Stigma in relation to the use of AAC devices is reported. Self-consciousness and the lack of normalisation of AAC within society is seen as affecting individual AAC communicators’ ‘willingness to use their communication aids, not just because of embarrassment, but at a deeper level because of the effect of the associated stigma on their sense of identity’ (Hodge, 2007, p. 465). While stigma around using AAC might be viewed as a lesser concern to the critical issue of accessing communication in the first place, the two issues of access and stigma go hand in hand. Social structures which involve relevant, universal adaptations that are available to everyone as part of the norm invariably reduce stigma. Strange-looking devices and unfamiliar books with picture symbols that few understand, let alone can utilise to ‘partner’ or ‘communicate with’, do not.

This also raises the question of how, in the event of people with CCN not becoming ‘communicatively competent’ in a manner readily translated into everyday society, do AAC communicators connect to the public sphere? The evidence in Chapter One goes some distance in answering this question by suggesting that the voices of people with CCN are not well received in the broader public sphere.

In the face of this, there are some inroads emerging. As previously mentioned, bodies such as ISAAC and Australian Group on Severe Communication Impairment (AGOSCI) provide opportunities for ‘consumers’ to present at their associated conferences, and in the last five years Two Way Street, a South Australian Speech Pathology service specialising in AAC, has introduced an AAC User Lecture Series. The website states:

> Twice a year we plan to highlight a different speaker with a topic of their choice to share. All presenters are paid for their presentations. We value their input and believe they should be paid appropriately.
>
> - Hear directly from those who use Augmentative and Alternative Communication (AAC) about a range of topics, including their experiences perspectives [sic] and topics of expertise or interest.
> - Others who use AAC can meet and learn from those who are competent users of their system.
> - A great opportunity for people who use AAC, their families, and service providers to network and socialise.
> - This lecture will be of interest to people who use AAC, their families, friends, service providers and those who make policy or funding decisions. (Two Way Street 2017)

There is an emphasis upon communication competence but the fourth bullet item suggests the possibility of connecting the presenter’s voice beyond the familiar realm of AAC communicators to the broader world of policy.

2.6 *Flourishing and Capabilities*

Concepts of the Aristotelian ‘good life’, as described by Nussbaum (2011), and of the fair and just have captivated philosophers across time. Contemporary justice debates build on the highly influential works of philosophers such as Immanuel Kant and John Rawls, and critical theorists such as Habermas. Yet, as noted earlier in the discussion of Habermasian theories, accounting for the ‘good life’ for people living with disabilities is significantly underworked. Political philosopher Martha Nussbaum (2006) critiques the assumption within Rawlsian social contract theory that individuals are equal, free and independent. Furthermore, Nussbaum (2006) highlights that the social contract (a moral and political obligation that exists between the individual and the state) relies on Rawlsian and Kantian notions of ‘personhood’ and ‘does not include people with severe and atypical physical and mental impairments’ (Nussbaum, 2006, p. 14).

Instead, Nussbaum embraces the notion of *flourishing* as first introduced by Aristotle. It is distinct from the social contract model and the capabilities approach of economist Amartya Sen in creating a list of capabilities required for people to live a good life. Nussbaum’s (2010) capability approach encompasses all persons, with or without impairments. These capabilities are for everyone and do not segregate people into a group called ’disabled’. Like the broadly enveloping ideology of status enhancement (Wolff, 2006), the capabilities listed by Nussbaum apply to all.

Nussbaum’s list of capabilities (below) dovetail with other influential theories that emerged around the same time as the capabilities approach. For example, stemming initially from the social integration of persons with cognitive impairment, the principle of normalisation seeks to make available patterns of life and conditions of everyday living as close as possible to the way of life of society to persons with disabilities (Nirje, 1980). Social role valorisation (SRV), founded upon the concept of normalisation, emerged from the premise that people are much more likely to experience the ‘good things in life’ (Wolfensberger et al., 1983) if they hold socially valued roles.

Capabilities assist in the achievement of these roles. Developed by economist Amartya Sen in the 1980s, this theory describes the significance of individuals' capability to achieve the kind of lives they have reason to value; this involves a set of 'beings and doings' (Sen, 1985) such as being in good health or actively participating in education. In his speech at the World Bank Conference on Disability, Sen (2004) distinguished the capabilities approach from other philosophical positions such as utilitarianism or resourcism. Sen identifies the shortfalls in these theories, including the redistributive justice position of Rawls, as the mistaken notion that a person's level of advantage can be judged in terms of their 'primary goods'. As noted by Nussbaum (2006), Sen argues that the capability approach, based on the varying needs for resources and also the varying abilities of individuals, can convert resources into functionings (being and doing, activities that individuals can undertake).

Robeyns (2011) describes Nussbaum as viewing capabilities as a theory with two legs; theorising about social justice on the one hand, and comparative quality of life assessment on the other.

> there is the problem of doing justice to people with physical and mental impairments. These are people, but they have not as yet been included, in existing societies, as citizens on the basis of equality with other citizens. The problem of extending education, health care, political rights and liberties, and equal citizenship more generally to such people seems to be a problem of justice, and an urgent one. (Nussbaum, 2006, pp. 1–2)

Nussbaum (2006) comments on justice issues inclusive of people with impairments, such as the delivery of care described earlier. However, Nussbaum takes these justice issues and places them in the context of Sen's conception of capabilities. Nussbaum claims that there is not a single type of flourishing for human beings, but

> rather, that these capabilities can be agreed by reasonable conceptions of human flourishing, in connection with the political conception of the person as a political animal, both needy and dignified, and thus these are good bases for an idea of basic political entitlements in a just society. (Nussbaum, 2006, p. 12)

Along with Sen, Nussbaum rejects the justice argument which calls for simply redistributing resources. Instead, what becomes of ultimate importance is supporting what people are able to do and to be (Nussbaum, 2001). Evolving from Sen's capabilities approach, influenced by Aristotelean notions of flourishing, and imbedded in a pluralist liberalist tradition (befitting democratic society), Nussbaum (2006) argues that a 'just society' honours the opportunities for realising a list of capabilities in tandem with the desires of the individual. From here it is possible to identify and benchmark the qualities that enable a 'good life'. This list was of particular interest for this study because it held the potential of offering a tool for explorative research in addition to a philosophical underpinning.

1. *Life*. Living a full-length quality life.
2. *Bodily Health*. Having good health.
3. *Bodily Integrity*. Safety from violence, including sexual assault and domestic violence; opportunities for sexual satisfaction and reproduction.
4. *Senses, Imagination, and Thought*. To have adequate education and able to use the senses, to imagine, think, reason, create and to exercise choice and decision making.
5. *Emotions.* Being able to form attachments and express emotions.
6. *Practical Reason.* Being able to reflect on notions of good and to engage in critical reflection about the planning of one's life.
7. *Affiliation.* Being able to enjoy relationships with others that help foster positive self-regard.
8. *Other Species.* Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. *Play.* To enjoy recreational activities.
10. *Control over one's Environment.* Both political (to participate in political choices, freedom of speech) and material (the right to meaningful employment, being able to own property and goods). (Nussbaum, 2006, pp. 76–78)

This list offers both a theoretical framework for understanding rights or 'social goods', as well as an evaluative reference point to understanding pathways or requirements for realising these rights. How effective Nussbaum's capabilities are in supporting the rights outlined by the UNCRPD was explored by Harnecke (2013), who concludes Nussbaum's capabilities approach supports the general requirements set in the UNCRPD; however, they are unable to guide the implementation process by setting 'priorities' of such rights.

Nussbaum's list of capabilities relates to communication access in some way or another, with 'Senses, Imagination and Thought', 'Practical Reason', 'Affiliation' and 'Control over one's environment' holding direct relevance. Further still, capabilities 4, 6 and 10 directly align with communicative rationality and communicative action, for example, 'to reason, create and to exercise choice and decision making', and 'to participate in political choices' and ‘have freedom of speech’. While Habermas appears to assume these capabilities are inherent in all citizens (or, at least, predisposes the equalising role of good government to ensure this), Nussbaum (2011, 2006) points to these, declaring them unequal, and suggests that they need to be tackled before social freedoms, democratic participation and quality of life can be realised (for all).

In relation to the current study, it is important to determine how communication needs and indeed priorities might align with Nussbaum’s capabilities approach. It can be argued that the list of capabilities is inherently connected to communication such as ‘affiliation’. Furthermore communication might also be argued to be a capability in its own right, particularly when considering the communicative life world and system worlds outlined by Habermas. A return to the capability question of what ‘one wants to do and to be’ is a helpful consideration for this study.

Relating the capability interest in what *one wants to do and to be* to CCN is not possible until enough research is conducted in this area. The research that comes closest to answering this question is a Canadian study comprising two focus groups of people with CCN. Participants were asked to list their AAC research priorities (Truxler and O’Keefe, 2007). The key areas of priority chosen by participants were: (a) preparing people who use AAC to succeed in situations such as maintaining friendships, dating and finding jobs; (b) improving service delivery of their AAC devices; (c) improving technology in high-tech and low-tech devices; (d) increasing public awareness of people who use AAC; and (e) improving methods of teaching reading skills to people who use AAC. Although these responses relate to ‘research priorities’, the capability element of to ‘be and to do’ is at least partially implied.

2.7 *Capabilities and Home*

In referring back to Dovey (1978) we are reminded

> [h]ome is a place of security within an insecure world, a place of certainty within doubt, a familiar place in a strange world, a sacred place in a profane world. It is a place of autonomy and power in an increasingly heteronomous world where others make the rules. (p. 46)

Nussbaum’s capabilities, as a theoretical underpinning of the study, not only must support people with CCN (and UNCRPD rights in relation to communication) but must be interpreted in relationship to the home environment of each participant. The locale of home appears vital in relation to capabilities, playing a range of roles in accordance with the achievement and management of met, partially met and unmet capabilities. This prompted an inquiry into prior research reporting on the use of Nussbaum’s capabilities approach within the context of ‘home’. At the time of the study, there was no prior research centred on Nussbaum’s capabilities approach, CCN and the home.

The topic of home and capabilities has received little attention in the theory or empirical literature; however, McNaughton Nicholls (2010) provides an exception, with many illustrations of how capabilities may be evidenced (or not) within the home environment. It is hard to imagine what connection to home number 8 on the list of capabilities would have: ‘*being able to live with concern for and in relation to animals, plants, and the world of nature*’ (Nussbaum, 2010). McNaughton Nicholls (2010), however, relates Nussbaum’s capabilities to people who are homeless, explaining that homelessness diminishes capabilities, including connection with ‘other species’ such as keeping pets, a situation which can in turn contribute to homelessness. Having the responsibility of caring for an animal can be motivating and emotionally vital. ‘People experiencing homelessness who have pets do not enter hostels, but instead remain on the street because hostels will not allow animals’ (McNaughton Nicholls, 2010, p. 34).

‘Nussbaum’s framework allows for a nuanced understanding of the role housing has as a component of the functions required to live a “well-lived” life’ (McNaughton Nicholls, 2010, p. 24). From here it can be inferred that notions of safety, security and protection, for example, are closely aligned with the capabilities of bodily health, such as having shelter, bodily integrity and safety from harm, and in relation to the social role of the home, the gaining of social affiliation and so forth.

While Nussbaum’s theory offers an avenue for this study, it also presents difficulties. The most notable critiques of Nussbaum, with respect to this study, are outlined in Harnecke (2013) and Khader (2008), who point to the unanswered question of how to bring about these capabilities for people with severe cognitive impairments. As noted earlier, people with CCN may or may not have cognitive impairment; however, the notion of a kind of ‘normative presence’ (as provided through spoken and written word) is a comparable assumption and equally problematic. Khader (2008) makes reference to McMahan (1996), who asserts that the justice claims of persons with cognitive disabilities rest on the unwarranted counterfactual that imagines that ‘normal’ individuals would exist in the place of all severely cognitively disabled individuals (1996, p. 15). It is possible to surmise that something similar occurs with CCN; that a similar, unwarranted counterfactual exists for imagining the speaking/talking person in the place of the person with CCN. From here it is possible to further surmise the advancement of VOCA (the automated voice technology that has made inroads to social acceptance) as being a stakeholder in this imagining, and therefore potentially overshadowing the individual who communicates in different ways.

2.8 *Summary and Discussion*

This chapter began with a positioning of the concept of ‘home’ across a multi-disciplinary perspective, such as its connection to social determinants of health (Baum, 2016) as ‘they happen and gather’ (Reindeers, 2008, p. 7). Home connects us to the private sphere (Laurence, 1987) and is the foundation for participation in social, economic, cultural and political life (Hulse et al., 2011). It is the heart of the private world, the lifeworld described by Habermas, in which everyday utterances feed into and contribute to creating the rationality of broader social discourse. Home represents the heart of the private sphere which, together with the public arena, and in concert with social leadership, contributes to the understanding and shaping of an equitable, moral, democratic society. To live in a home is to be *emplaced* in the heart of the private sphere. Howe (2005) describes *emplaced* as a sensory relationship between the body, mind and environment.

The participants in this study are persons who are *emplaced* in a private sphere which, through communicative action, shapes social norms such as policy, morality and the ‘doing’ and ‘being’ of democracy. Participation within private or public spheres is dependent upon common and mutual use of spoken and written language, which has the potential to lead to the omission of many people with CCN from this process. Habermas does not create this problem; rather he describes what he sees as the status quo to which he attributes a codes of ethical practice. Habermas has simply laid a theoretical and ethical structure onto an observed phenomenon. The norm of ‘one must speak and (when they do) they must be understood’ is powerfully inherent in socio-linguistic norms. Furthermore, as indicated in the literature, there appears to be little contemporary challenge to the accepted norms of communication. Aside from the views of isolated AAC linguists, the seats at the communication table of democratic society are fully taken by the ‘doing’ of spoken and written communication.

Despite the current gaps, this study asserts that CCN can be accommodated both in the reality of the communicative process and in the theoretical infrastructure Habermas applies to it. But to do this requires the adaptation of justice theories in concert with the guided contributions of research itself. Nussbaum’s conceptualisation of flourishing and capabilities, and Wolff’s description of status enhancement, need to be applied in a way that is capable of distinguishing between the socially created notion of disability and the embodied, cultural and individualised experience of impairment.

Nussbaum’s capabilities approach offers the study a way to demonstrate strong alignment to the doing of communication in general, and to Habermas’ theories in particular. Capability number 10 provides a clear example of this: *control over one’s environment.* Nussbaum declares a societal-government responsibility for enabling this capability, which may likely involve supports and resources related to the presence of communication impairment. Habermas partly concurs with this, as he too places responsibility on governments, specifically in relation to the social contract of the state providing for the welfare of its citizens. The related amelioration of injustice is pitched at the provision of supports and services to people with CCN; helping people to change and improve. This process of responding to needs is very important; however, it may not go far enough to address the need of broader society in relation to accommodating AAC, which requires people in broader society to become AAC literate. Sella and Muller (2011) suggest that discourse ethics, as described by Habermas, is possible for people with disabilities; however, for this to occur it would need to rely upon an appreciation of human diversity, and a commitment to plurality and human dignity.

Despite their noted differences, in combination the approaches of capabilities, status enhancement and communicative action provide a cohesive justice argument for this study. The notions of capabilities and status enhancement help address the gaps in access to communicative action. Nussbaum presumes a platform of status enhancement when declaring the list of capabilities. There is no ‘disabled’ section, no article 12,[9] just a wide door stating ‘this is what it takes for a good life’ with an invitation to the state to acknowledge, interpret

---

[9] Article 12, UNCRPD.

and enable these qualities for all citizens. The list of capabilities presented by Nussbaum (2006) as befitting a democratic society reflects the significance of communication and its inherent role within each of the capabilities listed. This list aligns with Habermas' concept of communicative action. However, unlike Habermasian theories, Nussbaum does not presume that all people have access to participation, suggesting that there first need to be processes in place to enable the meeting of capabilities. There are, however, problems emerging from this. Harnecke (2013) and Khader (2008) point to unanswered questions with regard to how capabilities might be applied to someone with severe cognitive impairments. This also applies to people with CCN (some of whom also have cognitive impairment).

Wolff's theory of status enhancement (2009) brings the study closer to finding a complete conceptual framework for understanding justice, housing and communication. From this position it is possible to imagine that the recipient of capability-building initiatives may extend beyond the person with disability; that diversity or social-pluralism capabilities are to be learned, perhaps not directly reflected in Nussbaum's list of what constitutes a good life, but nonetheless, capabilities deserving of a public platform.

Wolff's (2009) outline of personal enhancement, resource allocation and cash compensation also supports this process; however, as revealed in this chapter, these theories alone do not fully solve the problem. Let us imagine that the individual with CCN has been receiving regular speech therapy and AAC support, has the latest in AAC technology and has learned to operate it to the best of their ability. Can we assume that this person has now the capability to participate in political choices and freedom of speech? What appears to be missing is the society-wide communication partner. It may be that simply because the individual with CCN has these skills it does not necessarily equate to the community becoming more AAC literate. Something else might be needed to help bring about the capability and hence the connection to the public sphere and communicative action.

The question of how communication is experienced in the home comes to the fore again. What is the nature of the communicative interactions and discourses which shape those relationships, and how, if at all, do the content of these interactions find their way into the public sphere, contributing to rationality and active consensus? What processes of mediation or facilitation exist and how effective are they? Pomeroy (2004), outlining the public–private binary in women's lives, describes the deeming of gender issues in the political arena as attributed to familial and moral reflections rather than an authentically political stance. For people with severe impairments, CCN in particular, is it possible they might find a kind of similar experience in relation to the public arena? That interacting via third parties, for example advocates and disability agencies, means that their private discourse is interpreted as ‘disability issues’? Overall there appears to be an omission of the impact of people with CCN in public communication, involving lost opportunities, everything from shaping social policy to sharing views and opinions on daily life.

As outlined in this chapter, Habermas’ most influential works have widespread and ongoing influence. Yet from the perspective of CCN, they inadvertently reveal the hegemony of language and the author’s disdain for linguistic failure, at least at the time these works were created. It is therefore not surprising that there is an absence of a contemplative framework encompassing the possibility of CCN and AAC being accommodated, validated or even defended through the adaptations to notions such as discourse ethics. New ways of accommodating such discourse must be traversed.

Nussbaum’s list of capabilities (2006) together with Wolff’s status enhancement (2009) and Sella and Mulla’s (2011) call for a commitment to plurality and human dignity in the face of Habermas’ ‘discourse ethics’ provide the possibility of a path forward. Hereto, with growing CCN epistemology, progressive initiatives will likely have greater opportunities. The challenge, however, appears to lie in finding ways to unravel shortfalls in linguistic plurality. Empirical research plays an important part at this point, first, through the discovery and sharing of knowledge but, more importantly, from the use of AAC as the pathway to gaining that knowledge.

CHAPTER 3 – PRIMING THE RESEARCH CANVAS

3.1 *Introduction*

Continuing with the metaphor of painting, the priming (preparation) is an important first step. A primer is applied to the canvas to help the colours stand out. If this is not done well, dull patches can appear which impact the quality of the image. The first chapter raised CCN research gaps before launching into an investigation of methodology. The status of people with CCN as participants within Australian research and the perceptions of people with CCN must be considered (as participants, and perhaps also as researchers). Understanding the research practice 'lay of the land' in relation to CCN, and in particular, the problems contributing to the low profile of people with CCN, provides crucial foundations for this study. The Australian *National Statement on Ethical Conduct in Human Research* (2007) states that 'the relationship between researchers and research participants is the ground on which human research is conducted'. However, without adequate knowledge to form a relationship with participants, this process can be compromised. As Krogh et al. (1999) point out, 'Few studies have emphasised, explored, and documented the process of establishing a research relationship with augmentative and alternative communication (AAC) users' (p. 2). Although Krogh et al. (1999) were writing over 15 years ago, the literature search for this study confirms this conclusion.

The type of relationship formed with participants also needs to be considered. *Participatory action research (PAR)*, a sociological methodology, recognises 'the researched' (such as people with disabilities) as key partners in the research process (Whyte, 1991; McIntyre, 2008). 'At its heart is collective, self-reflective inquiry that researchers and participants undertake, so they can understand and improve upon the practices in which they participate and the situations in which they find themselves' (Baum et al., 2006). It is interesting to recognise that this study, and my role as a parent of a child with CCN, closely aligns with this notion. PAR exists within the science of AAC, with examples of co-participation reflected in Williams et al. (2009) and Blackstone et al. (2007) extending further to include notions such as this by Pullin et al. (2017):

> Fully inclusive research implies not just the participation of people who use AAC but also their shared ownership of this research. This suggests an open model that itself

> may need to be reconciled with an increasing emphasis on intellectual property in the academic and commercial sectors. (p. 146)

Yet the disconnect between the sociologist and the potential participant with CCN affords little room for any form of research, let alone the type of partnering described by Pullin et al. (2017). The sociologist seeking good practice methodology for involving people with CCN in research is often left to extrapolate what they can from AAC research which only partially explores this topic. The focus group is a familiar concept within sociology, and a relatively common method used in research, including AAC research (Blackstone et al., 2009; Iacono et al., 2009; Hemsely et al., 2009). Yet this research is conducted by AAC experts, often speech pathologists, and *how to conduct a focus group research with people with CCN* is often treated as assumed knowledge.

This gulf between researcher and participant appears to dovetail with the communication access problems raised in the first chapter. This disconnect bears upon the 'doing' of research of this kind (sociological studies of people with CCN), resulting in the absence of precedential road map(s) for ethics and consent in this type of research.

3.2 *CCN and Research*

> Qualitative interviewing begins with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit. (Patton, 2002, p. 341)

Yet the knowable perspective of those with CCN appears to slip through the 'open arms' of qualitative research; the insights of people with CCN are often not included in research (Ison, 2009; Hodge, 2007; Lloyd, 2006; Paterson, 2002), leaving little known of the day-to-day lives and experiences of those with communication impairments (Hodge, 2007; Duchan, 2006). Proxy interviewing for people with CCN is common, often undertaken by those persons most familiar with the individual. However, it is problematic as information from the proxy may not necessarily concur with the view of the respondent (Ison, 2009; Lloyd, 2006). This is particularly concerning when considering the previous discussion about 'care' and its various facets and complexities which can include less noble motives, such as the urge to meddle or to control others, as described by Sevenhuijsen (1998). From this perspective it is possible to imagine some proxied responses being askew from the opinion and interests of the participant.

The aim of this section is to outline some of the problems that have emerged in the ‘doing’ of research with participants who have CCN. In order to create this outline, the references used in this section are dated over a 20-year period, to the present day, which is suggestive of two phenomena: research interest in this topic is both scarce and sporadic; the issue of research barriers for people with CCN, whilst periodically raised, has garnished little ongoing response.

Compounding this problem is an absence of research standards and ethical guidelines specific to CCN. As Cascella (2014) indicates, federal regulations in the United States do not account for the respondent with CCN. As Philpin (2005) has suggested, communication difficulties potentially lead to failure in interpreting written or verbal explanations within the consent process. Resource restrictions, particularly in relation to the time it might take to interview someone with CCN, presents another problem. Castrodale et al. (2010), in reporting on a study of researchers investigating within the field of disability, highlight institutional pressures as a deterrent to engaging in certain kinds of disability research: ‘when one is working to deadlines and tight budgets, it is not always possible to use emancipatory or even participatory approaches. One must generally be pragmatic’ (2010, p. 96). Pragmatism is difficult to achieve when, as Krogh et al. (1999) reveals: ‘Few studies have emphasised, explored, and documented the process of establishing a research relationship with augmentative and alternative communication (AAC) users’ (p. 2). Without knowledge of fundamental research needs such as these, it is not surprising research ‘opts out’ of the inclusion of people with CCN.

The low empirical profile, alongside the absence of the thoughts and opinions, of people with CCN is hinged on two related problems. Firstly research generally relies upon written and verbal communication. Secondly there is a subsequent failure to know, acknowledge and adapt to participants with CCN. This situation relates specifically to the field of AAC because *access to research participation* adds another form of barrier to the frequently highlighted barriers and needs previously cited from the field of AAC (Caron and Light, 2016; Collier et al., 2012; Bryen et al., 2004).

Barriers to research participation for people with CCN is a significant problem. Not only does it deny the knowledge contribution of a section of the community it also diminishes opportunities for protest. Thil (2015) makes the point that ‘voice’ is an important tool in struggles for the recognition of disability. Moreover, Duchan (2006) reveals that arguments about access are prominent in the disability field, yet communication access is afforded little attention. This view is echoed by Levin (2013), who notes that people with communication impairments are largely excluded from disability politics. In light of these barriers, new approaches capable of fostering alternative research methods and of working in concert with augmentative and alternative communication will be pursued in this study including feedback and recommendations from people with CCN at various phases of the research.

There is also an interface at play which involves the ‘person’ of research. The necessity of the researcher, or indeed any communication partner, to adjust communication so as to successfully converse with participants with CCN cannot be overlooked. Critical to understanding the thoughts, experiences, yearnings and imaginings of participants with CCN is the capacity of the researcher to push beyond the boundaries of the familiar and comfortable.

> Some of the barriers that exist are undoubtedly social, related to disablist norms of communication, such as not allowing people with communication impairments sufficient time to construct their turns in conversation, finishing their sentences for them or speaking across them to non-impaired companions. These barriers are ones which will not necessarily be broken down by improving access to communication aids. Even the most efficient user of a VOCA will not be able to communicate as quickly as someone using unimpaired speech and so is likely to find that they are still marginalized in conversation. Furthermore, using a communication aid itself may serve to stigmatize an individual. (Hodge, 2007, p. 469)

Rapport building with the participants with CCN may be affected by these concerns. Without a mutual level of confidence and the ability to ‘break the ice’ using AAC, the researcher, and participant, might be left to manage a sense of awkwardness and incompetence. It is perhaps fears of events such as this that leads to people with CCN being overlooked as research participants, resulting in gaps in qualitative research concerning people with CCN.

Finding strategies for gaining consent, comfortably using diverse forms of AAC, and allowing the time and resources for ‘emancipatory approaches’ are highlighted here. Another aspect, however, has emerged in the reading of material related to the study: the concept of the vulnerable participant. What does this mean in order to adjust, learn from participants, and maximise effective communication?

3.3 *Vulnerable Participants*

These gaps and uncertainties in interviewing people with CCN indicate the need to understand how people with CCN are positioned or categorised within research processes. By discovering who people with CCN *are* in relationship to the function of research, it is envisaged the study will be better prepared, factoring into its design considerations that will enable its greatest opportunity for success.

In preparing for the study, ethical concerns were quickly highlighted pointing to the concept, and indeed 'participant identity', of the 'vulnerable adult'. Herein the research pathway in relation to people with CCN appears to be intrinsically woven with concepts of 'vulnerable' and 'cognitively/mentally impaired'. Nind (2008) appears to make an initial distinction between impairments of communication and of cognition in a paper titled 'Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges'; however, this does not venture much beyond the title, with the content of the article combining, rather than distinguishing, CCN from other impairments. This tendency to overlook the significant differences between types of impairments is problematic for several reasons. First, it offers little to the researcher seeking information to help plan and guide their research practice with specific groups of participants. More significantly it reinforces false assumptions which may diminish people with CCN. For example, the belief that people with CCN are also significantly cognitively or mentally impaired has propelled the campaign *Just because I can't talk, doesn't mean I have nothing to say.* This phrase has been printed on bumper stickers for sale on the SCOPE Australia website (2015).

This raises a significant shortfall within the relatively new field of what Nind (2014) refers to as the not widely used term of 'inclusive research'. This shortfall lies in the categorisation of 'CCN' as if it applied to a homogenous group of people. Inclusive research practice, at the present time, appears to lie largely within the domain of intellectual disability as explored in the works of Bigby et al. (2014a, 2014b) and Forster (2009). Inclusive Research is about people with intellectual disabilities doing research, not having research done on them. (Centre for Disability Studies).

This tendency to merge people with CCN and cognitive impairments into a homogenous group is evident in the protocols that governed research at the time of this study. I contacted the National Health and Medical Research Council (NHMRC), an agency with a legislated role in providing evidence-based health research advice to government and the community. There are no guidelines specific to CCN, however I was informed, in writing, that a person with CCN would be considered a vulnerable participant and that the relevant guidelines for the practice of research in this area pertain to Chapter 4.5 of the National Statement on Ethical Conduct in Human Research (updated 2015) ‘*People with a cognitive impairment, an intellectual disability, or a mental illness’*. It is noted however, that data indicating correlations between Australians with CCN who have cognitive impairment and those with an intellectual disability or mental illness is unknown, as is also evident in the absence of references in the above stated guidelines at the time of the study.

There are several problems which emerge from the tendency to sweep together CCN and ID:

- CCN appears as a ‘symptom’ or ‘sub-set’ of ID. Its integrity as an impairment in its own right is significantly diminished.
- People with CCN sit across the intellectual continuum and are counted amongst those excluded from research.
- It is difficult to describe and argue for ‘inclusive research’ practices for an entire grouping of people from such a narrow interpretation.
- The publications which tackle inclusive research and CCN rarely provide detail related to how communication access is overcome in research. The reader is left wondering how the ‘rights’, ‘participatory processes’, ‘support provision’ and so on of people with CCN are actualised in the researcher–participant relationship.
- Aligning the needs of people with CCN to the needs of people with intellectual impairment contributes to stigma based upon the assumption that people with CCN also have intellectual impairment. This is a highly sensitive issue within the community of ISAAC due to the stigma and inappropriate attribution of other impairments. This issue is central to the ongoing campaign ‘Just because I don’t speak doesn’t mean I have nothing to say’ spearheaded by Scope Australia.

Understanding ‘vulnerability’ therefore presents an important consideration for a study such as this. Liamputtong, author of the book *Researching the Vulnerable* (2007), cites Moore and Miller (1999), stating that a precise definition of the ‘vulnerable’ is problematic as the concept is socially constructed. Liamputtong also cites Silva (1995), who suggests that a vulnerable person is someone who experiences diminished autonomy due to physiological or psychological factors, or status inequalities. This includes children and the acutely ill (Grbich, 1999).

This definition of vulnerable, when applied to people with CCN, might consider the physical differences between people with CCN, such as those with reduced or nil capacity for speech, and the presence of a wheelchair for mobility purposes. It might consider communication access barriers. As suggested earlier, assumptions might exist concerning intellectual or mental incapacity.

Power differences between the agendas of research and those of the community of interest present another point for consideration. Nind (2008), in reference to Kiernan (1999), suggests that research questions are, in the main, not determined by the community of interest, but by the researcher (or funder). This might be extended to notions of communication competency in relation to the role of the researcher who discerns which voices are suitable for inclusion. '[I]t is evident that while seeking to value the experiences of people with learning difficulties, traditional qualitative research is likely to encompass substantial barriers between the powerful researcher and the less powerful researched' (Nind, 2008).

I return to a reflexive position to suggest that there is another form of vulnerability, which, in its more benign and temporary state, differs from the extensive social vulnerability of some participants. It is conceivable that some qualitative researchers themselves may experience a level of vulnerability when undertaking fieldwork with people in general. For instance, Mazzotti (2013) suggests that 'If qualitative researchers are inadequately prepared for the emotions they may experience in the field and poorly supported through the research process, then they may lose confidence and eschew qualitative research' (p. 287).

Although they are not 'vulnerable' in the research-ethics sense, researchers might be vulnerable in relation to both poor performance and emotional impact that might also be associated with being unable, or indeed *disabled*, in the research process. I further extend this point to encompass the possibility that the researcher has not been trained or supported in the use of AAC. That, coupled with the possibility of some participants presenting with severe impairments or irregularities of the body, and socially-less-usual behaviours such as drooling, jerking and groaning, may elicit a form of researcher vulnerability that is at least as powerful in its potential to exclude (damaging opportunities to learn from people with CCN) as any other form of vulnerability laid upon the research table. Even as a part insider in this study, I recognise a sense of this type of vulnerability in relation to my own skills in effectively adapting to multiple forms of AAC, bringing with it the possibility of finding myself AAC illiterate and unable to pursue the research objectives in the study. This feeling highlights the possibility of CCN presenting a shared impairment; a communication two-way street. A participant may be incompetent in speech and written communication, but likewise I might be incompetent in adapting to different forms of AAC.

When considering research from this perspective, there appear to be two possible sides to the ‘vulnerable coin’: one primarily serving the function of protection of potential participants who may be at risk of harm (exploitation, abuse, rights overlooked or withheld and so forth) within the research process. However, on the other, this labelling of ‘vulnerable’ might also serve to define people with CCN before (and, indeed, *instead of*) any valid ontological process. In light of the issues raised in the first chapter, it forms a compelling hypothesis that there is a plausible relationship between the concepts of vulnerability and incompetency. This is worthy of attention before laying down the foundations for research in this study.

At a reflexive level, the task of interviewing people with unfamiliar communication methods, possibly exposing my own AAC illiteracy, elicits a type of vulnerability in me which is underpinned by the significance of failure – not only in research function (resulting in awkwardness and embarrassment for participants and myself), but more importantly in discovering that research with people with CCN is extremely limited, or even impossible, and thereafter having to acknowledge another frontier of communication limitation for my own child.

By raising the topic of researcher vulnerability, the intention is not to diminish the physiological, psychological or status inequities that are likely to exist for many participants of the study. Neither does this approach seek to minimise the needs of potential participants. Rather, it suggests how the notion of ‘competence’, especially competence with vulnerability in language, might be better understood as a shared phenomenon. Both the participant and the researcher perhaps need to be subject to capability building of the competencies required to progress epistemology in this area. Essentially, in making preparations for this research, I need to embrace a core point in the literature which suggests that people with CCN *can* communicate but use different natural or more formalised methods of AAC. An unsupported or inexperienced researcher risks walking away in confusion from potential participants because these communication gaps are interlaced with methodological gaps. The researcher may be vulnerable to the feelings that can emerge, knowing that professional ends were left untied. An analogy is someone arriving in a town where the inhabitants only speak another language. I wonder if it would be laudable to consider the researcher of participants with CCN as vulnerable from the perspective that they may not be AAC literate, and if so, what might agencies such as the NHMRC, alongside its affiliates and research support mechanisms within universities, do to reduce this vulnerability?

To carve the shape of methodology, it is useful to momentarily reflect upon the ideology of disability and injustice as defined by the neediness of others. These discourses, as highlighted in the first chapter, are often revealed in the sentiment underpinning book titles such as *The needs of strangers* (Ignatieff and Ignatieff, 1990) and *Researching the vulnerable* (Liamputtong, 2007). In recognising this, the concept of vulnerability, and indeed responsibility for effective problem solving of research barriers, could be an open and two-way phenomenon.

Acknowledging communication-related ‘needs’, ‘vulnerabilities’ and ‘disadvantages’ as things that both researcher and participant face provides a stronger platform from which genuine communication resolution might build. In beginning a research relationship acknowledging joint (communicative) frailty (founded on a situation of communication diversity) might allow some sharing of communication barriers. Communication becomes a joint responsibility. It might also lessen the unintended experience of condescension, ‘pity’ or ‘benevolence’ from the researcher toward the participant. It would widen researcher opportunities as a listener, learner, researcher, AAC communicator, and so on. It would help diminish the assumption that the participant is not able to communicate and potentially enable some power sharing. Power would be shared in the sense that the researcher is compelled to learn, and formally demonstrate (including being formally signed-off by the participant during the recruitment process), the ability to use AAC effectively enough to conduct the interview. Communicative competence is therefore shared by both the participant and the researcher.

In light of the possibility of many other forms of disadvantage that may exist for participants with CCN (as outlined in the first chapter, greatly reduced platform for ‘voice’, increased risks of abuse, etc.), it is important not to disregard the harm that can be caused through inequities that might exist between the researcher and participants. The word ‘battlefield’, used by Kittay (2010) as a mother of a child with significant impairments, highlights the possibility of battlefields in the lives of some participants, battlefields which need to be understood before barging into their lives with a notebook and camera. This might include the assumption of incompetence, among other social myths and stigma related to disability, *or it may not.*

3.4 *Rapport*

Patton (2002) states: ‘Rapport is built on the ability to convey empathy and understanding without judgement’ (p. 366). He provides some brief examples and explains the balance between rapport and remaining neutral; neutrality being the state of the researcher not engendering favour or disfavour in relation to information provided by participants (Patton, 2002). Other qualitative research texts extend this further. Grbich (1999, p. 98) provides categories for children as well as for ‘aged and disability’, highlighting five main points:

- making prior contact with participants
- explaining rights to participants
- clarifying the nature, including funding, of the research
- stressing the importance of the person’s contribution
- addressing any concerns raised by the person.

The above five points are generic in that they apply to qualitative interviewing generally; however, Grbich (1999, p. 103) lists communication-specific suggestions for rapport building with people who are aged or with disabilities.

- Print in large type.
- Shorten interview times.
- Directly face participants with hearing impairments.
- Maintain a comfortable, supportive environment.
- Keep questions clear, short and simple and rephrase them whenever any confusion is evident.
- Wait longer than usual for responses.
- Demonstrate exceptionally empathetic listening skills.
- When people with severe intellectual disabilities are interviewed, encourage carers to be present, as they can clarify responses.

Some of these recommendations appear to be straightforward, such as facing participants with hearing impairments. However, Grbich (1999) does not elaborate on what ‘Maintain a comfortable, supportive environment’ or ‘demonstrate exceptionally empathetic listening skills’ might entail.

Both Grbich (1999) and Patton (2002) refer to the notion of power imbalance between researcher and participant; however, for people with CCN more specific detail is necessary. In recent years small inroads have developed within the medical field. In the formation of effective doctor and patient relationships with people with CCN but also intellectual impairment, Chew et al. (2009) emphasise a need to adapt to the communication methods used by the patient. They provide a list of recommendations.

Medical practitioners may improve communication by:

- speaking directly to patients, regardless of the severity and aetiology of the disability
- using short sentences and clear age-appropriate language – treating adult patients as adults and not using child-like or patronising tones
- encouraging patients to be actively involved – either verbally or nonverbally – regardless of communication difficulties
- providing clear explanations and checking regularly that they have effectively communicated key points to the patient (for example, by asking him/her to repeat key points in their own words or answer specific questions about the issues discussed)
- using pictures and diagrams to clarify their explanations
- checking that they have understood what the patient has meant by repeating the key points back to him/her and asking for affirmation or correction
- making good use of the patient’s health records to support good information exchange
- ensuring adequate time is available for the consultation
- obtaining information from other sources where necessary – after obtaining appropriate permission
- For patients who communicate with an AAC system, medical practitioners can:
  - ensure that the patient has access to his/her AAC system
  - find out how the patient’s particular AAC system is used (Chew et al., 2009).

Despite the considerable difference in the role and function of a researcher and participant to that of a doctor and patient, Chew et al. offer transferable practices. Some of these might appear to be common sense such as ‘speaking directly to the person’ and ‘clarifying points with participants’, but these are important features that Chew et al. (2009) do not take for granted in a medical consultation. Practices such as ‘ensuring the person has access to their AAC system’, ‘adequate time to formulate a response’ and ‘familiarising oneself with individual communication systems’ might not always come to mind when conducting research with people with CCN.

There is evidence of the need for reflexive practice when conducting research with people with CCN. In light of the earlier reflection on researcher vulnerability and the recommendations made by Chew et al. (2009), further preparatory ideas come to mind. These are:

- acknowledge one’s own vulnerability as a researcher and ‘learner’, creating a space where familiar and assumed processes of communication and language can adapt and thrive
- understand one’s role as a communication partner wherein competence is shared
- use well-planned methods which aren’t reliant upon participant verbal or written responses.

3.5 *Consent*

In relation to the notions of vulnerability, the issue of consent is significant. Cascella and Aliotta (2014) indicates that there are no federal research standards and ethical guidelines specific to CCN and processes such as the issuing of consent in the United States, which reinforces the absence of the voices of people with CCN. Confronting this study from its onset were concepts of capacity and consent. Essentially, in the absence of such standards and guidelines, how are people with CCN provided opportunities to clarify concerns, ask questions and demonstrate capacity, in other words, give consent?

> Research participants with communication disorders are, by the very nature of their disabilities, at a disadvantage in the informed consent process ... difficulties with language comprehension and expressive communication can deter fully active and responsive engagement during informed consent processes. (Cascella and Aliotta, 2014, p. 249)

With limitations in verbal and written language, consent will likely be less straightforward in a study such as this. For instance, in some situations it may be difficult to discern the cognitive capacity of a potential participant. It is important to have a process in place to sensitively manage this process.

Nussbaum’s (2010) question of what individuals are capable of being and doing leads to further questions about what is needed to ensure, to the greatest extent possible, that the research process supports a bridge to this capability. This suggests the need to ensure that people with CCN are provided with opportunities to demonstrate their consent. Without this an assumption of incompetence might lead to the subsequent loss of knowledge from people who would have otherwise helped shape important social understandings.

Preparation for research necessitates ensuring maximisation of capability in relation to the giving of consent and subsequent participation in the study. In essence it is a combination of a more formalised use of ’yes’ and ‘no’ communication supported by several of the points listed by Chew et al. (2009).

The subsequent study design required: a) participants to operate some form of AAC capable of conveying ‘yes’, ‘no’ or ‘neutral/undecided’; and b) the researcher to understand, adapt to and use this in the study. Consent will be acquired through a range of methods according to the severity, and nature of, each individual’s complex communication need. The consent forms followed the same format of answering a series of ‘yes’ and ‘no’ questions.

1) A completed, hand-ticked, and signed hard-copy form.
2) A completed, hand-ticked, and signed electronic form.
3) Researcher learns, from the participant, the individual’s ‘yes’, ‘no’ and ‘neutral’ communication signals, and tests this first on a series of ‘small-talk’ questions. Only once the researcher has demonstrated a clear understanding of the individual’s responses can the consent questions be asked (and the form completed by the researcher). A signature, where possible, is sought from the participant.
4) If there is concern (from the researcher or advocate) about the potential participant’s capacity to understand the research questions, a further assessment is conducted, asking simple comprehension questions, for example, do you live here? Is that your bathroom (pointing in direction of kitchen)? These questions serve the purpose of assessing the potential participant’s capacity to answer the interview questions in the context of the intended research (about the person’s home in their home).

3.6 *Study Objectives and Questions*

The research questions are a culmination of the questions raised in previous chapters. Qualitative in nature, they seek ‘meanings’, ‘experiences’ and ‘relationships between things’. They are also directive. In the face of methodological gaps, they require answers to problems such as *how might effective research practice with participants with CCN be pursued and achieved*? In order to discover answers and find solutions, a flexible approach and a willingness to adapt, even transcend, traditional methods appears to be required.

Objective 1. Investigate and discover the experience and meaning of home from the perspective of people with CCN including what it has been, what it is, and what it could be.

Question 1. What is the meaning of home for research participants with CCN? What has it been? What is it now? What could/should it be?

Objective 2. Investigate the relationship between home, place and wellbeing for people with CCN.

Question 2. How is the participants’ experience of home related to and promoting (or not) communication access and Nussbaum’s list of capabilities, with an understanding that most of these capabilities require various degrees of interface with the public sphere?

Objective 3. To increase the understanding of best research methods for research with people with CCN – including the benefits of and barriers to AAC from both the perspective of the participant and the researcher.

Question 3. What are the barriers impeding research with people with CCN and how might AAC be experienced by both participants and researcher in the research process?

Objective 4. To investigate, develop, test and implement a set of CCN-friendly research methods capable of capturing an in-depth understanding of the meaning of home and place for people with CCN.

Question 4. How might effective research practice with participants with CCN be pursued and achieved? Can AAC and visual research methods be combined to create a set of methods offering effective utility with participants with CCN?

3.7 *Recruitment*

Ten participants were recruited with third-party support from three specific agencies. All three of the services approached for the purposes of recruitment agreed to pass on initial information about the study to potential participants, either through website advertising, staff meetings, noticeboards or direct contact with clients/community of interest.

Established in 1981, the Australian chapter of ISAAC is described as

> [A]n inclusive group interested in enhancing the participation of all people with complex communication needs. It aims to build the capacity of society to achieve our vision. Our vision is that people with complex communication needs participate fully in all aspects of life. (ISAAC 2016).

The study was advertised on its list-serve and website, with a link to a new page about the research. The list-serve is a national email link consisting of people affiliated with the use of AAC, including professional groups, speech pathology in particular, and people who use AAC and their families/supports. The study was restricted to people living in South Australia or Victoria, so advertising it nationally was not optimum; however, in the absence of an alternative vehicle using the list-serve was necessary.

Another agency which defines itself as an agency primarily established for people with cerebral palsy, but now works more broadly, provides services centred upon educational, leisure and recreational activity for clients. I attended staff meetings at five metropolitan locations and introduced the study and explained what would be involved for participants. This resulted in clients being informed of the study (during hub-group meetings). Four participants were successfully recruited from this process.

A South Australian Government health service which ran an intervention group for people with CCN due to acquired injury such as stroke was also approached, resulting in email and phone conversations with a speech pathologist. From here, two women were recruited, one young and the other much older.

Diverse modes of contact with participants were used to set up the initial meeting. Two participants sent direct emails, two emails were received from partners of participants, and one email was received from a parent. A support worker telephoned on behalf of his client, two clients were referred in an email from a service agency, the mother of a participant telephoned, as did the sister of another. In addition to the two participants who emailed directly, a further three participated directly in phone calls facilitated by close supports. The personal support worker of one participant directly interpreted and relayed (back and forth) the AAC of his client; the spouse of one participant initiated and co-ordinated a phone call, but the participant was able to convey mostly single words (not sentences) from their mother tongue of German (the researcher is able to understand German); and finally, the mother of a participant was checking back with her child to ensure their agreement in the process. Each of these persons conveyed their interest in the study and their desire to be involved. With five of the participants, there was no direct prior contact until the initial ‘meet and greet’.

3.8 *Summary*

Priming a research canvas for a study such as this requires an appreciation of how people with CCN might be currently positioned, perceived and accommodated within sociological research. It is this knowledge that makes it possible to develop better-informed methods, those which are better able to build from established inroads and to avoid past pitfalls. It also requires research performance with extra researcher reflexivity. Papadimitriou (2001) suggests that disability research involves two approaches: reflexive and emphatic:

> In the reflexive mode the researcher looks within in order to bracket or ‘clear oneself out of the way’, and in the emphatic mode the researcher looks ‘outward to the world of disability in order to listen to the other’s experience’. (p. 48)

Part of listening to the Other’s experience, as described by Papadimitriou (2001), entails pushing beyond stereotypes. This requires a researcher capacity to transcend the images that come to mind when thinking of ‘the vulnerable’, their impairments and neediness. For people with CCN, dual risks arise from imaginings about ‘the vulnerable’, namely, being perceived as not able to speak and write, and further, to be perceived as not having much to say in the first place.

The literature suggests that people with CCN are ascribed with notions of ‘vulnerable’ and/or ‘cognitively/mentally impaired’. The first chapter supports this perception, with evidence of increased risks of abuse for people with CCN. Yet, one might wonder whether the notion of vulnerability, in the perceptions of some researchers, might be closely aligned to perceptions of incompetency particularly when considering the reported omissions of people with CCN from participant cohorts. It is at this point that the appreciation of people with CCN in research becomes more complex because (in)competency can also be ascribed to the researcher and indeed any person competent or not in the use of AAC.

Complex issues such as those centred upon consent and notions of vulnerability have a bearing upon the nature and shape of the research process. There is also the element of approach and preparation aimed at maximising communication with persons with CCN. For example, pursuing the initiatives suggested by Chew et al. (2009), such as developing an awareness of the types of AAC (and devices) used by people with CCN, will enable greater opportunities for better communication partnering.

CHAPTER 4 – BLENDING THE COLOURS OF NEW METHODOLOGY

4.1 *Introduction*

The previous chapters have introduced the CCN notions of home and housing across the Australian socio-political landscape, as well as how the theoretical structures and social perceptions of people with CCN underpin this study. The literature reveals the low empirical profile of CCN, as reflected in the research gaps highlighted by Lloyd (2006), Ison (2009) and Paterson (2002) within the field of sociology, indicating the difficulties that researchers have experienced in accommodating participants with CCN. Chapter Three argued that, as well as general research ethics and standards in relation to vulnerable participants, additional specific resources must inform research processes. This poses a methodological challenge and necessitates a problem-solving approach founded upon an understanding of the types of methods suitable for investigating the lives, opinions, thoughts and experiences of people with CCN.

These research gaps communicate more than a message about communication access barriers; they also highlight difficulties within research of finding way to make adaptations. This study therefore cannot rely on conventional methodological practices in relation to research with participants with CCN. Specifically, new approaches need to be sourced, potentially with advice and guidance from people with CCN. The study requires a methodology capable of understanding, valuing and using diverse forms of AAC, and operating with greater flexibility in incorporating other ways of gathering and disseminating data. This requires fostering alternative research methods that can work in concert with augmentative and alternative communication. From here the paintbox of possible colours and materials is opened and the palette of possibilities is explored.

In recent years, ethnography has evolved to include new facets of meaning. Sensory ethnography, for instance, has emerged over the last fifteen years, with anthropologist Sarah Pink describing its use in ethnographic fieldwork in the 2009 and 2015 editions of her monograph *Doing Sensory Ethnography*. Pink (2011) describes sensory ethnography as a re-thinking of ethnographic methods based on sensory perception emerging during time spent being with and sharing the space and experiences with participants. In her earlier work, Pink (2005) posits ethnography as more than a set of methods, defining it as a methodology *and* ‘a process of creating and representing knowledge (about society, culture, and individuals) that is based on ethnographer's own experiences' (Pink, 2005, p. 18).

The colours chosen and blended for this study will draw upon these variations of ethnography, beginning with an embodied appreciation of the senses. It is hoped that sensory ethnography, together with visual research as expressed through pictorial communication symbols, photographs and art, will combine with the participants' personal use of AAC. Sensory ethnography forms the methodology used for this study. The following section describes its position within broader ethnography as well as the reasons it was chosen for the study.

4.2 *Ethnography as Sensory and Communicative*

A number of ethnographical corridors potentially intersect with the core themes of home and CCN and offer passage for the study. For instance, the ethnography of communication is first described by Hymes (1962, 1964) as the analysis of communication in the wider context of the social and cultural practices and beliefs of the members of a particular culture or speech (later defined by Hymes as communication) community. It is a move away from considering speech as an abstract phenomenon and towards investigating the diversity of speech (communication) as it is encountered in ethnographic fieldwork.

Ethnographic communication seeks to discover the cultural particularities and general principles of communication (Carbaugh and Boromisza-Habashi, 2015). Johnstone and Marcellino (2010) refer Farah (1998, p. 125): '[T]he ethnography of communication ... is concerned with the questions of what a person knows about appropriate patterns of language use in his or her community and how he or she learns about it'.

As outlined earlier, it is unclear to what extent people with CCN may be established as socio-cultural groups or communities based upon the nature of CCN. Online searches did not uncover the existence of community-operated peak bodies, advocacy groups or any published forms of CCN community-operated interest groups similar to those existing for communities who have grouped together under the common experience of other forms of impairment, for example the deaf community.

Although the study sets aside communication ethnography in favour of the richer sensory ethnography emerging in this field, communication ethnography contributes a useful component to the expanded observation grid used here. It is therefore useful to consider why ethnography in general is a suitable field of methodology for this study. The theoretical scaffold of this study – concepts such as social affiliation (Nussbaum) and alignment with the public sphere (Habermas) – may connect with communication ethnography, which in turn might relate to the meaning of home. It could assist in other post-study inquires such as an investigation of communication ethnography (as related to CCN) and access to the public sphere. Additionally, any data that might emerge related to communication ethnography may contribute to the improvement of participatory research options for people with CCN.

A research methodology that emerged within anthropology and sociology, ethnography is described by Patton (2002) as a traditional method of qualitative investigation reliant upon extensive fieldwork and participant observation. Fieldwork refers to the immersion of the researcher in a particular social or cultural group expressly for research purposes. As the central activity of qualitative inquiry, fieldwork involves direct personal contact with people in their own environments (Patton, 2002). At first, the concept of observational ethnography, observing people with CCN and their lives at home, appears to offer an alternative to relying upon direct communication. In this instance, once the process of recruitment has been effectively managed, a researcher might simply observe and record with little need to communicate with participants at all. Under further examination, however, this arrangement is fraught with problems. Of paramount significance is the potential to undermine the integrity of the study. According to Crotty (1998), methodology is the strategy, or plan of action, which matches our choice and use of specific methods, relating them to the anticipated outcomes. The study's research objectives and questions would be undermined by this method. For example, Question 4: How might effective research practice with participants with CCN be pursued and achieved? Can AAC and visual research methods be combined to create a set of methods offering effective utility with participants with CCN? It is difficult to imagine how the discovery of the answers to these questions might occur through utilising the method of observation, particularly as an alternative to, or solution for, communication barriers.

Furthermore, the purpose of using this form of ethnography appears founded upon a communication cop-out, perpetuating an ongoing omission of the participant's direct voice (opinions, thoughts, ideas and so forth). It does little to address the communication gulf existing between AAC and research. There are also practical considerations. For instance, unlike possible spoken conversation audible during observational interviewing, any AAC communication that occurs could more easily be missed.

Other forms of ethnography might be woven into the study such as netography, emerging in social research articles (Yong, 2017, Vascuez et al 2016). It is defined as a specific approach to conducting ethnographic research using media such as computers, lap tops and mobile phones (Kozinets, 2016). Email as a qualitative method of inquiry, has been broadly used in sociological research for several years (James, 2016, Ison, 2009).

Sensory ethnography actively seeks other modes of participant expression. It seeks to gather knowledge from that which cannot be expressed in words. Further to this, it values the communication of findings in ways that are not necessarily reliant upon the verbal or written word. Rather, it is a re-thinking of ethnographic methods based on sensory perception that is guided by understandings of the senses (Pink, 2011). ‘The senses not only provide people with a means to experience the world but also link people to place, most notably through emotions’ (Hemer and Dundon, 2016, p. 10). This sensory connection to place provided even greater relevance to a study about the meaning of home. Instead of asking ethnographic, open-ended research questions such as ‘could you tell me about your home?’ sensory ethnographic questions guide the ethnographer to find, through observance of her own experience, something of ‘what it might feel, look, smell, taste and sound like to live in this home?’

As an emerging field of research practice, sensory ethnography extends beyond traditional ethnography as it draws on an understanding of interconnected senses, especially how these senses capture valuable information. It incorporates innovative methods through the use of multi-media, and the engagement of other methods of representation such as art (Pink, 2011). Sensory ethnography, applied in disability studies, acknowledges the embodiment of experience and the meanings that people make of places, others and ourselves through the medium of the body (Sunderland, 2012).

‘What does it feel like to live here?’, the title of an article authored by Sunderland et al. (2012), explores notions of health and place through the use of sensory ethnography. Sunderland et al. (2012) acknowledge the embodiment of experience and the meaning we make of places, others and ourselves through the medium of the body, opening up the opportunity to explore the corridors of inquiry existing beyond doors of common language.

The experiencing, knowing and emplaced body therefore becomes a core element to sensory ethnography (Pink, 2015).

This approach aims to collaborate with research participants, learning to know with them using methods that are similar to the ways they learn and know, and together producing knowledge (Pink, 2011). In making way for new ways of experiencing ethnography, Pink (2005) describes ethnography as concerned with enabling reflexive, collaborative or participatory methods rather than producing an objective account of reality. This approach sits harmoniously with the justice perspectives chosen for this study. For instance, Nussbaum’s (2010) capabilities validate the right of citizens to enact capability number four: Senses, Imagination and Thought. Some understanding of the opportunities for senses, imagination and thought might be gained in asking questions; however, a sensory awareness of the space and environment brings rich insight. Seen this way, the study takes up the opportunity to be and to share with participants, enabling a bodily awareness of the space as well as the communicative dynamic and stimulation existing with and around the space, including the research process itself. Working in this way, reflexivity is important as is the ability to distinguish oneself from the participant: ‘the researcher is expected to remain as closely aligned with the reality of the context and the “intersubjectivities” through which the knowledge is produced’ (Pink, 2005, p, 18). For example, in this study, I imagine some of the possible sensory experiences that might arise when spending time with participants will be:

- Art works, smells, music, TV
- Is there a computer in the home and is it on?
- Books
- What am I sitting on, eating from, what does it feel like, taste like?
- Are there interruptions to our interview from friends phoning/texting?

In linking this back to Pink’s (2005) comment about intersubjectivities, the subjective implications are evident. For example, a home without art works for me personally is unhomely. It will likely be the subject of one of my earliest sensory experiences upon visiting the homes of participants. Pink (2011) addresses this issue with an emphasis on the researcher’s reflexive ability to appreciate their own situatedness. Vannini (2008) describes situatedness as being two types.

> The first type refers to the involvement of the researcher within a research site. Qualitative researchers should be aware of the situated nature of the contexts in which

> they collect data. The word *situated* refers, therefore, to the researcher's physically being on site and consequently to research shaped by personal relationships and by linguistic, biographical, historical, political, economic, cultural, ideological, material, and spatial dimensions. A researcher who is keenly aware of the situated nature of researchers can be said to be reflexive. (p. 815)

The ability to apply a reflexive appreciation of my own 'situatedness' should therefore counter personal sensory interpretations of such things as 'what a good home is' (for example, art works as mandatory) to accommodate different, even opposing meanings.

In addition to offering a philosophical framework and a method of inquiry, sensory ethnography encourages new ways of thinking about and sharing knowledge:

> This task involves not only engaging audiences in ways that enable their sense of knowing, in some embodied way, about what it was like to be with – or even to be the person(s) who participated in the research. It also involves a theoretical narrative through which this knowing informs a scholarly knowledge and that convinces an audience through an established form or method of intellectual argumentation. (Pink, 2009, p. 153)

Just as sensory ethnography granted permission to explore beyond the written and spoken word, it also gives license to sensually experience. Here there is an invitation to translate this sensory knowing to knowledge that might be expressed in a multitude of ways. Installations of art immediately come to mind; however, the possibilities for disseminating knowledge *for, through* or *with* and even those researched *by* people with CCN appear endless: music, photography, performance, movement, dance, etc.

4.3 *Planning Methods*

> Every method has its limitations, and multiple methods are usually needed. (Paton, 2002, p. 247)

In light of the significance of AAC, the justice positions of the theoretical framework, as well as the methodology chosen for the study, sensory ethnography, the development of methods requires an approach or set of criteria to ensure it aligns with the theoretical framework and methodological approach of the study. In planning this study, a door will be left open for the possibility of communication ethnography. As highlighted earlier, the literature review for this study has not uncovered evidence of people with CCN being an established cultural community. If, during the research process, this situation changes, then communication ethnography will be utilised, possibly replacing sensory ethnography as the driving methodology.

This research approach represents a synthesis between sensory ethnography and communication ethnography and favours an immersive encounter with the person in their deeply layered context. The following principles were developed to guide the data collection:

- Sensory ethnography will serve both a methodological argument and be instrumental as method.
- Mixed methods will be utilised that enable cross-checking and give validity to findings.
- Participants will not be required to provide verbal or written responses.
- Communication assistants (support workers or friends chosen by the participant) will be welcome but their involvement will be limited to ‘assist the communication of (not answer for) participants’.
- Facilitated communication (FC) will not be used.
- The AAC used by participants will be understood, and wherever possible fully incorporated within the research process.
- AAC tools will be brought to the interviews, to be used by participants, in case there is a breakdown of participant device(s).
- Participant-centred and specific access to methods will be discovered prior to interviews. For example, finger pointing, eye gaze, body movements, etc.
- Wherever possible, the process will appreciate, promote and use participant capabilities, maximising and valuing the independence of each person.

The mixed investigatory methods align with sensory ethnography:

> a re-thinking of ethnographic methods based on sensory perception that is guided by understandings of the senses, with the task of a sensory ethnographer being to observe and register all sense-related aspects, including the scents, taste, temperatures, and textures involved in a context. (Valtonen, 2010)

This methodology embraces the vast possibilities of AAC through multi-sensory communication, whether it is formalised through such media as the visually engineered PODD (Pragmatic, Organised, Dynamic, Display) or the tapped vibrations of Morse code, or the informal grasp of a hand, sounds and body movements. It also allows for other forms of communication such as environmental smells.

Due to the level of innovation required to undertake this study, it is anticipated that the methods will require a period of experimentation. To support and help demonstrate accountability, the process of triangulation, wherein several types of methods are used in a study in order to check the results of one and the same subject (Rothbauer, 2008; Paton 2002) will be utilised, as will formal testing of all new methods developed.

‘Visual information can set a topic, provide details, or clarify an utterance’ (Teachman et al, 2018, p. 4). Alongside sensory ethnography, photo elicitation is a method of interest for the study. As an ethnographic technique it enables the researcher to analyse participant responses to images shown to them in the research process. The term and use of the method was first described by photographer and researcher John Collier (1957); however, data search results suggest that this method has only gathered momentum since the 1990s. ‘I believe photo elicitation mines deeper shafts into a different part of human consciousness than do words-alone interviews’ (Harper, 2002, pp. 22–23). This potential to arrive at a more profound level of meaning, particularly in light of the restriction to conventional speech, renders this method most suitable for the present study. Providing participants are not significantly visually impaired, an experimental approach involving the combined use of sensory ethnography with the approaches of photo elicitation, as well as the possibility of using AAC tools as devices for research, offers a rich array of approaches that can be developed for method testing.

There are variant forms of photo elicitation that are not necessarily limited to images selected by the researcher. Lapenta (2011) refers to other approaches such as participant-generated image production wherein the images are produced/provided by the participant. Photo-voice as community-based image production is another form; it requires the participatory action of community members centred upon the creation of photographs that relate to aspects of community life, resulting in the discussion of their meaning with other group members and the researcher (Lapenta, 2011). Allen (2012) describes the role of photographs taken by participants as a technique capable of providing manifestations of what may be difficult to articulate, and also highlights the value of empowerment for human populations whose voice has been historically marginalized. How these images are later discussed with participants with CCN appears to be currently unavailable in the literature.

Standardised open-ended interview questions are not lost in this communication repertoire. The use of a topic guide opened up through AAC may provide sufficient responses, choices for participants and also provide a benchmark for comparing the relative success of each method.

The study includes questions delivered by asking participants why they chose to participate in the study, and inviting them to provide an account of where they have lived in the past. However, responses to these questions are likely to require AAC using the participants' methods. These might be high technology-based methods such as computers operated by switches or via eye-gaze and with digital voice output, or low technology devices such as a book of pictorial symbols or icons. Low technology options will be provided by the researcher as a back-up and these included the Talking Mat, a Pragmatic Organised Dynamic Display (PODD) book[10] or other less formalised responses such as vocalisations, gestures, etc.

4.4 *Developing and Testing Methods*

With sensory ethnography forming the methodological framework, four new methods are developed and tested in this study. These are:

1) participant-generated sensory selection;
2) adapted photo elicitation;
3) symbol selection using a Talking Mat; and
4) researcher embodiment.

The methods are guided and shaped by the question of how research might best engage with, learn about, and validate the ontology of people with CCN.

> As researchers, we must continuously ask: who gets to speak and how? To what extent are we limiting this interaction to match our own abilities as researchers? (Sunderland et al., 2015, p. 54)

---

[10] Developed by Australian speech pathologist Gayle Porter, PODD is available in both book form and computer software. http://www.podd.dk/eu/index.php?funktion=blok_kurser_lux_july14_uk

In turn, throughout and after the research, these questions become tests of the variability and rigour of the methods.

4.5 *Method 1: The Embodied Researcher*

Because sensory ethnography entails the embodied experience of the researcher in being with a participant (Pink, 2011), it requires a new kind of analytic orientation that would bring to the fore the sensory aspects that commonly go unnoticed (Valtonen, 2007). In a study such as this it means paying attention to the sensory information present during time with the participant. This might include paying attention to any sensory experiences stemming from the use of AAC (when and how the communication methods(s) are used, how they look, sound, smell, feel to touch and use, etc.) alongside the more generalised sounds and smells of the environment, the sharing of food, soaking in the ambience of décor, and the feel of the furniture. These are examples of sensory experience that might arise while spending time with participants.

Arising from this approach is the question of how to note or record these embodied experiences. Merleau-Ponty's (1962) notion of embodied language assists in answering this question in that gestures, auditory and visual mechanisms link bodily experiences to meaning. The notions of embodiment and language (such as Merleau-Ponty's), and the idea that gestures, auditory and visual mechanisms link bodily experiences to meaning, are relevant here. Multiple methods of recording, including video, photography, drawing (not necessarily limited to written accounts), are validated by this thinking and further supported by the work of Pink (2011).

It is hoped that this method, interwoven with strong elements of subjectiveness and reflexivity, will contribute texture to the other methods that are largely reliant upon participant choice making or traditional interviewing (a method anticipated to be challenging).

4.6 *Experimenting with Theory, Photo Elicitation and AAC*

Photo elicitation offers an alternative, adaptable research method which connects well with some forms of AAC. It enables researchers to analyse participants' responses to images shown to them in the research process. The possibility of connecting theory to images offered the opportunity for participants to point directly to meaning without having to engage in lengthy descriptions of, for example, qualities of home and/or Nussbaum's list of capabilities as reflected in photographs. The challenge is to find a way to align images with meaning, for example, finding images to reflect 'social affiliation' or 'power in one's environment'.

This involves a lengthy process of image investigation commencing with the question *what would each of Nussbaum's capabilities look like if they were presented in visual form?* Investigation of the expression of these qualities through smell, sound, taste and touch is also opened up. The multi-sensorial approach is compelling because it provides an opportunity to explore research participation options for people with CCN and significant visual impairment. The question of what 'social affiliation' might look like as an image might evolve into the question 'what does social affiliation smell like?' However, once it moves into the less familiar sensory territory of smell, more challenges arise. The issue of subjectivity is highlighted. For example, the smell of a barbeque cooking might mean social affiliation for some, but for the person living in isolated circumstances who regularly smells the barbeque of the neighbours, it may mean something entirely different, for example 'frustrating noise' or 'violation of animal rights'. In this sense the only likelihood of obtaining an accurate interpretation in relation to smell, or other sensory descriptions, is to ask a question such as 'If your home could be described as a smell(s) what would that smell(s) be?' The issue of subjectivity also highlights the need to ensure the visual choices provide a common meaning wherein pilot testing of the images is likely to be necessary.

Having included the necessary question of how effective research practice with participants with CCN can be pursued and achieved, I am keen to ensure that my attempts to include one type of impairment (CCN) do not ironically exclude another. For example people with significant vision impairment may not respond well to visual research techniques. In the event of a participant having significant vision impairment, a substitute (back-up) tactile method is being developed for this study through the use of an Oxford word list (incorporating sound and smell). The opportunity to make selections through touch is also being explored. Secondly, a multi-sensorial approach potentially opens up doorways through which capabilities (as described by Nussbaum) might be expressed and known by others; a phenomenon with implications extending beyond the reach of this study.

An initial attempt to match an image to theory was undertaken by examining the photographs and art works used in the books published by the theorists themselves. This photograph on the cover of Nussbaum's *Creating Capabilities* (2011) suggests the realisation of capabilities through the appearance of a free and joyful leap of a young boy of African appearance.

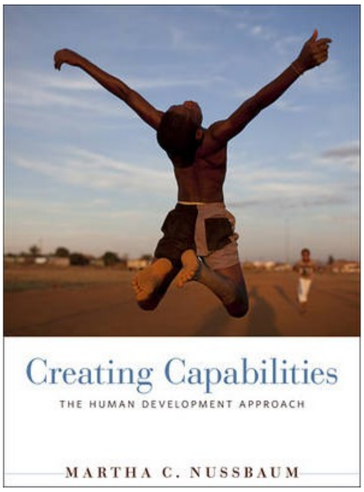


Figure 3. Front cover of Creating Capabilities by Martha Nussbaum

Front cover images are selected for their power to convey the topic and tone of the content. As book cover designer Peter Mendelsohn (2014) states, it involves 'finding that unique textual detail that … can support the metaphoric weight of the entire book.' However, it is clear that the type of images capable of reflecting the more nuanced experiences and meanings of home (inclusive of all the detail across the list of ten capabilities) would need to be sourced elsewhere.

The use of internet data sources generated thousands of images centred on the theoretical themes in the study. For instance, typing the word 'identity' (an important quality arising in the theory of home) into the 'Google Image Search' browser reveals numerous images centred upon the theme. Figure 4 provides some examples: an anonymous figure, suggesting the question 'who am I?'; a person holding a sign with the beginning statement 'I am ...'; a hand holding a blank business card; and a thumb being scanned for identification purposes.

Images (4) have been removed due to copyright restrictions

Figure 4. Identity

During the process of finding images to link with theory, a decision to reduce the images to a group of core theoretical meanings was made. Selecting images across a wide range of theoretical meanings of ‘home’ was found to be too encompassing and expansive. A selection of core meanings which commonly reflect the values of ‘home’ within the literature were identified and these were categorised under four headings (below). These dovetail with Nussbaum’s list of capabilities:

1) meaning and identity
2) safety and security/comfort
3) social affiliation
4) power, freedom, control over environment.

The task ahead involved the close matching of images to Nussbaum’s capabilities and the theoretical qualities of home.

4.7 *Method 2: Theory-Generated Photo Elicitation (Hands and Capabilities)*

Theory-generated photo elicitation, which has emerged from photo elicitation, deviates from participant-generated sensory selection, as the image choices are limited to specific themes constructed by the interviewer. In relation to home and place, it involves the creation of images symbolically representative of the underlying theories. This meant reducing theories of ‘home’ and ‘space’, as well as the correlating theory of capabilities (Nussbaum, 2007) down to core themes such as ‘freedom’, ‘social connection’, ‘safety’, ‘power over one’s environment’ and identity. To do this required selecting images capable of evoking an emotional connection to these themes, as well as the capacity to enable multiple differing viewpoints that could span a visual theoretical platform.

To test responses, topic-relevant internet images were informally piloted with a group of over 30 friends and associates, the details of which are outlined below. Examples of the images are shown below.

Image has been removed due

to copyright restrictions.

Figure 5. Social affiliation, comfort

Figure 6. Power, strength, control, resistance

Image has been removed due to
copyright restrictions.

Figure 7. Freedom

How these images might be interpreted was unknown, which led to the decision to undergo a process of testing images for the study. This was considered to be an important requirement for the purposes of both validity and investigative rigour of the first two study questions: Q.1: What is the meaning of home for research participants with CCN? and Q.2: How is the participant's experience of home related to and promoting (or not) communication access and Nussbaum's list of capabilities, this with an understanding that most of these capabilities require various degrees of interface with the public sphere? Yet it also served the purpose of directly helping to answer questions three and four: Q.3: What are the barriers impeding research with people with CCN and how might AAC be experienced by both participants and researcher in the research process? And Q.4: How might effective research practice with participants with CCN be pursued and achieved? Can AAC and visual research methods be combined to create a set of methods offering effective utility with participants with CCN?

The following discussion is in past tense as it reports on the findings of an informal test group. The test cohort consisted of more than thirty personal friends, family and university student peers; these persons, without CCN, were tested largely due to availability. The testing required significant numbers and the small minority of people with CCN living in South Australia would be required for the formal study.

The test group were shown 79 images sourced from the internet and asked the question: 'In three words or less, what does this image suggest to you?' The purpose was to identify whether there was a set of images that were frequently correlated with the theories, including Nussbaum's list of capabilities.

Most of the test participants tended to analyse the pictures rather than respond personally to them. This may have been due to the background of many participants (PhD students, etc.); however, others without research backgrounds tended to do this too. It was as though each person was attempting to solve a puzzle or investigate a story by looking at every piece of detail within the image in order to decipher its meaning. The distracting nature of some images was evident, with these images eliciting analytical rather than personal responses. Providing a cognitive rather than a personal response, one of the test participants was interested in identifying the nationality of a little boy photographed peering out of a basket. Another made comments and questions about the symbolism of objects in the photograph and wondered if they were 'codes' or 'clues'. These types of responses suggested that the images might need to be simplified with less detail to analyse but still be evocative enough to ‘talk’ to the viewer at a personal level.

General feedback was requested from test group participants, with many stating that they found the exercise interesting. Constructive comments and suggestions were offered during this testing phase. For example, one person suggested that the images were weighted too positively and perhaps did not allow the opportunity to select more negative images. This person commented, ‘Using mostly happy images suggests that home is a good place but for some people it won’t be’. This highlighted the potential risk of forcing participants to choose from images led by positive assumptions. It was imperative that the opportunity for variations on these valued themes was available and balanced reflection of the existence of, absence of, or partially experienced theoretical qualities of ‘home’ and Nussbaum’s capabilities.

The photographs which appeared to resonate the most with test participants were simple images, particularly those showing a hand and containing very little else in the overall picture. For instance, images of stacked hands, holding hands and hands joined in a circle all received similar meanings befitting social affiliation. The fisted hand (Figure 6) was described as ‘power’, ‘strength’ and ‘resistance’, but one person suggested ‘strong and manly’ and another ‘domestic violence’. The hand appears to be male and is squeezed tightly into a fist. I wondered if the hand were female and the grip looser whether it would result in the same response.

Overall, the greater success with the images of hands spurned an interest in the investigation of hands, some understanding of human reliance upon hands as communicative tools, and the realisation that the ability to symbolise meaning through hand postures has existed across time. In the 1500s French essayist Michel de Montaigne asserted:

> Behold the hands, how they promise, conjure, appeal, menace, pray, supplicate, refuse, beckon, interrogate, admire, confess, cringe, instruct, command, mock and what not besides, with a variation and multiplication of variation which makes the tongue envious. (de Montaigne, 2003)

There is also neuro-scientific evidence suggesting that the semantic representations of the concepts expressed by meaningful hand postures have similar properties to those of abstract words (Gunter et al., 2004). Fisted in power, nestled in companionship, isolated, stifled, comforted or imprisoned; these hands carried the hope of transcending spoken language, not to convey words (as in sign language), but to locate oneself within the context of themes.

This commenced a process of targeting the theoretical themes of the study with corresponding images of hands. The intention was not to signify a single meaning but rather to engage the participant in a thinking direction, based upon a theoretical theme, that might allow for some nuanced, even contrasting, responses. Despite the numerous pictures available, some of the images did not necessarily fit the theoretical theme to best effect. They were also often of young, white and able-bodied hands (demonstrating their use of fine motor skills), which poses a question about an assumption or bias that, once again, communication, if by hand images, *must be via able-bodied hands*. Some potential participants may have unusual hand postures as may be present with conditions such as cerebral palsy, hence more relatable images, not ‘model hands’ but without the condescension of deliberately mal-postured hands.

Added to this was the presence of copyright considerations associated with some images, wherein the process of obtaining permission was unknown. These concerns led to a decision to create photographs of hands specifically for the study. I used my own, albeit white, female and middle-aged, hands for all of the images, as well as the hands of a white, older, male (a university photographer). The decision to use the same hands was made for the same reason that faces and other details were removed: they tended to engage people’s cognitive rather than personal responses.

The creation of, instead of borrowing, hand images enabled a high amount of control over the images. Distracting elements such as jewellery, tattoos and nail polish would not be included. Furthermore, the hands adopted a subtle suggestion of impairment wherein it was possible for the hands to be associated with positioning that can occur from neurological injury, *or not.* The aim was to make the hands say as little about their ability or disability as possible; however, the status of ‘white’ remained.

4.7.1 *Creating Hand Images*

Using a small box of props (the box was also a prop), a studio photographer from the university faculty’s media and illustration unit was engaged to take the photographs. Sixteen images were created with broad themes centred upon theories of home and Nussbaum’s capabilities. The images aimed to include negative and neutral options with much less detailed images. The study hoped to direct participants to connect with deeper meanings of home. The intention of these photographs was to suggest theoretical features of ‘home’ and

Nussbaum’s capabilities, and if participants did not interpret images as broadly intended then this would be good too. When it comes to conducting the study, the thrust of this approach will be to enable a personal resonance with the images and to gain an overall sense of how the suggested themes might relate to participants (or not). Different or additional interpretations would be welcome, with meaning clarified with single-word responses. For example: ‘In a single word or two could you tell me what this picture (image selected by participant) represents to you?’

Photographs were taken from different angles which allowed for choice in the final set. Sixteen images were chosen and printed in different size formats. One set was laminated (with the rough edges rounded to protect participants from finger cuts), another was printed on thick card, and a set was left on traditional photographic paper.

A formal test of these hand images was conducted with twenty-two test participants (consisting mostly of people who assisted in the previous methods test). Each was shown these 16 photographs (the hand postures on the left side of the figure) and asked the same questions as in the previous test.

Figure 8. Study photograph – Identity (hidden) supressed (emotion/person).

Figure 9. Identity 2 (Google Images) - Image has been removed due to copyright restrictions.

The internet image on the right was one of four tested to reflect a sense of hidden identity/supression. Both images resonated with test participants with comments such as ‘eroded’, ‘hidden’ and ‘fade into the background’.

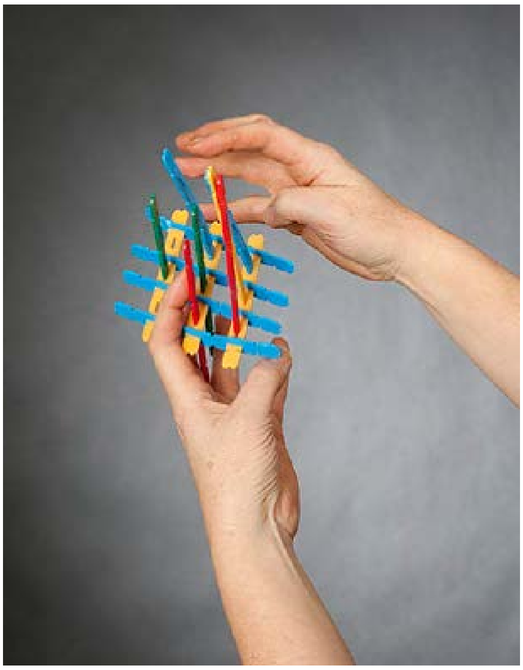


Figure 10. Study photograph – Thought, problem solving, play, imagination

Figure 11. Thought, problem solving, play, imagination (Google Images) Image has been removed due to copyright restrictions.

The image on the right was less desirable for the study due to the distraction of the Rubik’s Cube, with test participants talking about the cube itself and/or their memories of using it, rather than the activity itself. This image was doubled-up with Figure 32.

Figure 12. Study photograph – Comfort, warmth, safety

Figure 13. Comfort, warmth, safety (Google Image). Image has been removed due to copyright restrictions.

Several test participants focused on the concept of a ‘partner’, ‘husband’ or ‘wife’. This raised a concern about the unintended suggestion that one *needs* a partner in order to have a home. Recruitment had commenced at this point, with no participants, thus far, appearing to have partners. Hands gently stacked (Figure 14) was created to enable expression of the idea of a partner or ‘significant other’.

Figure 14. Study photograph – Social affiliation, relationships, connection, warmth, safety

Figure 15. Social affiliation, relationships, connection, warmth, safety (Google Images). Image has been removed due to copyright restrictions.

The images of social affliation from the internet tended to involve faces of people. Several test partcipants were distracted by this. One person believed that they recognised someone. Generally, however, the notion of social affiliation, relationships, etc. was interpreted.

Figure 16. Study photograph – Smothered, powerlessness, supressed

The notion of powerlessness or being supressed was not specifically included in the test group. This improvised image, created during photography, was taken for the purpose of balancing the number of positive options for participant selection.

Figure 17. Study photograph – Imprisoned

Figure 18. Imprisoned (Google Image. Image has been removed due to copyright restrictions.

The image on the right resonated with all test participants and as such it was adapted for the study. The only changes made were: a simplification of the image, removal of the suggestion of imprisonment as gaol (because other forms exist), and to present the hand as reflecting someone who could have (but also may not have) an impairment.

Figure 19. Study photograph – Bodily health, bodily integrity.

Figure 20. Bodily health, bodily integrity (Google Image). Image has been removed due to copyright restrictions.

Bodily health and bodily integrity was the most difficult concept to capture in image form. It needed to capture the sense of health and treatment but also provide the possibility of negativity (reduced capabilities). There was much expected of this image. Many internet images were sourced, with seven shown to test participants, but none were able to adequately convey the themes being sought.

Figure 21. Study photograph – Partnership, affiliation

The image created is very similar to two internet pictures that were shown to the test participants.

Figure 22. Study photograph – Strength, power, resistance, emotional expression

Figure 23. Strength, power, resistance, emotional expression (Google Image)

The fisted hand on the right captured the personal/emotional response of participants. However, in addition to themes of power and strength, domestic violence and masculinity was expressed. This evoked a commitment to use an image that would show a less tightly squeezed fist and be more gender-neutral.

Figure 24. Study photograph – Struggle, trapped

As with Figure 16, this theme was not specifically included in the test group. This improvised image, created during photography, was taken for the purpose of balancing the number of positive options for participant selection.

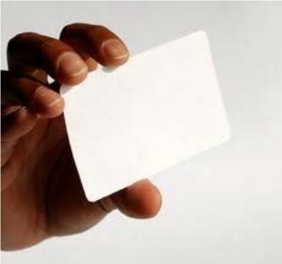


Figure 25. Study photograph – Identity

Figure 26. Identity 3 (Google Images)

Figure 27. Identity 4 (Google Images). Image has been removed due to copyright restrictions.

This hand image (Figure 25) was developed by combining two successful images shown to the test cohort (Figures 26 and 27).

Figure 28. Study photograph – Connection to world, travel, world beyond home, freedom

Figure 29. Study photograph – Freedom

Figure 30. Freedom (Google Images). Image has been removed due to copyright restrictions.

The freedom-themed images used in the test group contained distracting detail which I attempted to simplify through the use of the dove symbol and hand posture.

Figure 31. Study photograph – Warmth, comfort, play

This image is intended to have the same meaning as Figure 12. It was included to gauge which image might achieve a better response.

Figure 32. Study photograph – Challenge, thought, control

This image was intended to evoke a similar meaning as Figure 10. It was included to gauge which image might achieve a better response from the test group.

Figure 33. Study photograph – Strength, solidarity, social affiliation

This image was intended to evoke a similar meaning as Figure 21. It was included to gauge which image might achieve a better response and to uncover the possibility of different interpretative responses.

4.7.2 *Testing hand images*

Testing of the hand images was more formalised due to the potential of results contributing to the data collection for questions 3 and 4 of the study. This involved presenting the question in a similar way as it would be in a study. There were, however, significant variations, for example, almost all participants were known to me, and very few tested answered this question at home. This sample of test participants (n = 22) viewed the display of the 16 study photographs. The majority of the group had assisted with the previous test of general images obtained from the internet. This had both advantages and disadvantages in that the difference between the quality of responses was notable, but this was now a familiarised test group with greater insight into the process (which is unlikely to be the case in the field).

The results were remarkably different from the initial test of internet images. The test participants displayed an immediate, personal response to most of the photographs. There was less time taken in the analysis of some of the images (as there had been in the previous test) and considerably more personalisation of the images. For example, in response to the question (and with permission to use) -‘Which of these images most reflects what it feels like to live in your home?’, one woman selected three, displaying one at a time: ‘my home growing up’; ‘my home before I met (new husband)’, and ‘what home feels like now’. Examining the three photos in sequence, the test participant then stated, ‘I can’t believe how my life has changed’. The decision to remove additional content appeared to pay off, as reflected in the response to the fisted hand (Figure 22). There were no off-task analyses of such things as gender issues and domestic violence as had been the case in the previous test.

Responses to three of the images suggested that people were confused and/or less moved by them. These photographs (Figures 31, 32 and 33) were doubles of other themes with the coinciding images resonating more strongly with test participants. These images have been removed from the study. It was also evident that two other images (Figures 14 and 21) received duplicate responses relating to the notion of ‘social affiliation’; however, two of the twenty-two respondents selected both of these images to discern the connection they have with an intimate partner to that of the rest of their family or friends. This provided different information and for this reason the two similar images were retained.

The success of the method was evident in the large amount of positive feedback it received, most of which centred around enjoyment at responding to the question. Of the twenty-two test respondents, twenty-one were able to make a selection, with most selecting more than one image. Clarification was achieved by asking the respondent to provide one or two words which would indicate their interpretation of the meaning of the image. Although some of the test participants described, in detail, the reason for their selection, there were also some who adhered to the request of summing up their choice in one or two words. These responses provided a reassurance that an adequate depth of meaning could be obtained by image selection and single word clarification.

4.8 *Testing Method 3: Adapted Image Selection Using a Talking Mat*

Alongside plans to incorporate participants’ personal AAC, as well as to make available to participants (who may be without devices) the use of both high and low tech options, I was keen to identify AAC tools that might be readily adaptable for use with people with CCN from diverse backgrounds. As highlighted by Pennington (2007), people who use AAC vary widely in their skills and communication needs.

Investigation of the direct use of AAC devices and/or approaches for research purposes identified that the Talking Mat © has been successfully applied and evaluated (Mackay and Murphy, 2017) in AAC research in studies across a range of topics such as intellectual impairment (Murphy, 2008), Huntington's disease (Hallberg et al., 2013; Ferm, 2009) and dementia (Alm et al., 2011). Offered both as a physical mat, and in electronic application, the Talking Mat comes with several subject-based sets of vocabulary that can be extended and modified.

Communication is conveyed through the choices made. Pointing (with hands, eyes, etc.) is a possible main method that could be used in this study. A few participants pointed with their finger and one removed the images from the Velcro board. Eye pointing or eye-gazing is where one looks at an item from the selection set long enough for the communication partner to identify the direction of the gaze and confirm the selected item (Beukelman and Mirenda, 2005, p. 93).

In relation to the study, the possibility of the Talking Mat being used as a research tool emerged while attending a disability expo. The exhibitor, a speech pathologist trained in AAC, described its use and was confident it could be adapted for research purposes. At the 2014 Biennial Conference of the International Society of Augmentative and Alternative Communication (ISAAC) a Talking Mats representative agreed to help test the use of this device with a mock interview, essentially testing the utility of the mat as a research tool. I assumed the position of the participant (and remained non-verbal with little or no movements) and exhibitor asked me questions about home. I took a photograph of my answers, shown in Figure 34. As shown in the photograph, value measures were attained using the yellow 'thumbs up/down' and 'don't know' cards. Participants were invited to select cards and to either place them (or eye point to) the affirmative, negative or don't know categories.

Figure 34. Talking Mat mock interview – ISAAC Conference 2014, Lisbon

Later on, I added more specific language cards to reflect such core theoretical themes as ‘identity’ and ‘social connection’, as well as more detailed language specific to aspects of home, such as ‘house mates’, ‘communication access’, etc. This involved adjusting or creating new cards, using the templates in the Talking Mat kit. This method required an adequate selection of options from which the participants could choose as well as the researcher’s ability to identify the respondents’ ‘yes’, ‘no’ and ‘don’t know/undecided’ communication. The cards were chosen or shaped to reflect Nussbaum’s capabilities as well as theories of home.

This method was the first tested involving a small group of family and friends without impairments. This involved the presentation of thirty-five cards and asking test participants to select the top most important qualities of a good home. At the time this question had not been intended for the final study; however, it was used with slight adjustments in the final study. The test participants were also given the added task of doing as much of the exercise as possible without speaking, with selections ideally made through pointing, eye gaze or other forms of indication. Not all themes were available in the Talking Mat packs so some cards were adapted. Test participants were invited to make selections and then to allocate each card under

1) important (thumbs up icon);

2) neither important or not important (neutral or ‘don’t know’ icon); and

3) not important (thumbs down icon).

They were also offered the possibility to simply indicate all choices or remove all the cards that were not relevant to them. This simpler approach of selecting and/or omitting was initiated by test participants. They were invited to reveal which of the icons they selected (up to five) were the most important (most critical out of a group of overall important items) qualities for them personally.

From the outset, the exercise engaged strong interest from *all* test participants; it was as though they were about to play a game. However unfortunately a couple of people seemed to be concerned with picking the ‘right’ cards, not necessarily what was right for them. The number of cards made the task onerous for a few test participants. The gaze of participants often darted back and forth across the large black mat, and cards, at times, were flying around, falling to the floor, etc. In one situation, because there were so many cards to view, reflect upon and rank, one of the test participants was unable to complete the task due to the length of time it was taking to complete (she only had half an hour). This alerted me to the possibility of the increased burden it would place on some participants with impairments.

Test participants sometimes asked for clarification, such as ‘When it says “safety” do you mean …?’ I generally responded with the comment ‘Whatever that means for you’, sometimes accompanied with varied examples of how the card might be interpreted. It was also evident that card choices sometimes led to the detail being overlooked, for example, one man chose the card ‘Health’ and said ‘That’s all that I need (for a good home)’. The detail of what ‘health’ meant for this person was not clear. When I encouraged him to elaborate with some other cards, he said ‘Nope – just health’. This type of response did not provide the detail required to compare responses to theory, for instance, the list of capabilities proposed by Nussbaum (2010). As a result this card and others such as ‘environment’ were removed. Alternatively, cards conveying too much detail were removed; cards which specified the types of relationships or people (children, spouse, partner, sexual relationship and so forth) were removed on the basis that ‘Relationships’ and ‘Social’ provided a starting point from which a further question of ‘who?’ could be added.

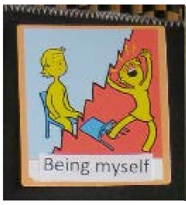
After the testing phase a final nineteen cards (qualities of a good home) were selected for alignment with theory. The qualities about home highlighted in the literature (identity, safety, comfort) were combined with Nussbaum’s capabilities in this way. Most of these icons were sourced from the Talking Mat pack; however, several were re-named or recreated to better reflect the theoretical content. For example, the card ‘being myself’ was created to enable a way to indicate identity.

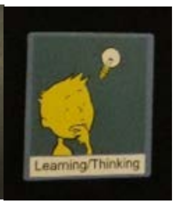
1. *Life*. Living a full-length quality life.

2. *Bodily Health*. Having good health.

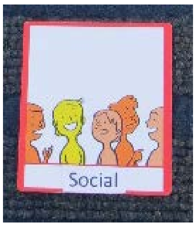
3. *Bodily Integrity*. Safety from violence, including sexual assault and domestic violence; opportunities for sexual satisfaction and reproduction.

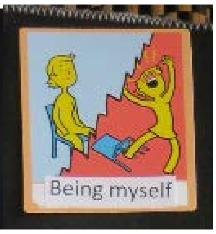
4. *Senses, Imagination, and Thought*. To have adequate education and be able to use the senses, to imagine, think, reason, create and to exercise choice and decision making.



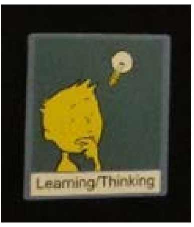


5. *Emotions.* Being able to form attachments and express emotions.

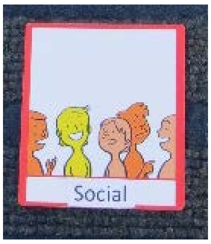


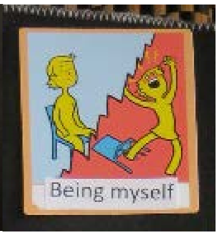


6. *Practical Reason.* Being able to reflect on notions of good and to engage in critical reflection about the planning of one's life.



7. *Affiliation.* Being able to enjoy relationships with others that help foster positive self-regard.





8. *Other Species.* Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. *Play.* To enjoy recreational activities.

10. *Control Over One’s Environment.* Both political (to participate in political choices, freedom of speech) and material (the right to meaningful employment, being able to own property and goods).

Figure 35. Nussbaum’s capabilities and adapted Talking Mat icons

Eighteen of the nineteen cards selected for the method aligned with Nussbaum’s list of capabilities and the themes raised in housing theory; however, the ‘spiritual’ card appeared to not fit as clearly. Nussbaum includes spirituality in the capability ‘senses, imagination and thought’; however, in the responses received from participants it appeared to align more with ‘affiliation’ (a relationship with God).

This icon (Spiritual) was included as part of this method despite its absence within the theories selected for the study, particularly the core elements of ‘home’ and Nussbaum’s capabilities. Four of the test group (n = 10) selected this icon and as such it suggested the possibility of an element overlooked in the theory.

Despite the effectiveness of the Talking Mat as a research tool, in this case to bring visual meaning to theoretical concepts, there was an important shortfall to consider. In common with many communication devices that rely upon pre-set displays of vocabulary symbols, is the impediment of limited vocabulary selection. This issue is raised by Bornman and Bryen (2013) who in outlining this problem cite Carlson (1981): ‘They [people who use AAC] are unable to spontaneously create their own lexicon and must operate with a vocabulary selected by someone else or preselected, not spontaneously chosen by themselves’ (p. 140). The authors suggest that, ideally, adults who use AAC should be leading the process of identifying vocabulary, but in reality this is often not the case. Instead, others, such as speech pathologists and residential support staff, with perhaps limited knowledge of the adults who use AAC are undertaking vocabulary selection (Borman and Bryen, 2013). Hereto lies the problem for research: ensuring the participant with CCN has adequate access to personal lexicon capable of best describing, in this instance *the meaning of home*, information of deep personal significance. From here I turned to experimentation to identify other ways to optimise participatory research involvement.

4.9 *Testing Method 4: Participant-Generated Sensory Selection*

The participant-generated sensory selection method developed for this study is built upon the technique of photo elicitation. Epstein (2006) cites Banks (2001) and Harper (1997) in claiming that photo elicitation interviews have been used mainly in ethnographic and social studies research, enabling researchers to analyse participants’ responses to images. Lapenta (2011) uses the term respondent-generated image production, which, for the purpose of this study, has been adapted to become participant-generated *sensory* production, wherein the elements of sound and smell are added. This involves respondents indicating something concrete or imagined from, for example, the internet or use of a camera (with wheelchair attachment) or the Oxford Wordlist© (2010), providing a word bank for sound or smell. It diverts considerably from the earlier described notions of sensory ethnography in that it directly asks sensory questions (essentially turning sensorial experience into a thinking activity). However, in light of the value sensory ethnography places upon the senses for ‘knowing’, as well as the possibility of maximising response opportunities for people with CCN, it appeared to be worth exploring. The overall purpose of this approach is, as described earlier, to create alternative options for the expression of meaning.

Underlying this method is the question *If you could explain what it feels like to live in your home by imagining or showing/pointing out a picture (or a smell, or a sound/song), what would it be?* This question was used without alteration in the final study. The aim of this type of question (whether used in research or practice) was to create the opportunity for the respondent to provide detail or depth about something of meaning to the person without the need for description. Meaning would then be confirmed by the use of word selection from the participant’s AAC, and/or the interviewer’s Talking Mat and/or word bank provided by the interviewer.

The group of twenty-two test participants were asked the question *If you could explain what it feels like to live in your home by imagining or showing/pointing out a picture (or a smell, or a sound/song), what would it be?* There was no time limit placed on the provision of a response and the test participants were invited to answer the question however they wished, such as referring to a picture on the internet, describing smells, taking a photograph, etc. Seven of the twenty-two did not respond to the question. There were negative comments including ‘Too abstract for me’ and ‘This will take me a long while for me to think of something’. There were, however, several test participants who responded comfortably, providing images such as a shed full of memorabilia and electronics, or a garden full of pets. Only a handful (four) people chose non-visual responses to answer this question; however, these responses were rich and informative. For example, ‘To sum my home up in smell, it would be the smell of baking biscuits, and detergent – I don’t bake biscuits anymore, but for me, probably still means a combination of comfort, visitors and work’. One person described the different types of music that correlate with different parts of the day for her.

4.10 *Test Participant Evaluation of Methods 2, 3 and 4*

The two cohorts of adults (without CCN) who volunteered to test the methods were asked to rank how effective each of the methods (2, 3 and 4) were in helping to reveal what home means to them from a selection of ‘good’, ‘okay’, ‘not good’ and ‘don’t know’. The results are outlined in Table 1. General comments were recorded, and respondents were invited to provide feedback.

The first group (n = 10) provided feedback on method 3, *adapted image selection (AIS) using the Talking Mat.* This group later expanded to 22 test participants and provided sample feedback on Method 2, *theory-generated photo elicitation(hands and capabilities),* and Method 4, *participant-generated sensory selection (PGSS).* The majority of test participants were female (two thirds). There were four people from non-English-speaking backgrounds and participants’ age covered most of the adult lifespan.

Recruitment of test participants was informal and involved directly asking family and friends if they would like to test the methods. I explained the purpose of the test was to ‘iron out’ problems so as to ensure that the methods would have the best chance of working well with actual participants. Test participants were invited to be open with their thoughts or concerns about methods. The methods were tested informally, and presented either individually or in small groups. The approach was informal and generated much discussion (part of the first test of internet photographs was done at the end of a meal with a large group of people). Test participants were not asked to sign consent forms because responses were not recorded or used as part of the study. However, comments of test participants have been included in the thesis, for which verbal permission was obtained.

Table 1 outlines the general feedback provided in relation to the three methods tested. The adapted image selection (AIS) was successful, with nine of the ten sample group selecting ‘good’ to rate its effectiveness as a method. Comments included ‘it’s easy’, ‘fun’ and ‘interesting’. Suggestions were provided, resulting in the re-making and addition (as opposed to removal) of cards. The theory-generated photo elicitation (hand images) also received strong feedback and evoked higher than anticipated emotional responses. Test participants appeared to be more emotionally engaged with these images than with the icons on the Talking Mat. Method 3, participant-generated sensory selection, was overall not highly received. There were a few test participants who seemed to take to this approach very well, easily providing visual images or descriptions of smell or sounds, but there were comments indicating that it was too difficult or required too much time to think of a response.

Table 1. Test participant evaluation of methods 2, 3 and 4

Method	n	good	okay	not good	don't know
Theory-generated photo elicitation (hands)	22	16	4		
Adapted image selection (Talking Mat)	10	9	1		
Participant-generated sensory selection	22	8	9	2	3

4.11 *Interview Plan*

The interview component with the study participants is based upon seven questions; however, it is anticipated that much of the 'interview' will include other questions (for example, 'Please can you show me how you say yes/no/neutral') and general conversation and taking breaks. Method 1 (embodied researcher) will be undertaken over the duration of the time spent with each participant.

The following seven questions will be read aloud to the participant so they know what the questions will be and are given the opportunity to plan their time and energy to focus on the questions, allowing them to have the greatest expression of meaning. They may also decide to not answer a question or add additional information.

1) (Method 5: structured questions) Why were you interested in participating in the study?
2) (Method 5) Where have you lived in the past? What was good/not good about these past places?
3) (Method 4: participant-generated sensory selection) What does it look like, feel like, sound like or smell like to live in your home? Can you think of a picture, a song or sound, or a smell that can give the sense of what it's like to live in your home? (Discuss options for this.)
4) (Method 2: theory-generated photo elicitation) Which of these photographs of hands (maximum of 3) best reflects what it is like to live in your home? Please indicate with a single word (or more) what this image means to you.

5) (Method 3: adapted image selection – Talking Mat) Which would be your top qualities of a good home? Please choose up to 5 icons.
6) (Method 5) Where do you feel most at home with your AAC?
7) What suggestions do you have for anyone thinking about interviewing people with CCN?

4.12 *Pilot Test*

The final element of the testing phase involved a pilot study of a man in his mid-twenties with CCN. The young man is a personal acquaintance who is actively involved in the world of disability, including volunteer work. He has cerebral palsy, uses a wheelchair and, with limited use of his arms and hands, operated a communication device throughout the pilot interview. Accompanied by a support person (his mother), it was negotiated during the pilot consent process that she would not provide responses to questions unless he invited her to provide more descriptive detail to explain his thoughts. The purpose of the pilot interview was to test all the methods with someone with CCN.

Method 1: Researcher Embodiment was included in the pilot. The venue was not his home but a café, so the shared experience of time in his home was not available. Despite this, I was keen to apply an embodied awareness of the interview, which at first appeared to deaden sensory experience as the café sounds drowned out the voice output capacity of the young man's communication device. It took a few minutes to realise this *was* a sensory experience, and unfortunately likely to be a regular experience for this young man. As a researcher struggling to listen to the voice output of his Liberator (communication device), I took note of how easily the environment could nullify a communication device, despite its sophistication in design and technology. The Liberator clearly was not at home in this environment. Without this embodied experience as encapsulated in sensory ethnography, this important piece of data may have easily been overlooked.

The interview began with an explanation of the study and some familiarisation with his AAC which, in this session, consisted mainly of a high-technology communication device, some vocalisations and nods or laughter to indicate 'yes'. The young man was communicating his choices by pointing with his eyes and then affirming with vocalisations, sometimes accompanied with a short laugh or via the use of his electronic communication device. The three previously tested methods were used but with some modification. The hand images were now thirteen (not sixteen) and there were now only nineteen Talking Mat icons, not 35. The participant-generated sensory selection was presented but with something of a disclaimer; I spoke about the very different experiences from the test group.

In using Method 3 (adapted image selection using the Talking Mat) to answer a question about what is most important to him about a good home, the first two cards the young man chose from the Talking Mat were ‘privacy’ and ‘body safety’ and he placed them next to each other. He then looked at his mother (indicating his wish for her to speak). She related a story of a young man they knew who lives in a group home, who went to hospital with serious burns. While his mother told the story, the participant typed ‘shower carer left’ into the Liberator. It was noted that the choice making led to conversation rather than just simply making a choice (as had been anticipated).

The length of the interview session was an hour and forty minutes, which included additional time for feedback. Feedback led to the card ‘nature’ being added to the AIS (Talking Mat pictures). The young man rated the three methods tested as ‘good’. He found the use of smell for expression not good (he agreed to the suggestion it was weird). He wanted more time to think about a song that would sum up what it feels like to live in his home because he found that question interesting. He suggested that the question should still be included for the study. The participant’s mother commented that some of these questions would be useful to take back to the psychologist in relation to exploring housing options for her son.

Through his valuable assistance, the young man helped clarify some important points:

- More time than I had anticipated might be needed for participants to collect thoughts, prepare and deliver responses using AAC. This will likely require more than one interview session.
- It will be useful to leave room for, or invite, additional ideas and icons from the participants to ensure that unanticipated meanings can readily be included.
- Intimacy will need to be considered such as the possibility of needing to sit close to participants (to read devices, or to provide assistance if required).
- The potential need to ask support people to let the participant answer the question, rather than answer on their behalf, emerged during the pilot. There were a couple of occasions where this occurred in the interview; however, the young man managed this by using waving away movements of his arms and/or using a ‘protesting’ vocalisation and preparing his own response with me responding to his lead.

- The interview was interesting and engaging for this young man, which matched the feedback from the test exercises.

4.13 *Reflexive Testing*

The researcher should acknowledge their own values, biases and position in relation to persons being researched (Alston and Bowles, 1998). This, together with Pink’s (2010) description of awareness of one’s own situatedness as a researcher, has encouraged me to answer the questions and to realise my own ‘meaning of home’. The example below provides an illustration. Method 4, participant-generated sensory selection, seeks answers to the question, what does it look like, feel like, sound like or smell like to live in your home? Can you think of a picture, a song or sound, or a smell that can give the sense of what it’s like to live in your home?

The scent of fresh lavender and urine help describe, literally and metaphorically, what it feels like to live in my home. Lavender: nurturing, pretty. Urine: intimate, difficult, authentic. Lavender is a dominant plant in our garden – I bring pieces inside and we sometimes have lavender oil burning. It is relaxing, nurturing and I associate it with my family across its lifespan: my parents who visit, and in the massage, bath and pillow oil I have used with my young children. Urine is present in the awkwardness of the toilet chair that often leaks. There is a large bucket by the back door that fills over the course of the day with incontinence pads. There is often urine all over the toilet seat and floor from my five-year-old who misses. Most days, for one reason or another, the smell of urine is noticeable. Aside from a bad smell that I wish was not there, the smell represents intimacy, caring, difficulty and authenticity – all things that help explain what it feels like to live in my home.

The single words ‘lavender’ and ‘urine’ were retrieved by me using the PODD (the word ‘lavender’ was not available in the Talking Mat kit I was using).

4.14 *Chapter Summary*

This chapter has outlined a suite of new methods developed and used in combination with AAC for the purpose of finding a methodological solution to a gap in the epistemology of CCN. Multiple methods have been relied upon in a process of triangulation so as to ensure accountability, but also to make comparisons between the effectiveness of these methods. Traditional structured and open-ended ethnographic questions will accompany the combined use of photographs, sensory references and AAC that, together with the sensory ethnography of the embodied researcher, will provide five corridors for discovery of the meaning of home for people with CCN.

The methods are founded upon the adaptation of alternative and traditional methods in combination with AAC. The hand photographs were created to align with theory. I am not aware of this having been done before, nor am I aware of the use of sensory selection (based upon open questions related to smell or sound) having been used in this way. These new methods have each been provided with a small level of testing. Greater amounts of testing and development of these methods, particularly with people with CCN, is required. However, I have been somewhat reassured by the results obtained in its testing phase. In addition to discoveries of the meaning of home for participants, feedback will be sought from participants in relation to the efficacy of the methods.

At this early stage, I do not claim that these combined methods are an optimal methodological solution, or even (at this point) a successful solution. Rather, I posit an arrangement of elements which appear conducive to the meaningful inquiry into the lives of people with CCN. These elements are centred upon emerging notions of ethnography which are able to transcend the limitations of spoken and written language, to support the combined use of AAC, visual research methods (adapted photo elicitation in particular), traditional ethnographic questioning, and sensory embodiment of the researcher in partnership with participants. Furthermore, by allowing some consideration for shoulder-roads of inquiry such as communication ethnography, and applying processes such as triangulation, the research process is compelled to account for, and more fully understand, the humanity of communication.

CHAPTER 5 – PAINTING, CAPTURING ESSENCE AND TRUTH

5.1 *Introduction*

This chapter paints as close as possible an account of participants' stories and responses to questions. Painted with their generous assistance and willingness to share the colours, textures and emotions of their lived experience, an understanding of each person's unique meaning(s) of home was successfully rendered. The findings on the meaning of home, and assessment of the methodology, is presented in Chapter Six. The following pages focus on the approach and execution of the five methods developed for the study and detailed in Chapter Four.

1) Sensory ethnography and the emplaced researcher;
2) Theory-generated image selection (hands);
3) Adapted image selection (Talking Mat);
4) Participant-generated sensory selection; and
5) Ethnographic structured and unstructured questioning.

The value of this mixed-methods approach lies in its capacity to offer accountability to participants, particularly in the context of gaps in research with this cohort. This chapter begins with a demographic outline of the participants, followed by revelations of the researcher arriving at the homes of participants, and a description of how communication was established. It then moves onto describing how the above methods were introduced to and used with participants.

Throughout this and subsequent chapters, indented paragraphs written in italics indicate notes taken during the fieldwork, either immediately after an interview or after watching video recordings of interviews.

5.2 *Demography of participants*

Before entering the analysis phase, the demographic backgrounds of the participants of the study are briefly outlined (Table 2) which involves information (age, gender, address) obtained during the consent phase, as well as that which arose naturally within the interviews. An understanding of education and employment status, as well as religious affiliation, arose during conversations with participants. With four of the participants, religious status was raised either by the participants themselves or their family/support person present during the interview. Two participants indicated their involvement in a Christian church community, the mother of a third participant stated that the participant attends church, and an enrolled nurse revealed Judaism as the religion of another participant. The participants, with the exception of one living in a rural community, were situated across the Adelaide metropolitan area.

All participants were from white Australian or European backgrounds, including one who had migrated to Australia before acquiring the brain injury that diminished her capacity to communicate. Four participants lived in group homes, two lived with parents, two lived with their spouse and/or children, and two were sole occupants of their own home (SA Housing Trust owned). There were four female and six male participants with ages ranging from 23 to 77 years.

Most of the cohort (seven) had cerebral palsy, and two were people who had suffered one or multiple strokes in adult life. One had an unknown neurological condition resulting in physical and intellectual impairments. Two of the ten were confirmed as having intellectual impairment, with a further two being described as ‘unknown’ or ‘partial’ – for example, one individual with cerebral palsy indicated her ‘thinking’ was ‘good’, but ‘numbers bad’ (including elementary mathematics). A woman in her forties, who was previously a university academic before suffering a stroke, indicated that she has partial intellectual impairment due to the loss of some elementary cognitive functions.

At the time of the study, four of the participants were holders of university degrees (three with completed higher degrees, including one with a PhD). Two were studying, including one person with severe cerebral palsy who was a PhD candidate. Only one participant was involved in paid work at the time of the interviews.

Six of the participants used some level of vocalisation (sounds, utterances or speech); however, I experienced considerable difficulty understanding the vocalisations of four of those participants. With nine of the ten participants, we relied upon AAC to varying degrees (in most cases solely) for communication and/or for the benefit of my clarification. Some of the demographic factors are listed below.

Table 2. Demographic characteristics of participants

Participant	Age	Gender	Condition	Housing type	Education	Employment
a	23	m	C/palsy	Parental	TAFE	Student
b	25	m	C/palsy/unknown	Grandparents	Yr 12	Online course
c	37	m	Unknown syndrome/ID	Disability group home	Special school	Supported disability employment
d	44	f	Stroke	With partner & children	Higher degree	Not employed
e	44	m	C/palsy	Own rental SA Housing	Higher degree	Student (university)
f	46	f	C/palsy	Own rental SA Housing	Higher degree	Part-time student (university) /part-time employed
G	46	m	C/palsy/ID	Disability group home	Special school	Not employed
h	50	f	C/palsy	Disability group home	Unknown	Not employed
i	59	m	C/palsy/ID	Disability group home	No schooling	Not employed
j	77	f	Stroke	With partner	Degree	Retired early due to stroke

5.3 *Research in Context: Reflexing and Sensing*

Picture this: a woman wearing a smocked shirt is about to leave through a front door. She is laden with bags and a large, black folder of pictures. The woman looks like an artist on her way to a place of creative production. Looking closer, one of the bags is branded ‘Talking Mat’. There is camera equipment in the woman’s hand, including a device to mount a camera on a wheelchair. The folder of photographs, images and symbols is tucked under one arm and over her shoulder hangs a backpack containing a low-tech communication device and an iPad mini with communication applications. Although not art materials, these tools can make real the hope of channelling expression and understanding of what home means for a person with CCN.

Before commencing a description of meeting the participants and establishing communication processes, I see benefit in digging deeper into the detailed reality of what occurred and sharing it as part of the thesis. I did not simply climb into my car and drive to the participant's home *end of story*. A great deal of both inward and sensory awareness occurred, as reflected in my journal notes:

> *On the drive to the participant's home the mindful state of embodiment is evoked – the doing of what has been rehearsed in recent weeks being practice in self-awareness of senses – understanding the bodily experience of self in setting. Years of counselling work, some brief training in mindfulness, as well as yoga at a local women's community centre has encouraged my focus on my senses. For example, every yoga class would begin the same way – lying on the mat – we would be invited to notice what we could see around us without moving our heads – then shut our eyes, then focus on our breathing, then notice the sounds, then focus on our breathing and then feel our bodies on the mat the texture of the mat – the feel of our clothing. Although the interviews are likely to be quite active, rather than meditative like the yoga, the bringing-in of the conscious awareness of one's reception of sensory information is intended for the study.*
>
> *The experience of noticing the information that is 'picked up' by the senses is the cornerstone to sensory ethnography. This began at the earliest point. Before leaving home I would spend a few minutes noticing my thoughts and feelings before actively noticing my senses. This would continue while travelling to the home of the participant. Noticing the suburb and street that the participant lived in, the front yard, the neighbouring buildings and sounds, objects, adapted equipment such as ramps or grab-rails, sounds and smells, the texture underfoot on route to the front door (and imagining how it might be experienced in a wheelchair). Adding smell and taste to the list of senses was not difficult.*

5.4 *Doing interviews in AAC*

Three of the participants greeted me unaccompanied; two at home and one at the Botanic Gardens Kiosk (later visited at home). The remaining seven participants were introduced to me by another. This section begins with a brief background and description of those participants who were unaccompanied in the interview, and follows with an outline of those who had either family or support workers, or both, in attendance.

The initial meetings were a little challenging as there was much to learn quickly and each participant used different ways to get their message across. Learning the communication styles of a variety of different people, at times, presented challenges. Meeting Anna, 40 years old and a permanent resident of Australia, originally from France, with an academic background prior to injury from a stroke, and married with two children, provides an illustration of this. I noted:

> *Anna, who uses a crutch to assist mobility, cut across her large leafy front yard to find me (I had gotten myself lost in her neighbours' yard and required rescuing). Anna spoke one or two isolated words in French which spurred my efforts to speak in French. It was apparent she was trying different ways to tell me something, but for about 20 minutes I could not comprehend what she said. It was a tense time, we both were stuck and frustrated with the communication gap. I felt I had failed, that I was letting her down. I could see the frustration on her face and hear it in her voice. All I could say is 'I'm sorry, I'm sorry – so sorry, I'm not understanding'. She, with effort, wrote 'Eng' on my note pad and spoke the word 'okay' and I finally understood. 'Agggh – you mean it's ok for me to speak in English rather than keep going with my dodgy French?' Anna laughed with relief. 'Oui' her voice on the video exclaims. Anna could nod and shake her head for yes and no and sometimes speak the words (in French). Anna's partner had informed me during our three-way conversation that Anna had reverted to only a few words in her first language or 'mother tongue' as a result of a stroke. I had completed preparatory reading about stroke and aphasia (speech impairment resulting from injury to language areas of the brain), but had assumed her receptive understanding of English was also affected. This clearly was not the case.*

During this time, the sophistication of Anna's AAC was also revealed, appearing to maximise all her possible strengths and capabilities. Anna had the use of one arm, so in addition to the few words in French and gestures, Anna also used an iPad mini with a communication app Proloquo2Go[11] and Google Maps, an iPad camera to photograph images for explanation, and internet and Facebook applications to support communication. Anna also demonstrated her use of number and symbol writing to explain time relationships, etc. She used dates to explain the difference between past and present, such as what home was like in the years she was an academic living in different countries around the world, to the home she has now after experiencing a stroke.

Two other participants attended the interviews without others. Emma, in her mid-40s, a woman with an Honours degree qualification, works part-time for a disability advocacy service and lives with severe cerebral palsy. Emma greeted me with body language, arms flung wide, and I was embraced in a hug. ‘How are you?’ she asked using dysarthric[12] speech. Due to my limited experience communicating with persons with dysarthric speech Emma was required to repeat or clarify much of what she was saying. Remarkably she did not appear to be frustrated or annoyed by this. Often she assisted my understanding by pointing or gesturing, smiling and nodding encouragingly when I was ‘on the right track’. I noted:

> *The second time I met with Emma, I could tell something was wrong, she was pointing behind her wheelchair and speaking words to me which I mostly didn’t understand. Emma’s pointing told me she was requesting something from the back of the wheelchair, but I didn’t understand what it was. The word ‘Jumper’ stood out and I fetched a cardigan from the bag at the back of the chair and was about to help her put it on when she waved me away with an arm that said – let me do this myself.*

John, also in his mid-40s, has a university education background, is involved in disability advocacy, and is currently undertaking a PhD. John is living with severe cerebral palsy. He uses speech as a primary form of communication; however, when communication became too difficult for us, John employed high-tech VOCA, gestures, internet and interpretation from a support worker who was called upon by John to assist with communication. He, like Emma, enjoys a wide circle of friends and participates in a variety of community activities within, for example, a church.

---

[11] Proloquo2Go is a symbol-based communication app for children, teens and adults who cannot speak.

[12] According to the ASHA website *dysarthria* is a motor speech disorder. It results from impaired movement of the muscles used for speech production, including the lips, tongue, vocal folds and/or diaphragm.

While Emma and John live on their own, four participants live in group homes, two live with their spouse (one with spouse and young children), and two with their parents or grandparents. In all of these situations there was a high level of information provision from the accompanying person(s). It was evident that support people were keen to assist and to ensure that I was able to effectively communicate with the participant.

Carl was introduced to me by his nurse Wing, who explained that Carl, a 59-year-old Jewish man with severe cerebral palsy, has lived in residential care for several years. Before that he lived with his mother, who had passed away five years previously. Carl's health issues are significant, as evidenced by the care provision of a nurse. He is unable to use a wheelchair, and instead lies in a partially reclined bed at all times. After greeting Carl, who acknowledged my verbal hello with his eyes, I asked him how he says 'yes' and 'no'. Carl demonstrated this by the positioning of his head with eyes rolling back and left for 'yes' and eyes lowered for 'no'.

George, 49 years, who has a diagnosis of cerebral palsy and intellectual impairment, shares the group home with Carl and has lived in different group homes for many years. Prior to this he lived with his father. During the interview, George communicated in several ways: pointing, gesturing, dysarthric speech – usually just one, sometimes two words uttered at one time – smiling, and by the assistance of a support worker. George has a defiance about him, a determination in telling a story he wishes to have known. He appears fragile, angry and vulnerable, but also empowered in the exceptional manner in which he commandeered the interview with his stare and the gestures he used to ensure his greatest advocate – support worker, Neil – spoke when he was required and withdrew when not. It was apparent from the tears that were visible in Neil's eyes at two points of the interview, that the support worker holds a deep, genuine regard for George.

Neil is also a support worker to Ruby, 50, who lives in another group home managed by the same agency. Ruby was introduced to me by her mother, Iris, with Neil waiting in the background. Within minutes, I was learning about Ruby; she, like George, presents as a vibrant mixture of fragility, anger and defiance, but in this situation she appears to have the power to direct Neil and to sometimes agree (or not) to Iris' explanations, although there were times when I could see dismay expressed after her mother had spoken. Ruby, in the interview, primarily used facial gestures and eye gaze (and some limited hand pointing) at core written words that were attached to the underside of the clear plastic tray of her wheelchair.

Photographs were handed to me – Ruby at Flinders University holding a certificate. ‘It’s not a degree or anything – just a certificate for completing a short course’, said Iris.

Sean is 37 years old and lives in a group home operated by a different agency. He has an unknown syndrome together with an intellectual disability diagnosis; his health and independence has declined in recent months, as indicated by the introduction of a wheelchair for most of his mobility. Sean works four days a week in what his Mother called a ‘sheltered workshop’, enjoys social contact, and has regular contact with his family: his mother, his sister and sister’s family, spending at least a day each week with them. Jane, Sean’s sister, made the initial contact with the project. It was during the first phone conversation that Jane revealed some information that appeared to not match well together: Sean had a lovely home but was also depressed. She described Sean’s behaviour of covertly not taking medications while in hospital so as to delay his discharge. One-word utterances, hand gestures such as ‘thumbs up or down’, smiles, nodding and shaking his head were the initial forms of communication used in the first interview. The PODD was introduced in the next interview.

David, 23, has lived most of his life in the joint care of his grandparents and other family members. He has minimal contact with his separated parents who live interstate. Having not been provided with access to schooling until a later age, David is a part-time SACE (South Australian Certificate of Education) student completing Year 11 and 12 subjects. During the interviews, David communicated using VOCA – Liberator, but also gestures, facial expressions such as smiles, nods, head shakes and finger pointing.

Liam is 25 years old and lives in a rural community with his parents. The family are well connected to the community, including through church activities. Liam, the youngest child of a large family, has severe cerebral palsy. He enjoys regular contact with his wider family, and attends regular day activities, including ‘outings’ provided by a disability service provider. When communicating during the interview, Liam used eye positioning and eye pointing (staring at picture icons affixed to the underside of the clear plastic tray of his wheelchair). Liam also used smiling, laughter, facial expressions, some pointing using wide arm movements, and vocalisations to communicate.

Clara, 77, is a retired school teacher who lives with her supportive husband who provides the majority of her care. Clara sustained a brain injury from two strokes, the initial stroke occurring over 20 years ago, the second a year ago, which has affected her ability to effectively use her limbs or to speak, other than one- or two-word utterances. Clara, however, uses an iPad, computer (with communication applications), facial expressions, and some limited writing (one or two words at a time with letters often written back to front).

The ability to discern ‘yes’, ‘no’ and ‘neutral/I don’t know’ was a fundamental step in communication partnering for the study. My ability to distinguish between these was a critical element to the consent process which needed to be ‘signed off’ by the participant. The consent process (including a space on the form to be ticked) required the participant to be satisfied with the communication partnering of the researcher (me) in understanding and representing what they were saying. For participants with reduced capacity to sign their consent, a third party person (chosen by the participant) was required to witness this process and affirm the researcher’s communication competence. There was the added benefit of sharing power during this consent phase, as part of the criteria for recruitment involved the researcher demonstrating to the potential participant their ability to understand and respond to the unique ‘yes’, ‘no’ and ‘neutral’ responses of the individual. I noted:

> *He’s had a lifetime of cultivating this message – this ‘yes’. His ‘yes’ was sophisticated and consistent – all it needed was my willingness and ability to observe and wait for the message, and to check that I had understood. … The steadying of the breath, the focus of the eyes, the labour of pulling a chin up and to the left and the rolling of the eyes with a body that does not move on command. This ‘yes’ was slow, deliberate, calculated and laborious. There was no way I was going to say ‘no’ to recruiting him due to his obvious fatigue when he just told me with everything he had that he wanted to answer my questions – right now.*

A sense of power is closely linked to competence (Hepworth et al., 1997) and in the situation of CCN no-one is more competent in this unique language than the person about to be interviewed. A willingness to immerse oneself and learn something of another language is, however, a critical requirement of the researcher. It would also seem to benefit the researcher. I noted:

> *I feel invigorated – pumped. Today I had to think on my feet and focus on what he was saying – and yes, there were many times I had to stop the conversation and say ‘I don’t understand’ or to ask him to use his device rather than speech. Over the course*

> *of time I've gotten better at listening, waiting for responses and perceiving, with confidence, the initiation of a communicative act.*

Each of the ten participants possessed unique language in this area. For example, saying 'yes' included vocalisation such as 'naya' and humming; eye movements such as eyes looking up and left or eyes looking down and left at a 'yes' symbol on the tray of their wheelchair; gestures such as a thumbs up; or a forced smile that looked like a grimace. These all meant 'yes' to a participant. The following conversation transcript provides an illustration.

B-J. So what's it like staying in the hospital?

S. [no response, no eye contact]

B-J. [opens the PODD – *communication device brought to the interview*] Here is the 'opinion page', 'turn the page' – this section shows words and pictures you can point at to say 'things' 'good' 'bad', etc. Here's the word 'interesting', 'great', 'fun', etc. On this side are some words you can show when things are bad or negative – to say when things are bad – 'yuck', 'bad', 'annoying' … so, what's it like to stay in hospital?

S. [points to the quadrant of positive word descriptions and then to the word 'good']

B-J. Is it good to stay in hospital? [asks twice]

S. [Smiles and does a 'thumbs up']

B-J. Hospital stays are good.

Liam, a man in his mid-twenties, revealed how communication ensued using his AAC. Liam demonstrated how his eyes looking down to a symbol on the left side of his tray is his main way of saying 'yes'. A sharp turn of his head to the right being 'no' and looking straight up to the sky (up to God is how Liam's parents described the action) conveyed his 'don't know'. The following extract from the interview with Liam illustrates how the use of 'yes' and 'no' can be used in interviewing.

B-J. To live in a group home?

L. [Head turn (no)]

R. To live with other young people?

L. [Eyes down left to the 'yes' icon on the tray (yes) and head turn (no)]

B-J. Do you mean yes *and* no?

L. [Eyes down left to the 'yes' icon on the tray (yes)]

The interview with Liam relied predominantly on yes/no responses, and a few of the core message icon pictures adhered to his tray, as well as the photographs and Talking Mat icons which accompanied the methods. Liam (as well as two other participants) had high-tech communication devices which I was informed by his parents were not used often.

Furthermore, participants were able to indicate the extent to which something was a ‘yes’, communicating whether the feeling/experience was positive, negative or on a scale in between. The Talking Mat ‘thumbs up/down’ and ‘don’t know’ icons pictured in Figure 36 were used for this purpose; not only in the use of Method 3, adapted image selection, but for any question where a scaled response was desirable. This was done by me pointing to the icons or the spaces in between the icons to determine how far along the scale a participant’s opinion was situated. The verbal prompts (me speaking aloud) that I used to describe the scale were: thumbs up = ‘good’, the gap as ‘okay’, the neural position as ‘neutral or don’t know’, the next gap = ‘not very good’, and the ‘thumbs down’ symbol as ‘not good’.

Figure 36. Talking Mat icons: yes – don’t know/neutral – no

Some participants used other methods, for instance, Anna had initiated a process of communicating amount, volume and time through her use of numbers and size, and with references to Google Maps. At the beginning of our conversation, Anna wrote down the date of her stroke and used this as a reference point throughout the interview. Pre- and post-CCN experiences had not been factored into the questions, but it clearly offered valuable information about how home experiences have changed due to impairment(s), CCN in particular. To support Anna’s direction, I abandoned the use of the Talking Mat and used her date reference. I also drew a picture of a glass jar (or beaker) and asked her to show how full the jar was in relation to how socially connected she felt before the stroke compared to after the stroke (now). Anna pointed to the level and I drew the line across from the position of her finger and shaded to indicate volume (Figure 37).

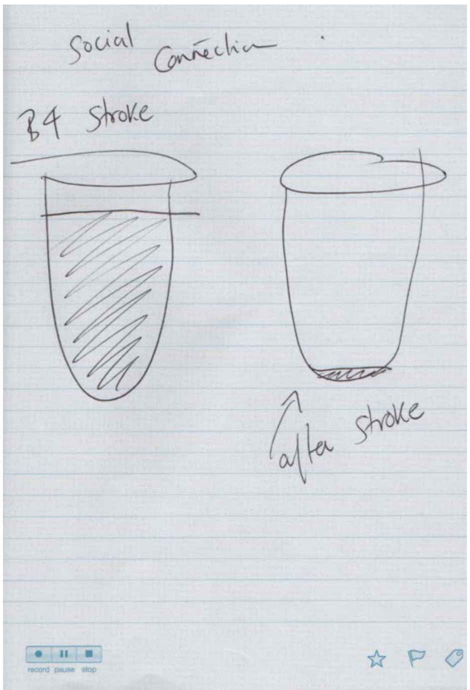


Figure 37. Scaling a response

To help illustrate how questions were presented to participants, some still shots (photos) taken from the interview videos are included below. These images are not optimal as they have been taken from film that was not originally made for this purpose; the photographs have been cropped to remove material that might identify a participant.

Figure 38. Method 3: adapted image selection

Emma used speech, pointing and gestures to communicate. This image demonstrates how the ‘Talking Mat’ (adapted image selection method) was shown to a participant. I am holding a mat with the Velcroed icons and firstly ensuring that each icon can be seen. As I call out the written text accompanying the icon, I point to the image, and then check with the participant that they have a sense of what each icon might mean to *them* (with reassurance that there are no right or wrong meanings, and that it may not represent anything to them either and that is okay too).

Figure 39. Emma made selections by pointing to the icons of most importance to her

Figure 40. Liam's selections

In this photograph Liam (not seen) is contemplating the thirteen hand images displayed. I am assisted by Liam's mother, June, to hold up the board of hand images (Method 2). June pointed slowly to each of the hand images (drawing Liam's attention to the images and ensuring he had captured his own sense of it). This allowed me to fully focus on Liam's eye gaze as he made choices, switching between 'yes' and 'no' or 'I don't know', as well as his gestures, facial expressions and vocalisations. There was a puzzled look on his face as he contemplated one or two of the images. I could also see what at first appeared to be an expression of apprehension which turned into a fixed 'I'm choosing it anyway' look as he said 'yes' to one of the cards. From here I could discern which images resonated with him and which did not. Once he had selected the images June and I separated them from the rest of the hand images, and checked each one again, using Liam's 'yes' and 'no' style, to ensure that these were his choices.

The next part of the method involved discovering what those images meant to Liam. This was done by first confirming whether each photograph represented a positive, negative or neutral value/experience for him. The next step involved asking him to eye gaze any icons from his tray (Liam's everyday AAC) that might match what each picture means to him.

Liam was using eye pointing from a seated position in a powered wheelchair. After a few seconds of prolonged gaze at his choices/s he then confirmed his selection with his eye gaze going down to the symbol for 'yes' on the left side of his tray to communicate his choice. He also combined this process with the use of vocalisation/sounds to affirm a 'yes'; a strategy which reinforced his communication of a decision.

Figure 41. iPad, notes and numerations

Anna guided the communication used in her interview. With partial use of one side of her body, Anna used apps from her iPad to help her explain a point, and wrote numbers and drew lines with a pen to express concepts of time and make to comparisons. By following Anna's use of the apps, I discovered that I too was pointing with her (using them too) to communicate.

Figure 42. Using the PODD

Sean does not have a communication device. When I asked Sean about this, his mother and sister explained that when he went to a disability service[13] (to live), the BLISS system he used at home was exchanged for ‘sign language’, which worked well for a while. However, in recent years Sean’s condition has worsened and he is no longer has full use of his hands. Unfortunately a return to using pictorial symbols or icons was not initiated and Sean’s communication has been reduced to a few hand signs and spoken words which are difficult to understand. Sean vocalised ‘yes’ and ‘no’, which enabled much of the interview to progress. In order to capture more detailed meanings, I introduced one of two PODDs (shown). Sean’s family stated that they have not seen him use this form of communication before. The PODD was used to clarify his choices, for example, what the hand images he selected meant to him. After showing him the pages and choices he could make in using the device, I was surprised at how quickly and easily Sean was able to flip across the pages and choose the words he wanted.

---

[13] This service provides support to children and adults with intellectual disabilities in Adelaide, South Australia.

Figure 43. Carl’s selection

Carl is a man in his late fifties who, due to health reasons, lives mostly in a reclined position. He has an enrolled nurse providing support. This image shows a moment in the video when Carl’s nurse and I held the board of hand images above the participant who was lying down. Carl used eye pointing followed by verbalisations to make a choice.

5.5 *Doing Sensory Ethnography. Method 1: The Reflective Emplaced Researcher*

In *Doing Sensory Ethnography* (2009) Pink emphasises that her approach is not intended to be prescriptive, with a ‘how to’ account of doing this form of ethnography, rather she provides descriptions of the working principles of sensory ethnography and the interpretation of multisensory research. The placement of the researcher as an active, reflexive participant is central to this:

> if ethnographers can come to occupy similar, parallel or related places to those people whose experiences, memories and imaginations they seek to understand, then this can provide a basis for the development of ways of knowing that will promote such understanding. (Pink, 2009)

I note that there is already some alignment between my life experience and that of the participants from whom I was seeking to learn about an uncommon situation. My familiarity with and appreciation of the use of AAC proved to be a significant advantage during the study; however, it required careful reflexivity so that the situatedness (Pink) of my own experience would not cloud the meanings of the people I was seeking to learn from. There were many things I could directly relate to, such as the anxiety of parents of participants, and the increased secretions (and drooling) of a few participants with cerebral palsy as the increased focus of attention to the interview/conversations diminished their focus on swallowing; an act of giving that I suspect few would appreciate.

My role was limited to visiting, rather than staying with or sharing, the home places of participants. While this is not necessary for sensory ethnography, it is important to acknowledge that not all important aspects of meaning would be obtainable. Furthermore, much of the time spent with participants would be centred on a research interview (not a natural part of their lived experience of home). Sensory ethnography was also dovetailing with other methods, including the combined use of structured, unstructured and participant-generated material that would occupy much of the time spent together. The photographs and film taken during these interviews reflect this diverse experience. Photos of participants and myself playing with cats, going for walks, being in the garden, eating lunch, snacking and looking through photo albums are mixed with the types of photographs shown earlier (such as figures 38 and 43) showing the action(s) of interviewing.

As described briefly in the previous chapter, a concentrated focus on sensory embodiment commenced on the travel to the participant's home. I put the car window down as I drove into the suburb of a participant. I was looking, hearing, smelling to gather information about the neighbourhood. This experience varied considerably; for instance, turning into the street of one participant's home meant leaving behind the screeching of truck brakes on a main arterial road. I noted: *There is the smell of oil from a business selling earth moving equipment – it's blending with the lunchtime aroma of McDonald's on the corner.* Another home was surrounded by leafy bushland. I noted: *I drove too far and found myself outside of the built environment; bitumen leading to dirt roads, smelled like wet leaves and bark. There was a distant sound of cars, but bird sounds dominated.*

The sensory experience escalated the closer I came to meeting (and being with) the participant. I noted my sensory experiences as I arrived at their home. For example:

> *It is one of several identical group homes – a short walk up the street reveals one of South Australia's largest nursing homes. I know it's a 'residential care setting', as it shares the same sparse garden as all its neighbours – same saltbush style plants and bark chips laid in the same way. I couldn't smell anything. How can it be possible to smell nothing? There's the traffic sounds and the two little drought-hardy plants –*

> *like a copy-paste from the neighbour's and the next house and the next. Nothing to support a conversation – not a conversation starter like at J's place.*

I found it interesting to observe my sensory experience of a front yard. Before this study, I had not considered how much information could be gained from an ordinary, everyday front yard; simply by noticing oneself, one's senses, in a place such as this. To do this required a focused self-awareness.

> Whether performing a simple skill like standing and looking or something more exotic like detecting oestrus, your perceptual experiences are fundamentally multisensory. … for all of us perception's multisensory nature helps provide a robust experience of the world as well as a way to convey that experience in a vivid, poetic manner. (Rosenblum, 2010. P. 293)

In taking this approach, I needed to stop thinking, allowing the sensory experiences to become conscious awareness, taking note of these experiences and then using them in combination with the information gathered from the more traditional aspects of the study to help build a robust and palpable understanding of what home means for the participants.

5.6 Making the Case for Case Analysis

At this point of the study the following data had been gathered:

- Responses to seven questions by a cohort of ten people with CCN. Where relevant the responses were photographed.
- Video footage of the interviews and time spent with participants (where possible).
- Reflective memoirs of the embodied experience of time spent with participants.
- Participant feedback on the research process, specific to questions 3 and 4 of the study.
- Pilot and test group feedback specific to questions 3 and 4 of the study.
- A secondary quantitative analysis of ABS data.

The variety of data collected offered options for analysis. The minor (or supportive) elements of the study used different forms of analysis. The secondary study of ABS data was reflected in SPSS frequency tables and the feedback provided by participants about their experience of the study was built on content analysis. These approaches to analysing data provided

a) the statistical context (how many people in Australia have CCN and, in broad terms, where they might live); as well as
b) an evaluation of the research study (undertaken by people with CCN) in relation to study questions three and four.

The interview material had originally been planned for content analysis; however, the amount of detailed information received from interviews was far greater than anticipated. Part way into the interviews, the decision to cap the number of participants at ten became necessary due to the burgeoning amount of data needing to be managed. It was at this point that the opportunity to consider case study analysis arose. The data included: interview material (video, notes, photographs); researcher reflections of the embodied experience (several pages of notes from each interview); items provided by the participant to further explain/provide detail (images, copies of lists or documents); participant feedback on the research process; and photographs, Google Maps and other material related to the various homes visited. ‘Case study research offers a credible, original and creative approach to the investigation of complex phenomena’ (Taylor and Thomas-Gregory, 2015, p. 40). The creative and somewhat original element of the methods employed in the study, combined with the detailed complexity of the data obtained, provided a rationale for using case study analysis.

The use of case study analysis enables the researcher to closely examine data within a specific context. Tuan (1984) describes this method as a selection of a small geographical area or a very limited number of individuals as the subjects of study. Case study as a research method ‘investigates contemporary real-life phenomenon through detailed contextual analysis of a limited number of events or conditions, and their relationships’ (Yin, 1984, p. 23). Case studies are units of analysis that can be layered, with data consisting of all information related to the case (Patton, 2002). Related information for this study included the incorporation of material from the literature and comparisons drawn to the theoretical notions such as Nussbaum’s list of capabilities. It also included applying the contextualised data of the statistics drawn from a secondary analysis of ABS data. There was another layered element to be considered, being the relationships and patterns that were forming within the cohort of people interviewed. Through this study I learned about the homes and living of a group of ten adult South Australians with CCN. Two people live alone in their own home, four live in small group homes, two live with parents, and two people live with their spouse and/or children.

As the interviews ensued, strong themes arose which resonated with the literature. The differences and the tensions between living in one’s own home and living in residential care settings was particularly evident. Layered with this major theme were sub-themes such as ‘hair’ and the way in which one’s hair is styled.

CHAPTER SIX – REVEALING THE CANVAS: CASE STUDIES IN ART

6.1 *Introduction*

The findings of this study are presented in two parts. Part A is the description of three case studies alongside the production and discussion of accompanying analytical art works founded upon the core findings of the meaning of home. The case studies are created from a compilation of data collected from each of the methods used in the study, with attention to consistency across methods as they pertain to individual participants. For example – the meaning of 'autonomy' selections of photographs ought to be reflected in the Talking Mat icons and so forth. These case studies are titled 'Provisioned', 'Immured' and 'Suspended', reflecting three significant states of home emerging from the study. Within each of these themes, the meanings, experiences, beliefs and imaginings of the participants are explored in theoretical context to home, to Nussbaum's capabilities, and to the philosophical underpinnings of democracy in an emergent NDIS Australia. The second part of this chapter, Part B, involves the description and evaluation of the methodological findings, outlining what methods worked and what did not work well. The recorded feedback from participants, in relation to these methods, is displayed alongside their general feedback and recommendations for future research with people with CCN.

The choice of which participant experiences to evolve into case studies was organic and largely driven by the unfolding stories themselves. The data revealed three distinct groupings of 'home' types with detailed threads that appeared to organically cluster together. These common threads matched the natural relationship of typology that was forming when benchmarking with Nussbaum's list of capabilities (2006). These strong themes were difficult to ignore, and included factors extending beyond where people lived, with whom they lived, and the way (and extent) to which the condition of their disability, its definition and meaning, was (is) the property of non-disabled people (Lawson, 2001). Each of the case studies depicts common aspects from among the individual participant experiences, forming themes such as 'messiness' and 'hair' as well as shaping themes which bear the thick influence of sensory ethnography, including qualities such as smells and the sound of locking/unlocking doors. These emerged to tie an otherwise disparate group of individuals to each other. Drawn from the multiple methods of inquiry used in the study, these threads were built from both information gathered directly from participants and their supports, or from reflections on the embodied experience, recorded through video and in journal entries written immediately after interviews with participants. Collectively the three case studies of ‘Provisioned’, ‘Immured’ and ‘Suspended’ emerged as described below.

6.2 *Provisioned*

Emma and John are both aged in their forties with stories that are different from all other participants interviewed. They live in single-person households where brief care and domestic support is administered at appointed times of the day. They have minimal direct family contact, but enjoy a wide network of friends. John was born into state care and Emma’s parents have passed away, leaving a sibling from whom she is estranged. Both reside in their houses rented from the Housing Trust and have done so for twenty years or more.

They have ongoing extensive connections within the disability (and broader) community, including work that is both paid and unpaid such as membership of boards and committees. At the time of the study both Emma and John were affiliated with organisations within the disability arena and have presented publicly at conferences with the support of AAC. Their stories defy research findings, such as those by Levin (2013), suggesting that people with communication impairments are largely excluded from disability politics as most policy arguments are dominated by people who communicate well and fluently. Furthermore, contrary to the evidence (Lloyd, 2006; Ison, 2009; Paterson, 2002) that research has overlooked the inclusion of respondents with CCN, John and Emma report considerable experience as participants of research. In addition, they have conducted research themselves within their respective higher degrees. After our first meeting I noted: *I sense Emma is over-utilised with respect to research and disability advocacy/interests. (Not surprising as when planning the recruitment for the study Emma was twice suggested to me as an ‘ideal’ participant.)*

John and Emma share many similarities. They have leadership and advocacy profiles within the disability community, but their interests extend further. Describing herself as feminist, Emma has studied and worked on community projects regarding women and on violence projects. John has interests in technology. Both attend Christian church communities, have completed higher degree qualifications, have travelled and lived in other parts of the world and are devoted pet owners. Emma and I met twice at the Botanic Gardens, the first meeting for the purpose of introductions, the second to complete the more formal aspect of interviewing. A few weeks later, I visited her at home, which provided the opportunity to add a sensory dimension to the descriptions she had earlier provided. The interview with John was conducted in a single session which lasted over three hours.

Cerebral palsy, as an existing condition from birth, has meant that John and Emma have always known impairment which affects the functioning of limbs and other muscles, including those for speech. Both Emma and John use a wheelchair for mobility. Both of the participants use speech, Emma as her predominant form of communication, and John in combination with AAC. Their speech is difficult to understand, particularly for people who are unfamiliar with it. I noted:

> *At first it felt awkward to keep interrupting Emma to let her know that I was not understanding. I was applying the suggestions from John (previous participant) being to relax, and to not keep apologising (not to be so hard on myself for not understanding) and this helped. Emma was not at all annoyed or concerned. She told me the story of a recent phone conversation with a utilities officer who kept asking in a loud voice to speak to her carer. There was no support worker with her and even if there was, it was Emma's phone call.*

In their 'bricks and mortar' physical sense, the houses of John and Emma did not come easily. From birth, John's institutional residential care settings changed four times with intermittent periods of placements with fostering families. John used the internet (eye gaze controlled), referring to his blog pages to provide me with some of the names and details of his housing history. 'At the time of (name of institution), they tried to get me living with a family, but I was more at home at the (institution) … some would argue that it isn't really home, but for me it was home', said John.

This comment from John aligns with normalisation theory (Wolfensburger, 1972, 1989) in relation to people with impairments taking up a place in as close a way as possible to everyday life. Living with a family (as the alternative to institutionalisation) was a likely reason for staff encouraging John to do this. John's comment also connects back to an earlier point raised by Shakespeare, who suggests that residential institutions 'were often places of security and friendship for disabled people' (2006, p. 175). For John the residential care setting was home, which reinforces the idea that people might value and feel 'a sense of home' in less typical housing arrangements. The question of whether negative feelings would have been eased growing up in a family, rather than in institutions, came to John's mind:

‘there were periods of feeling down, depressed, living in these places. Was this more than the normal crap or extra? I don’t know – can’t compare’, explained John.

There are so many variations to family life that this question is difficult to answer. However, John described his need, at the time of becoming a young adult, to have his own home where he could make his own choices. In pushing for this and eventually realising this goal, John spoke of the luck he had in the support of an advocate who assisted this to happen; reflecting that this was the period of deinstitutionalisation which, in combination with the support of the advocate, worked in his favour to find his current home of over 20 years.

Emma revealed how she left her parental home at seventeen. She described as ‘not good’ the living situations which followed: residential care for a few months, followed by living with a family for a few months, before moving to a community setting of people with disabilities. After this, she moved into independent Housing Trust homes, with her father moving in to help her. These were times of powerlessness and struggle characterised by living in impoverished areas with poor access to public transport and avoidance of access taxis because she had previously experienced abuse at the hands of drivers. Emma described this time as a breakdown into depression, social isolation and low self-esteem. Mohnen (2011) highlights that neighbourhood social capital is an important determinant of an individual’s health, as it is affected by high unemployment, poor access to transport, and the stigma of poverty.

From here, Emma revealed a turning point in her life and a desire to ‘take control over my own life’. Emma vehemently advocated for a home that would be accessible to public transport and not stigmatise her. Emma described the influence of her mother and how her ‘fighting spirit’ helped her to do this. A house came up. It was not particularly wheelchair friendly and at a distance from the city, but it was close to a train station, and she could access a train in her wheelchair. Emma stated that it was okay for her to walk within her own home (a downside being that it was not particularly wheelchair-friendly for her friends), but overall the good outweighed the bad, and for several years this is where Emma has lived. It is a home that she enjoys, with friends who visit, pets and, in the past, a partner (who passed away some years ago).

As Emma and I travelled along a path in the Botanic Gardens, I introduced the participant-generated sensory selection question: What does it look like, feel like, sound like or smell like to live in your home? Can you think of a picture, a song or sound, or a smell that can give the sense of what it's like to live in your home? Emma responded after a few seconds of thought with the words 'warm fire'. I asked her to clarify whether this was visual, a sound, a feeling or a smell. A few moments went by before her reply. 'All' she said. I later noted: *I could see her thinking and realise too – fire is so much more than something warm, it is light, it's colourful, it's bright, it crackles and spits!*

For John, this image (Figure 44) came in response to Method 4, participant-generated sensory selection, and the questions 'What does it look like, feel like, sound like or smell like to live in your home?' and 'Can you think of a picture, a song or sound, or a smell that can give the sense of what it's like to live in your home?' The idea of home being in more than one place emerged with the 'Warsaw Town Square' photograph.

Figure 44. Warsaw Town Square. Image has been removed due to copyright restrictions.

When I asked the question, John initially looked perplexed. I noted: *As the moments went by, I began an apology for the silly question. John turned his chair to the computer, as he did this I suggested we move to the next question. Operating the computer with eye-gaze technology, John began a search of the internet*. The image of the Warsaw Town Square emerged. I was confused. John waved his arm about the room and used speech that I did not understand and I was even more confused. After a few moments I realised he was gesturing towards the walls. I looked from the walls to the image and back to the walls. I noted:

> *… and a sudden wave of understanding emerged. It was like a journey into Maurice Sendak's 'Where the Wild Things Are'. John had shown me an image of what home means – a beautiful photograph of the town square – I followed John's gestured hand indicating the walls all around, each wall coloured as in the picture, and realised that Warsaw surrounded us.*

Theories of home connect strongly in this experience of painted walls. Human experience is both embodied and emplaced (Pink, 2009; Sunderland, 2012), but that memories of that embodiment can be recreated and emplaced through colour is evident too. Residential practices are recognised as central to a sense of belonging, self-identification and to how individuals define their position in society (Butler and Robson, 2003), presenting as inherent in symbolism and decor. Through our choices and selections of place and house, and thereafter the shaping (bringing in of objects, shaping of space and decor) we evoke reflections of who we are, how we choose to live, and what we stand for.

These walls mean much more than just a nice colour. Evoked by buildings of the town square, they connect John to his heart home in Poland. John explained that he has travelled to Poland three times and feels unusually connected or 'at home' the moment he arrives. 'Day before the day I leave I had an argument with God – why do I feel this way?' he said and explained that having been relinquished as a baby, he wonders if his biological father may have been Polish.

The next question (drawn from Method 2: theory-generated photo elicitation) asked 'which of these photographs of hands best reflects what it is like to live in your home? Please indicate with a single word (or more) what this image means to you.' Emma selected six photographs and, as requested, provided a word or words to confirm their meaning. These choices were photographed and are illustrated below (Figure 45).

Figure 45. Emma's selections

The dove image was selected with the explanation ‘freedom in my home, freedom to travel’. The fist image was explained with the statement ‘I hire my own supports. I fire my own supports’ (in reference to personal support workers). The ME image was selected and accompanied with the words ‘my identity’. The photograph with the mug and the glove was paired with the word ‘comfort’. The puzzle image was explained with the words ‘how I solve problems’, and the photograph of the world map with the words ‘open to the world’.

Emma elaborated on her selection of the hand in a fist, which was followed with stories about support workers. On all three occasions I spent with Emma, we discussed the topic of support workers. Despite having had some good support workers in the past, Emma conveyed a general dissatisfaction with the ‘carer’ system of support staff; describing a kind of trade-off for support requiring losses to self. She illustrated this with reference to incidents when support staff would answer questions for her and speak about her in front of her. ‘Support workers are meant to enhance lifestyle’, Emma said, but that has often not been the case, and it has taken a long time to finally have control over how support is provided for her and how it is shaped. Emma described as a major obstacle (to genuine participation) the pervasive practice of others deferring to a support worker instead of to her: ‘If I have no support worker with me – then they [public, reception persons, cashiers, tour guides, etc.] have to talk to me.’

Literally, and as a topic, support workers entered the conversation I shared with John. A woman arrived to prepare John’s lunch. After greetings, she asked for instructions; what needed to be done and what John wanted for his lunch. There was seamless communication. The woman understood everything John said and then walked to another part of the house to begin work. When her mobile phone rang and she could be heard having a conversation with someone John groaned, looked at me and rolled his eyes. I noted:

> *It was not appropriate to delve into this issue so we didn’t discuss it, but John was annoyed and I can relate to it – when support staff chat on the phone, they are not doing the job they are there to do. But, in my own thinking, there’s something else that’s not right about it – they are bringing their private world into our home – our space and we don’t have a share in theirs.*

Participants in this study raised significant issues related to care, which made me ponder who is the employer of the carer: the person needing the care, or the service agency or their family. This raises further issues about the role of speaking for, and therein replacing, the person, and issues of power. Research in the fields of nursing and aged care suggests that for in-home ‘clients’ being able to control one’s own life is a source of power, but this power is overshadowed by the powerlessness experienced in relationships with staff (Oudshoorn et al., 2007).

The day-to-day dynamics of care in one’s own home appears to have received less scientific focus, yet navigating the tensions and dilemmas is significant. For instance, I noted:

> *The noise of the mobile phone ring and the chatting of the support worker interrupted our space. I understood and felt some of John’s annoyance and wondered if the call may have been necessary – what if the agency may have been phoning to ensure the care of the next client? Or was it just chatting with a friend as she cleaned the kitchen? There were a few ‘what to do about it moments’ and then the call ended. It was hard (for me) to remain annoyed with the support worker who we also had to call upon to help translate some of what John was saying to me. … I was impressed with how well she understood John’s speech.*

Care work is of low status (Bleasdale, 2006) and is gendered (Nussbaum, 2006), suggesting a range of considerations for both the worker and the client. This is likely to become more poignant as the NDIS rolls out to include adults.

In answering the theory-generated photo elicitation (hands) question, John selected only one image: the photograph of the hand holding the business card with the word ‘Me’, and explained ‘Is my home, I’m on my own, just me and my dog’. I noted:

> *A few moments after he selected this image he received a text message and explained it was from his neighbour, on the other side of a shared wall, asking if he was free to catch up for coffee. John explained that he sees this neighbour often and described their close friendship. ‘If I won the lottery and got to move somewhere else [closer to the university had been discussed] I would buy [a home] one for him and one for me.’ You’re not quite living on your own, I thought.*

Outlined in the box below is Emma’s use of the Talking Mat to describe her top qualities of a good home.

- Method three centred on the question ‘which would be your top qualities of a good home?’
- Please choose up to five icons, using the adapted image selection (via the Talking Mat).
- Of the 21 images, Emma selected 17 (see Figure 46) as very important to her.
- Thereafter, Emma reduced her selection to the seven most important icons: Pets, Public Transport, Choice, My Identity, Being Myself, Spiritual, and Comfort.

Emma spoke about the critical nature of access to public transport for her connection to the world, to be with people, to work, to socialise. ‘Without it [public transport] home becomes a prison’, said Emma. Her top priorities were the love and companionship provided by her pets, to ‘nurture spirituality’, and to be comfortable.

Emma described her home before I actually saw it. I noted:

> *It was wonderful and a relief to hear about Emma’s home. I’ve seen enough of group homes now. The [name of accommodation] homes have left me depressed. The smell of the OMO is still with me. But the sound of Emma’s place – I pictured it as Emma described it – tall, shady trees – not far from the beach and the train – an older 40s/50s style – modest. Emma said it’s Housing Trust that doesn’t say ‘Housing Trust’ or yell out ‘disability lives here’ – and that it has character. I imagine her garden and the cats and the fish and her stuff – art – visitors – the things she likes.*

Figure 46. Emma's selections (7 icons displayed at the top of the mat)

John's selections for Method 3 are shown in Figure 47. Identity and pets are strong themes for both John and Emma. The importance of visitors and the physical environment attests to the centrality of relationships with others. In these homes there are ample seating for visitors, a spare room(s) for people to stay, a rack of wine and there is long-life milk for visitors (Emma drinks soy). Neighbours did not feature in the conversations with Emma, but featured strongly with John. John relayed the story of an abusive neighbour – a man who resents the provisions afforded to John – but greater focus was placed on the man on the other side of the wall (John lives in an older, modest, semi-detached home). He and his neighbour meet several times in the week.

Figure 47. John's selections

As with all the participants, sensory ethnography began during the drive to their homes, particularly upon entering their suburb and the street they live on. My embodied experience upon arriving at Emma's home is outlined below.

> *It's an industrial area, but interesting – quirky – close to the beach and I drove over train tracks – transport access is here. The smell of the sea, not factories, is what wafted in through the car window. The homes on Emma's street are so interesting – each one different – mostly older style with trees and all kinds of oddments (statues, old boats, etc.) in front yards. Emma's home is modest, but what Emma said about 'character' is evident. 'Old world' flowers were in the garden and hanging pot plants and an ornament was swinging from the veranda. Before getting out of the car I found myself wondering about the era and style of the house. I could smell plants. Emma greets me at the front door, she's expecting me. I ask her about the garden and we spend a few moments exploring. She laughs and makes wide gestures with her arms that tell me 'this is my place – yeah – I love it'. I mis-reflect this back. 'This is your garden and you're pretty proud of it.' Emma corrects me: 'My home.' (My whole home.) Emma, who is not in her wheelchair, supports herself in a standing position by holding the wall at the doorway. I walk past her. There are photos and art work covering the walls, a fish tank, cats and computers – one computer is on.*

It was good to just spend time with Emma in her home, not interviewing (as we completed this at the Botanic Gardens), but just drinking tea and eating some bun, playing with the cats and chatting. Based on my experience as a social worker who has visited many Housing Trust homes in Adelaide's north, I could detect a few subtle indicators of Emma's home being state-owned. For example, the fence shown in the photograph below (Figure 48) is evidence of the simplicity and 'standard-issue' durability of some features; however, overall these combine with a house shape, garden, and Emma's additions, which avoid the type of stigma Emma had spoken about when living in previous houses. With Emma's permission I photographed and have included within the thesis images from her home: the view from her front veranda, and one of her cats in her kitchen (Figures 48 and 49).

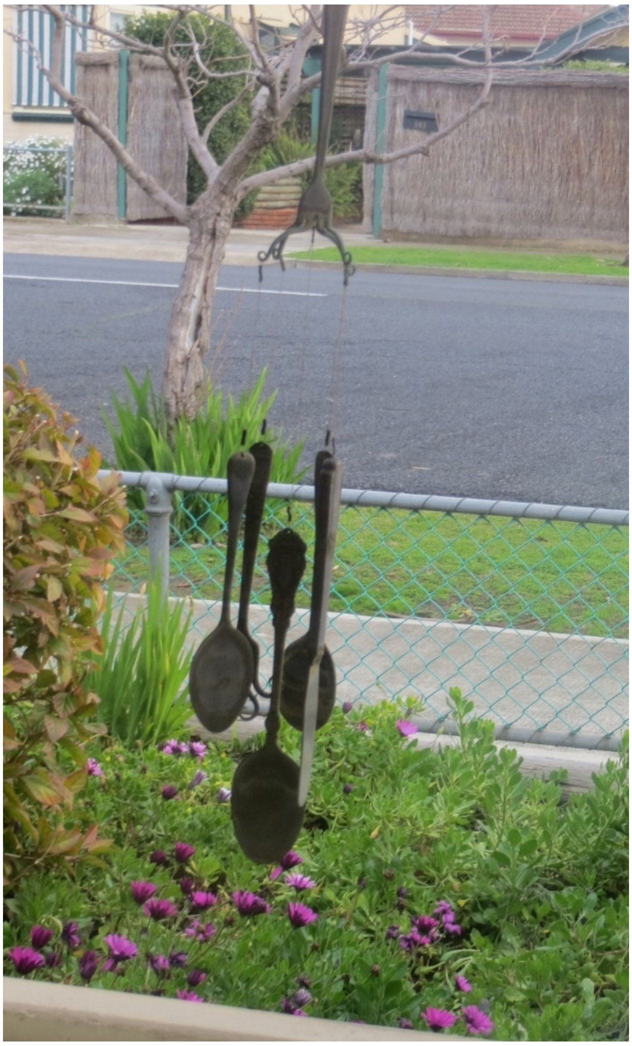


Figure 48. View from the front porch of Emma's house

I chose this image because it tells a small fraction of a 'home' story. It represents a tiny slice of the private world that is on visual display to the public. The windchime, the flower pots, hanging baskets, trees and flowers collectively tell a story to any passerby on the street. Moreover, these objects do not buy into the stigmatised stories of 'Housing Trust poverty' and 'disability lives here' that Emma has experienced in the past.

Pets were a strong theme in the lives of John and Emma. Time with Emma and John revealed the importance of and commitment towards their animals. Emma showed me a large home-made cat run she had installed which allows her cats to safely be outdoors at night. The cat run commandeered an entire window with interesting tunnelling and a large space for the cats to move around. I noted:

> *very friendly, affectionate cat – we laughed and enjoyed him … soft fur and wet mouth as he rubbed his face on my legs, the legs of the kitchen chairs, and on Emma's wheelchair.*

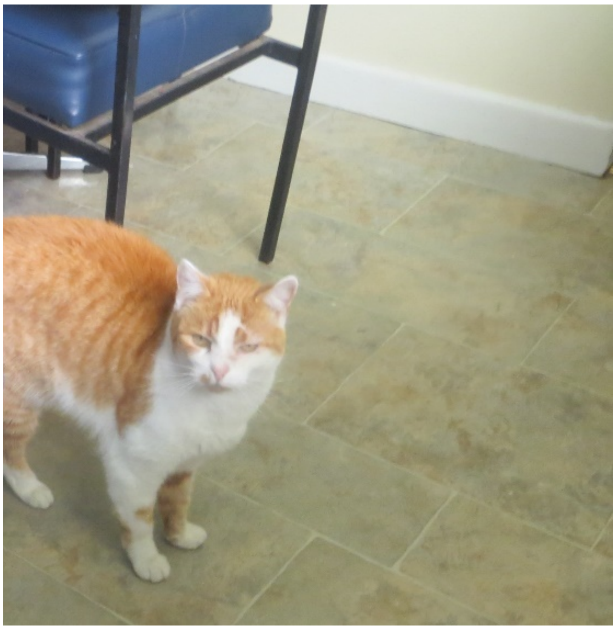


Figure 49. One of Emma's cats in her kitchen

The responses provided by John and Emma, coupled with the sensory experiences of being with the participants in their home, provided a rich source for analysis.

6.3 *Analysing Provisioned*

Figure 50. Provisioned

Some packing crate is used for the frame, cheap but durable, the type that often surrounds the delivery of whitegoods to the home. The humble wood is embellished with wallpaper, giving it personality and character, making the most of its quality. Central is the hands holding the dove. Emma and John defy much of the literature; they have access to a public voice, live in their own homes, have histories of research participation, and enact the capabilities described by Nussbaum and express contentment in their homes. This is no way denies the types of difficulties and discrimination, that they commonly experience in daily life, but highlights they have provision for much of having ‘home’ and ‘capabilities’ mean.

Emma was the only participant to choose the photograph of hands holding the dove – linking it to *freedom*. The dove is held aloft to a choice of open doorways, suggesting moving in and out of home, encompassing the notion that home can exist in more than one place at more than one time. John’s choice of the single image from the photographs – the hand holding the business card saying ME – was not integrated into the art piece as identity is already conveyed in other ways. A religious icon is present, connected to a network representing friends and community interests. The gold thread of communication weaves its way between these networks, the home and the opportunities of open doorways. There are spills and stains within the image. A ring from a glass of red wine has seeped into the mount-board and directly above it is a dirty paw print. Together, these stains represent three important themes: closeness to pets; social affiliation and lifestyle choices (in the enjoyment of wine/alcohol) and associated social-drinking opportunities; and the theme of ‘messy’ as woven with the notion of power and identity within one’s own environment, a theme sharply contrasting with the case study ‘Immured’.

There was a lot of information gathered from the emplaced researcher as sensory ethnography (Method 1). The smells of ‘house’ were similar to my own home; a mixture of many everyday household smells as well as an old-house smell that I find difficult to describe – not mouldy or stale, but a complex oldness that comes with houses that have existed for a lifetime or more. Overall, these houses smelled ‘homely’ to me and, coupled with the art works, the clutter, multiple items in reasonably neat piles, conveyed a myriad of interests. I noted:

> *The wine bottles and the computer carcasses across the surface areas of the main living area told the story of IT interests – I didn’t see anything like this in any of the group homes. The pets, even the boxes of medication left lying around (not risk-managed into a locked cupboard), converged in such a way as to create a sense of a good home.*

Other core themes were not included in the collage *Provisioned* (Figure 50); however, they impacted upon me in such a way that I created art works to express these. Hair (having long hair, not shaved or buzz-cut short like most of the other participants I met) became a prominent theme by the time I met Emma. Before her, all the people I had interviewed, except John, either had shaved or close to shaved heads. Sitting opposite Emma at the Botanic Gardens, I watched how she flicked and arranged her hair. My eyes filled with tears and, without making sense at all, I blurted out, ‘You’ve got hair, lots of hair – your head’s not been shaved or buzz-cut.’ In Figure 52, my embodied experience of hair combines with Emma’s indication of freedom and the symbolism of ‘warm fire’.

Returning once more to *Provisioned* (Figure 52) there is a clear alignment with theory. Some of Nussbaum’s capabilities speak clearly from the image, such as the care and companionship of pets (for John and Emma), which is strongly aligned with capability number 8: *Other Species* –being able to live with concern for and in relation to animals, plants, and the world of nature (Nussbaum, 2010). Capability 4 was also evident as it related to the *Senses, Imagination, and Thought* where participants had adequate education and were able to use the senses, to imagine, think, reason, create and to exercise choice and decision making. The open doorways of choice (reflected in Figure 50) dovetail with the books and art works in the homes I visited. The open doorways adjacent to the dove, which has a choice of direction to fly in pertains to capability 6, Practical Reason, and the ability to reflect upon notions of good and to engage in critical reflection towards planning one's own life. Social affiliation is symbolised by the gold thread of networks, and the red ring of wine, with both Emma and John forming strong emotional attachments, and having fun with friends (capabilities 5 and 9).

Other capabilities are less straightforward for some persons such as capability 1, *Life, living a full-length, quality life*. Conditions such as cerebral palsy can affect life expectancy and bodily health (Reed et al., 2012), but the extent to which this might, in turn, be affected by other factors, such as Nussbaum's other capabilities, social determinants of health, and future treatments is unknown at this point. Capability 3, *Bodily Integrity. Factors like safety from violence, including sexual assault and domestic violence; and opportunities for sexual satisfaction and reproduction* was more difficult to discern. The participants have experienced violence and abuse in the past, leaving some residual mistrust of support workers and access taxis. Indeed, consistent across most of the participants' responses was their awareness and concern about the ongoing risks from support workers who may not do the right thing. Emma spoke about one such support worker who deliberately hid Emma's items from her which led to situations of distress.

Opportunities for sexual satisfaction and reproduction were not discussed. This was regrettable as it may have allowed a greater appreciation of this capability in relation to the participants. However a couple of Emma's comments indicated that she had past partners.

Capability 10, *control over one's environment, both political (to participate in political choices, freedom of speech) and material (the right to meaningful employment, being able to own property and goods)* appears to be only partially realised. Significant under-employment despite the flourishing of other capabilities (education, social affiliation, etc.) is a significant concern. 'Access to employment is a major issue', said Emma. In relation to employment options, wishing to work, and having tried very hard to secure employment, John and Emma are instead occupied with capability 4 (Senses, Imagination and Thought) by returning to higher levels of education with some small pieces of paid (and unpaid) work which were mostly related to the disability field. These roles, I sensed, are important aspects of their identity in the face of barriers to employment which keep John and Emma reliant upon Centrelink. In turn, this situation has meant barriers in relation to other capabilities, such as Capability 10, to own property, etc. Instead, they are provisioned with basic state resources.

Factors emerging from theories of home – identity, comfort, power in one's environment and social connection – were inherent to the selections made by John and Emma as well as in general conversation. These points of theory align with Nussbaum's capabilities, in particular, Capability 7: Affiliation, and 10, Control in one's environment. Comfort and identity are not necessarily 'spelled out' in Nussbaum's list but it can be argued that identity is an underlying prerequisite for several of the capabilities listed by Nussbaum, such as number 1, as it is difficult to imagine living a quality life without a sense of identity.

Figure 51. Warsaw: 'and the walls became the world all around …' (Sendak, 1963)

The above photomontage (Figure 51) represents a careful selection of core meanings of home for John that were not included in Figure 50. In particular, it represents the synthesis of a range of meanings of home including a place on the other side of the world as well as the power in one's environment and strong identity reflected in the dominant position of the hand holding the card.

The following photomontage (Figure 52) captures some of the specific themes that arose in meeting with Emma. The circle of hair on a background of fire, with the photograph of the dove in the centre, symbolise freedom, warmth and self-expression.

Figure 52. Provisioned: freedom, hair and warm fire

In combination, Figures 50, 51 and 52 reflect the meaning of home for those viewed as ‘Provisioned’. Put simply, home means (and is) freedom, power, pets, relationships and connections with others including God and neighbours. Home means access to the outside world through technology or trains or the merging of more than one place (a bringing in, or combining with other home connections to the outside world through the vehicle of symbolism and decor). Home means art and pictures and ‘stuff’ piled around – whether it be books or wine or computer carcasses. It also means a structure that was fought for and eventually provided. It means modest living, despite the hard work and giftedness of the tenants. It also means navigating the tense world of care, which can oppose the meanings of home, and where threats of ‘biting the hand that feeds you’ have an ominous presence.

John and Emma, despite the presence of CCN, appear connected to the public sphere, particularly within the area of disability advocacy. In the face of CCN they have used their voices – both in dysarthric speech and AAC – to speak at disability events and conferences. Involvement on committees, in community groups such as a church, and their use of social media and establishing personal blogs all allow Emma and John to connect to the public sphere.

Another aspect to both Emma and John which assists this process of public connection appears to be their personalities and their usefulness in relation to such things as advocacy, as was demonstrated during the interviews.

> My mum taught me a lot about standing up for myself … to fight for my rights. Means tough love. Just want people to be empowered to run their own lives. (Emma)
>
> I think I was just too bloody minded. (John)

Up until this point, I had only considered extrinsic aspects of the topic; however, the findings suggest that there may been intrinsic (personality) elements present. For instance, resilience and agency were strong qualities observed in both Emma and John. Qualities such as intelligence, religious orientation/faith, and internal locus of control are identified by Werner (2000) as integral features of resilience. These were displayed throughout the time spent with these participants. For example, an internal locus of control underpinned Emma's decision to 'take control over my own life'. It was also evident in John's reflections upon his past life living in institutions in which blame or a sense of being a victim was in no way portrayed despite the difficulties he described. The reasons why these characteristics were more evident in some of the participants merit further investigation, as will be discussed in the final chapter.

6.4 *Immured*

Four of the participants described and demonstrated the existence of immurement as a lived *meaning of home.* There are core themes derived from each of the five methods used in the study which tie this topic together. These themes are: descriptions of routines; lack of choice; violence and abuse (similar to the 'bloody-mindedness' described by John); displays of resistance from participants; low access to communication device(s) and increased barriers to communication overall; receptive rather than expressive communication with television being a dominant form of information and social connection; loneliness; physical appearance of shaved or very short hair; and very limited access to the public sphere. These were common stories among the four participants described in this case study.

The prevalence study, described in Chapter One, which used ABS data to estimate the numbers of people with CCN provides a useful beginning reference point for analysing this case study. The study findings indicate that people with CCN are over-represented in residential care settings in comparison with people with disabilities but without CCN. The comparative findings in Figure 2 demonstrate the percentage gaps between people with disabilities residing in establishments (disability/nursing/group homes), compared with people with disabilities but without CCN. In 2012, 40 per cent of people with CCN in the age group 65 to 69 were residing in residential care settings. For people of this age range, but without CCN, results continued at the 0 per cent baseline. All of the residents of the group homes visited in the study, including participants and non-participants, were people with CCN. This concurs with both the secondary analysis findings, and what Wolfensberger (1991, 1983) outlines as social role valorisation, which, alongside segregation, describes the congregation of persons with similar impairments.

Distinct within the overall research cohort, the four participants in the group homes case study reveal divergent experiences and related meanings of home. Yet the experience of residential care settings is not confined to them. Emma and John, now residing in their own homes, have some history of residential care living when they were young, but unlike the participants described in ‘Provisioned’, the participants in ‘Immured’ have remained in these settings.

I visited three group homes, two belonging to a non-government disability agency who describes group homes on their website as ‘an accommodation option where up to four people live together in a suburban house, with support from staff as needed’ (Website, 2016), and another disability service owned home.

Figure 53. Front garden of Ruby's home

Ruby, the first participant living in a residential home, lives in a group home.

I noted:

> *I'm struck by its duplication – the houses before it and after it and the house after that all look identical. There's a rudimentary sense of order and anonymous utility blending in with the continuation of purpose-built housing along this street. This is disability housing and a gigantic nursing home nestled together on a large piece of re-developed land.*
>
> *Arriving was like walking back into [disability accommodation service]. Purpose-built accommodation very similar to the neighbouring aged accommodation. A strong sense of utility and order, clear bench surfaces, clean, same décor – white walls, wide hall and doorways, pragmatic, but someone else's order and arrangement. A large 'shift work' roster on the wall near the door (a prompt for Ruby's purpose? I should have asked). No place for friends/family – barely enough chairs for us to do the interview. Another chair had to be found for me. Neil (support worker) sat on an uncomfortable looking stool. There was a small couch for visitors to sit, but no spare room for people to stay, although the support worker explained that there was currently a vacant room and that might be able to accommodate an overnight visitor if needed. There appeared to be little evidence of a space that welcomed visitors or social interaction. There was no PC in Ruby's room; however, an electronic communication device was perched in the corner. Ruby's mother explained that it is too difficult for Ruby to use and that no-one else knows how to use it. About 40 to 50 'core' words (no pictures) were stuck to Ruby's tray from which she would eye gaze her choices.*

Ruby, fifty years old, lives in a group home with one other resident, an elderly man. There is one spare room at the moment but, as a support worker explained, this situation can rapidly change. Ruby is well educated, including the completion of a short, non-award course at a South Australian university. Her skin is pale, her body thin and petite and her hair is near shaved.

Ruby, who has severe cerebral palsy, was accompanied by a support worker, Neil, and her mother Iris. A computer fitted with an eye-gaze tracking device with voice output is on display in a corner of the room, but Ruby does not use it. ‘It’s too hard. Nobody knows how to use it’, says Iris. Within a minute of meeting Ruby her preferred way of saying ‘yes’ and ‘no’ was established by asking her how she best likes to show ‘yes’ and ‘no’. A grimace-like smile for ‘yes’, a head turn away for ‘no’ and no movement for ‘don’t know’ or ‘neutral’. Ruby first entered institutional/residential care at the age of seven, drifting between living with her mother and various residential care settings. Iris, with Ruby’s permission, provided me with a printed lengthy list of these settings – eleven residential group homes, and nine residences with her mother.

Ruby’s motivation for being a participant in the study was recorded. The following is *Transcript – Ruby Question 1*.

> B-J: Why were you interested in participating in this research topic? [Offers some examples] Interested in the study, interested in the topic of home …
>
> Ruby: [series of repeated grimaces] Yes.
>
> Iris: This is a big issue. Ruby has had many problems over the years about where she lives.
>
> B-J to Ruby: Is this true? Is this correct?
>
> Ruby: [grimace] Yes.
>
> B-J: Are there any other reasons such as ‘you were just curious, bored, got a voucher, etc.’
>
> Ruby: [head turn] No.
>
> B-J: So you are interested in the topic of home.
>
> Iris: Big interest of Ruby’s.
>
> Ruby: [grimace] Yes.

B-J: How important is this topic to you on a scale of 1 to 10? This hand [shakes hand] being 1 and this hand [shakes other hand] being 10, and the gap between these parted hands representing all the numbers in between.

Ruby: [staring fixedly at right hand] 10.

Neil: Ruby is pretty determined now – wants to stand up, to speak up for herself.

B-J to Ruby: Has it been a push and a fight for things to be okay enough for you to feel at home?

Ruby: [grimace] Yes.

B-J: How difficult has it been to find that sense of home on a scale of 1 to 10? 1 being very easy and 10 being extremely hard.

Ruby: [staring fixedly at right hand] 10.

B-J: Are these problems and issues current? Or are you talking about the past … Sorry – I'll ask the question again because that's no good for a yes or no response. Is the situation still difficult now?

Ruby: [grimace] Yes.

In addition to the actual process of gathering the information, this conversation highlighting the agency and determination of the participant, as was evident in John and Emma, and now Ruby.

The interview process was altered a little so as to gain an understanding of what Ruby was concerned about. Rather than go to the next question, the Talking Mat with the 21 icons was presented and Ruby was asked if any of the icons indicated where the main problems have been. Using fixed eye gaze, Ruby selected the following icons: Support Workers, Body Safety, Relationships, Housemates (Iris suggested this and Ruby agreed), Access, Social, Public Transport, Choice, Comfort and My Routines. I noted:

> *The limitations of our communication were very noticeable at this point with my question 'Why?' requiring descriptions, but little way that I could see of capturing these.*

Ruby negotiated with me and Iris and Neil to assist with the provision of information, explaining the reasons for her for choices. The skilled facilitation of the support worker was particularly instrumental to her valid contribution. Neil observed Ruby for facial and gestural responses – waiting for her response so he would know where he needed to place emphasis in relaying her stories. At each new piece of information, I checked with Ruby to see if this was a grimace or a head turn or a ‘neither’.

Stories of fear and of not always being safe with others, such as co-residents and support workers, emerged. Ruby has endured past experience of abuse, including sexual abuse, from both support workers and fellow residents. Ruby has only recently been transferred from another group home where she resided with three male residents. Neil and Iris revealed that Ruby had initiated and was currently seeking support in relation to the abuse through a government agency.

Neil described the expressed intent of the accommodation service to match housemates to each other, commenting that in reality they often have little choice about whom they live with. This is usually due to crisis demand coming from other sectors such as hospitals and rehabilitation centres to find accommodation for patients unable (for whatever reason) to return to previous home settings.

Ruby indicated to Neil that she wished for him to talk about the housemate situation. I noted:

> *Past Ruby’s bedspace was another room. I was told it was housemate J’s area. J is elderly and yells during the night. I look at the bed space and the thin wall, I imagine the quiet night perforated by yelling. I see R in bed upset. I imagine myself in her place. I look back at R and interpret her expression. This is terrible for you, I reflect out loud. ‘Yes’, she grimaces.*

George is 50 years old and lives in a new group home facility (Figure 54) purpose built within a new housing estate. It is owned by the same non-government community agency that leases Ruby’s home. During the interview, I discovered that George, diagnosed with cerebral palsy and intellectual impairment, has lived much of his life with his family. Later as an adult, George lived with only his father. Since his thirties, George has lived in several residential care settings. He can speak a few isolated words, but they are difficult to understand. There are communication symbols that he can hand point to attached to the tray of his wheelchair.

In comparison to Ruby, George’s current home has a modern design with nuanced contemporary colours. It fits in with the neighbourhood. It avoids the stigma of typically identifiable state housing as described by participant Emma (Figure 53). I noted:

Arriving at George's home, it was 42 degrees, the hottest part of a very hot day. I was unable to discern it as a 'group home', as has occurred with the other residential homes, it was new – less than three years old. It was too hot to dwell in the car or in the front yard. I couldn't detect garden smells or any other (except the smell of heat as it radiated from all the surfaces). Sounds were of suburban traffic. There was an absence of ornaments or any front yard/door accessories with the garden consisting of the similar plants as were featured at Ruby's home. Still there was hope that this home might perhaps be different from Ruby's – a new design and now perhaps a new way of living.

Figure 54. George and Carl's home

Neil, the same trusted support worker of Ruby, met me at the door. Walking inside George's home I was confronted with a different story. Again, as similar to Ruby's, a sense of utility was paramount. The voices of the television dominated. The smells were there too, strong cleaning product smell. Wide hall and doorways – purpose built. It looked more modern than Ruby's group home. The bedrooms gave me a sense of compartments. Three men living in this group home with two male support workers currently present. A very hot day – the blinds were down – so the home was darkened. George and another resident, a young man called Luke, were sitting in front of the television – the involuntary movements of the young man, the wheelchairs, slumped bodies and fixed stares told me they were residents. Two male support workers hovered nearby. Suddenly I felt conscious of myself as being female – the residents'

> *stares persisted. I'm a novelty. I wondered if they have female supports. It occurred to me too that this may have been Ruby's last home.*
>
> *There is pure utility in the living space and kitchen; very little that was non-functional. The décor, art, photographs, interests and wine of the homes of Emma and John were far removed from the plain, clean function of this home. There were no photographs and personal knick-knacks in this area. For George, these were in his bedroom which was the only private place to conduct the interview. Like Ruby's home, identity, access to space, the private and the personal were located in the bedroom.*

Sean is 37 years old. Up until his late twenties he lived with his mother, Connie, before living at the group home. Angela, Sean's sister, told me that he has an undiagnosed syndrome which has caused significant intellectual impairment, and in more recent years physical impairment. He lives in a relatively new group home with three other residents and works four days a week in a sheltered workshop (supported employment) owned by the same organisation that operates the group home. His sister, Angela, made contact after hearing about the study to register Sean's potential interest. During the first of our two phone conversations, Angela conveyed the information that, while Sean has a good home, he intentionally does not take his medication when in hospital so he can stay there rather than go home. Consent was later obtained from Angela to incorporate her input into the study. Angela stated that Sean has depression:

> He deliberately does not take his medication so he can stay in hospital, he can get very sick without it – he could even die without it … He loves hospital because there's people there, but there's nothing wrong with his home; it's one of those nice new places, you know those new Minda homes, he shares it with four other people; he even has his own carer because of his bad epilepsy.

I noted:

> *Today [second interview/visit] there was a pungent, overwhelming smell of air freshener and perfume at the front door (participant's mother and sister upset). Sean had arrived at Angela's home but had not been given his medications or a change of clothes. Connie and Angela were upset about this. I could hear Connie on the phone explaining to someone that if Sean doesn't have his medication he could be at serious risk. He'd also had a toileting accident and Angela had poured a great deal*

> *(accidently) of aftershave over him to disguise the smell of urine and she unnecessarily apologised to me. ‘I’m the poo and wee queen’, I announce to everyone. ‘This is a really common smell in our place’. We sat down to tea and chocolates. There was a scented candle in front of us. A lot of effort had gone into presenting Sean to be at his best – but he looked unhappy.*

Sean did not have access to supportive communication tools. His family explained that as a child he was introduced to Bliss Symbols and was doing okay with that, but when he attended the local special school he was told that he must learn to sign (Auslan) for communication. According to Sean’s family this went okay, but in recent years physical impairments have increased, resulting in his use of a wheelchair for mobility and no longer being able to use his hands to sign effectively.

Looking tired, Sean was offered the option to ‘opt out’ of being interviewed but he agreed to continue (I think more for his sister). Sean’s interest and animation increased when I showed him the photobook of my son. This first meeting with Sean did not involve interviewing, rather it was drinking tea and sharing photographs (those of the family around the room) and my own album. Only the first two questions of the interview were posed with the rest of the time given to general conversation about CCN and communication tools. Sean was interested in the devices I had brought to the interview. His family demonstrated the love and pride they have for Sean by talking about his many achievements. Sean was very happy to hear these stories – how clever he was to find his way home – taking two buses and a train after he got lost. Sean’s eyes would flicker and a little smile appeared with this story.

There was also some infantilisation of Sean; Angela referred to him as a ‘boy’ not a man. Several times I heard the statement ‘Sean’s not silly’ and each time I watched his eyes flicker and a small smile when this was stated. I realised that these women, in many ways, are his voice and advocate – a situation he is well accustomed to. I raised the importance of hearing directly from Sean which was validated by Angela: ‘I know I speak for him all the time.’ This, I realised, is a difficult road for family – knowing when to step back.

Carl is 59 years old. He lives in the same group home as George (and the other resident Luke). His bedroom is the front room – a spacious room, the projecting white part of the house with the three windows (Figure 54). I met with him after interviewing George and, by this time, I had gained some insight into life in this group home. Carl’s experience of home, however, was particularly confronting.

Carl was reclined, strapped to a bed chair, his head was almost shaved – there was great malformation of his limbs, legs and feet. I thought of twisted like gnarled tree roots as he lay in a structure that was neither bed nor chair. He looked pale, fatigued and fragile. Wing (Carl's nurse) was also present. There were sounds. Carl's breathing was audible and at times laboured. There were times that he struggled to cough saliva from his throat. The screen door banged. Over the course of the time at the group home, shifts changed. New support clocked on and off. He too had a television humming away until Wing turned it off. No more smells could be detected and I wondered if this was due to the adjustment of the smell of cleaning products.

Wing explained that Carl has cerebral palsy. I wanted to soothe Carl, not bombard him with questions, but Carl demonstrated through his vocalisations and movement in my direction that he was okay to have me there. Wing left the room and I asked Carl to show me his 'yes' and 'no' – as I needed to discern his consent for the interview. His eyes rolled left and up for 'yes' and down and right for 'no'. He also said yes to the interview, but as later stated by Wing, Carl often says yes to everything. I asked Wing for examples of when Carl will say no to things. Wing mentioned a few examples, one was to do with the fact that Carl is Jewish and still takes some food by mouth. If an unknown meat is being served, he will say 'No Pork'.

There were concerns about how to adequately assess Carl's capacity to give consent, further still that it would be unethical to interview someone who appeared as fatigued as Carl. Every minute or so, Carl would close his eyes, looking like he was falling asleep, but then his eyes would spring open again. I relayed these concerns to Carl, but his eyes repeated his expression of 'yes' – he wanted to continue with the study.

The following is from *transcript Carl Consent*.

B-J: Why do you want to participate in this study?

A few moments pass.

Carl (speech): Shops.

B-J: Do you mean the voucher for being a participant?

Carl: [eyes roll back and left] Yes.

Wing: He likes to buy things.

B-J: Hey, the voucher is yours whether or not you keep going with the interview.

Carl: [eyes roll back and left] Yes.

B-J: You don't need to keep going.

Wing: Can you let him have a go anyway? Is that what you want to do, Carl? Would you like to answer questions?

Carl: [eyes roll back and left] Yes.

I stood by Carl, facing Wing, thinking. A decision to pursue was prompted by three things: Carl's interest, Wing's feedback, and gut instinct to greatly modify the process. I decided to ask him only one question – Method 2 – to show him the photographs of hands and ask him which of these best reflects what it feels like to live in your home. It was the method that I felt would be the least fatiguing but also what, I had begun to learn, was the most effective of the methods developed for the study.

As seen in Figure 43, the board of photographs was held aloft by Wing and myself. Carl, lying beneath, scanned each of the images and then stopped at the image (Figure 55). Staring, he called out the word 'Mum' and then turned to the nurse next to him 'Waaaa hooome' he gasped. We did not understand him at first and he twice repeated the words. Wing affirmed 'Oh, you want to go home, but you are home, here with George and Lukey and all of us.' Carl was visibly agitated. 'Nooo waaaa gha hooomme' he insisted. This photograph represented home to Carl, but a home that he had lived in with his mother. Wing explained Carl's mother had passed away about five years ago.

Carl only answered this one question, but within his single response the meaning of home for him was revealed. It was clearly *not* the group home. Home, for Carl, was what he once had living with his mother. The desperation in his voice and actions as he begged to go back to 'home' was, in itself, an expression of anguished entrapment.

Figure 55. Carl's selection

The theory-generated photo elicitation method (hand images) received a strong response from others from the situation defined as ‘Immured’. Ruby made the following selections: puzzle, blankets, syringes, cage, and the photograph of a hand covering a photograph of a face. Using a series of yes and no questions beginning with the question ‘Does this photograph say something positive or negative about home?’ the following meanings were obtained. The exact meaning of syringes was not discovered, other than it revealed something negative. I noted:

- *Puzzle (tricky/difficult)*
- *Blankets (oppression) – very strong affirmation from Ruby*
- *Syringes*
- *Cage (imprisonment)*
- *Hand over face (loss of self)*

The choices made by Ruby contrast sharply with her notions of what a good home is. This is detected in the selections she made using the adapted image selection (Talking Mat) to answer the question ‘Which would be your top qualities of a good home? Please choose up to 5 icons’ is shown in Figure 57. Ruby indicated that she wished these to be known in hierarchical order with support workers at the top, followed next by safety, body safety and choice, then housemates, social, my routines and comfort. Body safety arose as a significant issue, and I was informed that authorities had been alerted about this.

Figure 56. Ruby's selections (photographs)

Figure 57. Ruby's selections (Talking Mat icons)

> *The sensory experiences of sitting on a low and uncomfortable chair and the smells of detergent were superseded by feelings of anger and sadness – the oppression George described, the loneliness and isolation from others who do not want to visit this home was revealed to me. His father and sometimes his sister would visit George but, as with Ruby's group home, there was nowhere to welcome visitors – nowhere for privacy – as George indicated – visitors would have to contend with the other residents and 'not want that'. Having to eat and shower and stick to routines that are governed by the support workers is a great sore point for George, with loss of identity being at the core of it. I felt my eyes filling with tears when Neil (trusted support worker) revealed George's guttural 'You don't know me' to a support worker who was trying to make him take a shower when he didn't want to. It was the most words Neil said he had ever heard George say – that it was a miracle that he said them. George displayed an ability to fight back, to resist. Neil had tears in his eyes as he told this story and others of George's social isolation. 'Home was better when you lived with your Dad – wasn't it mate?' stated Neil. George nodded. As Neil spoke, George would indicate by staring fixedly at my eyes, using his voice and gesturing that he wanted to be sure that I was fully understanding the major points as Neil relayed them.*

In response to the theory-generated photo elicitation method (hand images), George made the following choices (Figure 58). The Talking Mat scale with the thumbs up and down icons

(Figure 36) was used to determine if the selected photographs conveyed a ‘bad/sad’ or ‘good’ or ‘okay/neutral’ meaning. The syringe image and the hands tied represented ‘bad’ or negative experiences – being forced do things (fit the routines of support workers) was the meaning – and the feeling of being tied to rules. ‘Me’ was the word George spoke in relation to the photograph of the clench-fisted hand. It was at this time that the story about the support worker insisting George take a shower at a set time was relayed. The image of the handshake represented a good experience. ‘Him’ said George, indicating Neil – ‘Trust you’ he added. George responded to the invitation to add more meanings or suggestions to describe what it feels like to live in his home: ‘boring’.

Figure 58. George’s selections

When answering Question 6 – Where do you feel most at home with your AAC (communication)? – George pointed at a photograph in his bedroom. It was a photograph of him with a small group of men in wheelchairs with Neil (and what looked like another support worker) at the football. Neil suggested that the unusual noises and speech of George and other people with CCN all blends in with the loud noises of the football.

Sean’s selection from the images of hands was far less clear than the other participants. He carefully scanned and selected the map image (Figure 59) and then the image with the man’s face concealed and then the fist and then he stopped. He then indicated all of the images are what it is like to live in his home. When asked which image was perhaps stood out the most for him, he selected the photograph of the map (Figure 59). The reason for this choice is unknown. Sean indicated that he could not explain why he chose it.

It seems apparent from watching the videos of the two interviews that this man enjoys the company of others and wishes to please. There was a lot of contradictory information. In order to discern whether home held mostly positive meanings for Sean, I resorted to using the PODD (opinion pages) to ask him if home is mostly good or bad. Sean used his finger to point at two icons ‘good’ and ‘bad’. Thereafter ‘yes’ and ‘no’ questions revealed that he liked the look of his home; he could display personal items and the food was good, but he did not like any of his housemates and only some of the support workers who visit the home. Sean’s sister and mother relayed a story of being contacted after an ambulance was called to his home. Sean had apparently been assaulted in an unprovoked attack by a housemate, a woman with both intellectual and mental health concerns. Sean had apparently been choked and may have lost consciousness for a few seconds.

Sean used the PODD to outline his feelings about hospital and the reasons why he does not take medication in order to delay going home. Sean pointed to ‘happy’ to describe his feelings of hospital and the word ‘people’ to describe why he liked to stay in hospital. He chose the words ‘nice’, ‘pretty’, ‘handsome’ and ‘good’ to reveal what he thought about the people he sees in the hospital.

Figure 59. Sean’s selection (photographs)

Figure 60. Sean's selections (Talking Mat icons)

Sean's choices for the adapted image selection (Talking Mat) question were photographed (Figure 60). Using the PODD and with support from Sean's sister Angela, I was able to understand that planning is connected to social events – without good planning, Sean does not get to go out – seeing a friend at rock and roll dancing once a fortnight being one of these times.

The collective stories of Carl, Ruby, Sean and George have come together to create a picture of immured.

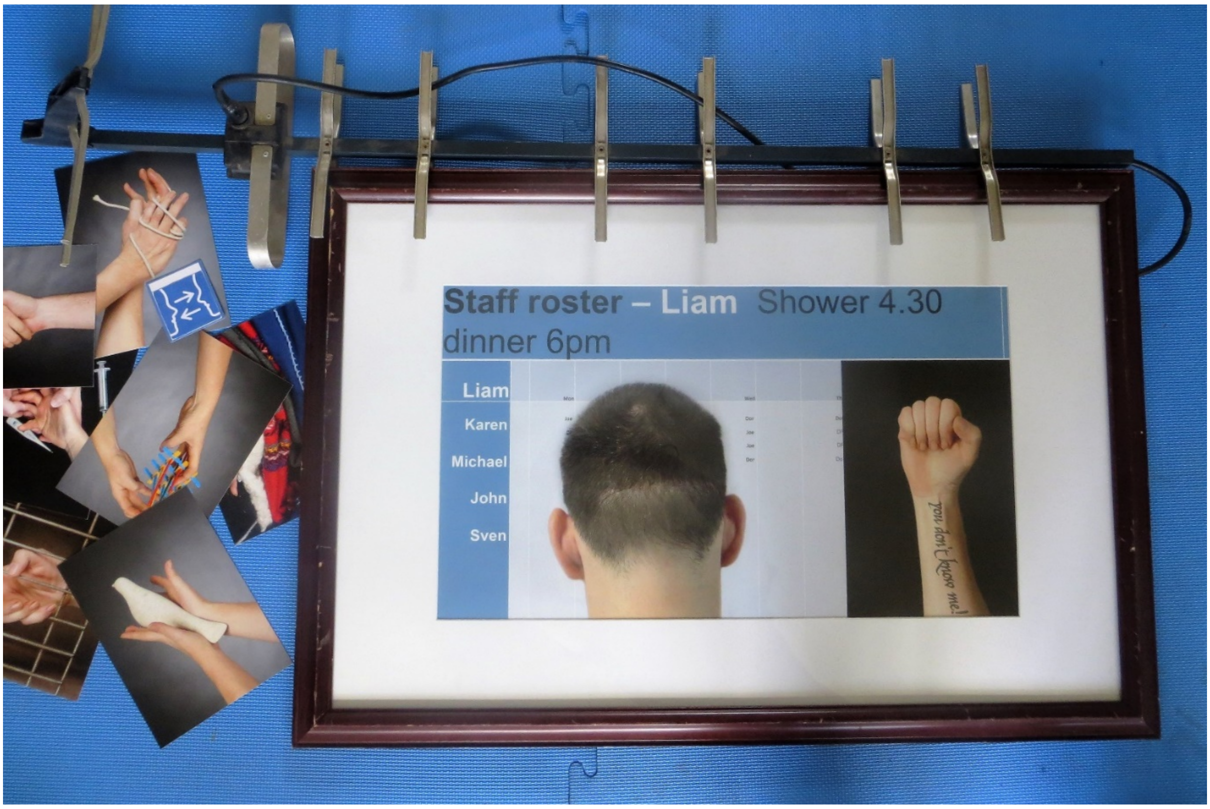


Figure 61. Immured

6.5 *Analysing Immured*

Figure 61 draws the viewer's gaze to the near-shaved back of a young man's head. He sits as an anonymous figure surrounded by the frame of his clean and rostered life and the names of his fellow housemates who, like himself, live by the click of the front door and the endless exchange of support workers who clock on and off. The television aerial symbolises the architecture of communication which, in this immured setting, is predominantly receptive, one-way communication; it, unlike the residents, does not listen back. The television is influential in the house – not just as entertainment but through the critical role of connecting the residents to a one-way understanding of the world. Counter to this routine is the 'expressive' communication fist of defiance and resistance. It emerges from a dark background to tell the tattooed story of 'You Don't Know Me' (Figure 61).

Described by Goggin and Newell (2005) as quasi-institutions where residents are often excluded from the local community, 'group homes' often recapitulate institutional practices. Unlike 'Provisioned', in which relationships with friends and neighbours were evident, the stories within the case study Immured reveal not only a lack of relationship with people outside of the home but also a lack of knowledge (in both residents and staff) of who actually lives across the street or at the neighbouring nursing home, or, as was the case in one group home, even next door.

A sense of being immured, imprisoned and shut-in emerged from several pieces of information, including the selection of tied hands, caged hand and hands with syringes, alongside the absence of stories of choice, freedom and social connection. In the case study 'Immured', the comment from Clifford (2012, p. 12) comes alive: 'Failure at linguistic competence threatens to result in "denied reciprocity" in which a person is no longer recognised as a free and equal citizen'. That George found the capacity to speak this using every part of his being to form the sentence – a whole phrase when he is only usually able to speak two words at a time – suggests his experiential knowledge of the power of spoken, conventional language.

The experiences of the participants whose stories reflect the sense of immured differ from the rights and justice of Nussbaum's capabilities (2006) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2007) which asserts:

> Article 9: Accessibility – *To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures … shall include the identification and elimination of obstacles and barriers to accessibility.*

In homes of the 'Immured', these human rights are on the other side of a glass ceiling. These rights might exist, but the bridge, strategies and vehicles to access these rights do not.

There were stories of resistance, resilience and defiance in these homes: keeping oneself unwell so as to remain in hospital rather than go 'home'; the incredible feat of clearly uttering a phrase when single word verbalisations are difficult; the decision to fight – to take a stand and speak out against the experiences. 'It is not freedom from conditions, but it is freedom to take a stand toward the conditions' (Frankl, 1963).

Once again, as observed within the participants of Provisioned, the intrinsic qualities of the individual emerge. Personal qualities such as resilience and resistance emerge as does something as simple as hair. I noted:

> *Whether short or long and flowing, hairstyles speak about our personality. It's one of the first things people notice and can say so much about who we are.*

Key elements of the conceptual framework laid out in Chapters One and Two take on a fresh intensity in this section. The claims by most of the cited authors who suggest significant shortfalls in relation to the housing needs of people with disabilities are upheld. Goggin and Newell (2005) describe how deinstitutionalisation has not achieved its aim, with people finding themselves socially, culturally and politically isolated in the so-called community with a continuance of smaller-scale institutional practices. The participants whose stories shaped the notion of immured confirm this in their own lived reality. These stories of

‘Immured’ suggest that home is a place where the meeting of housing and ‘home’ needs are incompatible with the delivery of support needs and where human rights are breached.

Immured takes the thesis back to the ‘profane world … where others make the rules’ as described by Dovey (1978). Here too, Nussbaum’s capabilities (2010) shine a light on restriction and resistance and their impact on relationships. Issues of basic needs and rights, power, connectedness and identity emerge. The list of capabilities is again referred to so as to enable a convenient reference when considering the meanings that Carl, Ruby, Sean and George attributed to home. The absence of multiple opportunities for flourishing is evident in their stories.

As previously stated, living a full-length life with bodily health is difficult to achieve with cerebral palsy, and with an undiagnosed syndrome perhaps even more so. That Ruby, George, Sean and Carl live lives reflective of met needs and rights is doubtful. From the information gathered from the four participants, Sean has the closest connection to his needs and rights. His strong connection to family potentially contributes to this. Overall, he says that he likes his home, he enjoys the social outings, but he indicates he is not happy with his housemates and that loneliness is a serious enough issue to warrant him seeking ways to stay in hospital where the attention he receives is preferred. Within these people’s stories we also find some positive elements. Three of the four participants have some enduring family contact while there was evidence of three of the four participants having a positive relationship with the support workers who were present during the interviews. Neil, in particular, appeared to be exceptional, and indeed instrumental to participants accessing the study. The residents are each connected to disability agencies, with three attending some ‘outings’ with these agencies entailing group outings with other people with severe impairments. However, this appears to be limited to a homogenous group of ‘disabled people’ rather than an authentic integration into the wider community.

Bodily integrity was raised as an area of concern for at least two of the participants within the topic of Immured. One participant had recently made a complaint to ‘authorities’ and an ambulance was called to another after he was choked by a housemate in an unprovoked assault. Capabilities 4 to 7 appeared grossly insufficient for all four participants described. Boredom, loneliness, lack of choice, and a lack of power to make decisions in their lives were extensively illustrated. Unlike John and Emma, these participants did not own or have access to pets or a garden that was theirs in these homes; herein capability number 8 appears superfluous. Recreational activities were noted for George and Sean. Football for George, and dancing for Sean were both activities they enjoyed. The recreation of Ruby and Carl was not discovered.

Sean's home was only viewed from photographs. However, the other group homes provided very little evidence to suggest that play was a feature of home (descriptions of, or items observed in the environment, such as pets or jigsaw puzzles, a PlayStation, board games, billiard table, etc.). In contrast, play was not only observed in the Emma's home, but included my sensory involvement by my playing with a soft, curious cat who wanted to rub its face on every stationary surface; the kitchen chairs, the wheelchair, my legs. He was a delight who made us laugh.

Capability 10, Control Over One's Environment, does not resonate within the stories of participants. The group homes observed provided a visual illustration of the notion of control and uniformity, as indicated by Barnes (1999) wherein the delivery of care needs is in tension with 'home' needs.

Resistance and the agency of participants was strongly evident, contrasting somewhat with my earlier thinking in Chapter One wherein I state that 'communication is paramount to human agency – without it, it is difficult to accommodate a notion of agency at all'. Yelling at support staff 'You don't know me' as an enormous feat of communication fits this thinking, as does Ruby's decision to contact an agency for support related to abuse, and indeed, to engage as a participant of the study; arguably an act of protest in itself. Yet the act of not taking medications so as to prolong time in hospital suggests that agency does not always require communication. Rather, agency can be an action which produces an effect: *still sick – don't have to go home – get to enjoy being with other people.* The discovery of agency, however, is a communicative shining light into the unmet needs of the individual.

Political choices and freedom of speech, an aspect of Capability 10, seem extraneous and less attainable when freedoms such as taking a shower at the time of one's own choosing are questionable. Employment is another facet of capability 10. Sean, employed four days per week in a disability enterprise affiliated with his group home, was the only participant of the group of four who was working. He indicated that he neither liked nor disliked the work. Other than this, employment was not discussed during the time spent with participants. However one of the participants described the 'boredom' of the home. This capability indicates the owning of property and goods. Without employment, it is difficult to purchase anything and Sean’s mother explained that he is only paid a pittance. The property owned by the participants appeared to be limited to what was located in their bedroom space: TV, audio devices, personal knick-knacks, clothing and possibly a few items of furniture. However, the study did not investigate this area, so it is possible, but unlikely, that property may be owned elsewhere.

6.6 *Home and Technology*

In contrast to Emma and John’s experiences, access to the rational public sphere described by Habermas (1989, 1990) is significantly impeded for these four participants. Access to spoken and written language differed considerably between those I consider under the theme of ‘Provisioned’ and those under ‘Immured’. Both John and Emma used speech as a primary form of communication. Although not necessarily easy, Emma and John have computer access through such avenues as eye gaze and some slow, laborious finger typing. This enabled access to social media, writing public blog pages, preparing papers for conferences, as well as letters, comments, complaints, and suggestions. The internet, combined with access technology, was a vital communication channel enabling two-way receptive and expressive communication through applications such as email and Facebook. Both John and Emma had more than one computer displayed in the living room of their homes, but it was not the only vehicle driving their connection to the public sphere. Well established community networks through church and disability advocacy have afforded them a place in the public sphere. Travel, socialising and even the items displayed in the open front yards of their homes all support this connection to the world beyond the private realm of the home. Personality traits appear to also play a role in the shaping of access to the public sphere. Acts of agency are inherent to ‘Immured’ wherein, despite the barriers, each participant finds a way to protest – to call for what they want. Yet unlike the participants of ‘Provisioned’, these acts are not enough to build a home.

There is a profound relationship between communication access, the home, the public sphere and rationality. To be denied freedom and equality due to communication impairment Clifford (2012) is likely to bear upon the experience of ‘home’. Following on from this is a realisation of Levin’s (2013) previously highlighted point of people with communication impairments being largely excluded from disability politics, since, as with all other politics, arguments are dominated by people who communicate well and fluently.

For the participants whose stories form the theme of ‘Immured’, communication linking them to the public sphere appeared largely, if not entirely, brokered through others: mothers, a sister and support workers; Neil, in particular. Neil facilitated the access of two participants (residents of group homes that he worked at) to the study. He informed residents about the study, facilitated a phone call between Ruby and myself to arrange the interview, and then attended and shared in hers, as well as George’s stories, as guided by each participant. What appeared evident from these visits to group homes was the element of good luck in having found a trusted support worker willing to step outside the main role of personal care (showering, meal assistance, toilet assistance, etc.) to assist with their participation in the study.

6.7 *Suspended*

This study discovered a type of half-way place or ‘limbo’ that accommodates some compelling qualities of home but equally raises some significant themes of struggle and yearning. I looked out onto a perishable tightrope of care, the insecurity that comes with knowing the fragility of the tightrope, and the stories of ‘Immured’ that have found passage into the imaginings of the participants. I discovered the power of the need for autonomy and power over one’s environment; to spread the wings, to test capabilities, to hope for greater things, to want for more. These were evident alongside the insecurity and complexity of ‘care’. Strongly evident were the fears of not being understood by others, along with a fear of unsafe, inappropriate or just ‘not good’ care. That these fears stood in tension with the yearning for greater independence was strongly evident. Cultural anthropologist Victor Turner (1967) developed an interest in the rituals and rites of passage, and it is from this framework that he describes the position of ‘limbo’ and the thwarted social rite of passage for some people; children leaving home to create homes of their own provides a relevant example.

There were four other participants in this study: two sons living with parents, and two women living with spouses (one with dependent children). The stories of these participants, each living very different lives, align to create the theme of ‘Suspended’. Central to this theme are a series of parallel tensions. The comfort and love of home is in conflict with the mindful awareness that the care received by loved ones (parents and spouses) is or could become temporary due to the ageing and health of these partners or parents. There is the tension between the current home and the need for more independence, and one’s own home, identity, choices and power. There is the tension between the loss of independence previously enjoyed, and the current, extraordinary dependence on loved ones. Each person expressed these tensions to a stronger or lesser degree. The stories culminate in a bittersweet meaning of home underscored by a sense of suspension, either by being lifted out of a home that meant much more (in the past) or in waiting for a new home to address unmet needs. This theme is underscored by the expressed concerns of participants and/or their families about the impact of care on ageing parents or ageing partners.

Liam is 25 years old. He is the youngest of three children and has always lived with his parents and, until recent years, also with siblings. He has cerebral palsy and uses a wheelchair for mobility. I made the following notes about arriving at his home:

> *attractive, accessible and no ‘invalid lives here’ messages in the front yard – neat, pretty garden – the smell of trees and the smell the hot sun makes on driveways. Wide and light and spacey hallway and rooms and Christmas decorations everywhere, tasteful and cheerful. A food bowl –a dog or cat? An aquarium of fish – a sense of joyful – light and a happy home when I entered.*
>
> *Liam appeared curious about me. His hair was very short – a buzz-cut – number 2 or 3. He was wearing an orange t-shirt and had a tray with picture symbols attached to his wheelchair. Janice (Liam’s mother) hovered nearby waiting to translate for him. I felt her anxiety, her glances moving swiftly back and forth from her son to my face – I imagined her thoughts – her concern that he would ‘come across okay’; that I would be able to see past the jerky, snake-like involuntary movements to see him for the great guy he is. I understood this as a protective mother. This is me too. Discovering Liam’s‘yes’ and ‘no’ was easy – he also had many expressions – I could see his confusion and uncertainty, his sense of certainty and sense of humour.*

Some topics were difficult to explore due to the presence of family members; however, there was sufficient data suggesting the possibility of identity and power in the environment being compromised simply by living with parents (or anyone) who has so much power in relation to when, where and how a young person goes, moves and lives. For instance, the 25-year-old is the only child of the siblings still at home and attends church with his parents. His sister and brother have their own homes, and I was told they do not attend church. The décor of the bedroom of one of the participants does not reflect a young man. I found myself wanting to ask: Do you like going to church? Do you like the orange-coloured bedroom and the soft toys on your bed? I felt these questions were value-loaded and potentially undermining.

B-J: So your choice, if you had one, would be to *not* live with your parents?

L: [eyes down left] Yes.

B-J: That’s a ‘yes’ – right?

L: [eyes down left] Yes.

B-J: To live in residential care?

L: [head turn] No.

B-J: Got it – No. To live in a nursing home?

L: [head turn] No.

B-J. That’s a ‘no’. To live in a group home?

L: [head turn] No.

R: To live with other young people?

L: [eyes down left] Yes and [head turn] No.

B-J: Do you mean yes and no?

L: [eyes down left] Yes.

B-J: Ah … you’d like to live with other young people, but ones you choose to live with? Is this right?

L. [Laughs. Appears relieved at being understood. Moves eyes down left.] Yes.

There was considerable tension in the room when this exchange occurred. The man’s parents were affected by their 25-year-old son declaring his desire to live independently, but a home without their care appeared to be inconceivable. They spoke of the type of care he would need and emphasised their fears of others not being able to understand or communicate with Liam. These fears were also shared by Liam, yet still it was what he would like to do if he had the same choices as most young people leaving home have: to have some choice around with whom he lives. Janice, after a few minutes, said: ‘The letting go will be probably harder for us than Liam. We just want to know that when that time comes he’s going to get the same type of care that he gets here with us.’

Anna is in her early forties, with shoulder-length hair, and is a parent of two children who are eight and thirteen years old. Prior to her injury, she was a research academic at a South Australian university. Born in France, Anna (and her partner) have lived in other countries before settling and having children in Australia. The changes to Anna’s life (and experience of home) after the stroke were extensive.

> *After Charlotte (Anna’s daughter) left us, Anna revealed the loss of the quality of her relationship with her daughter, and her perceptions of not being the parent she wanted to be since the stroke. But this is countered somewhat by her acknowledgement of the greatness of Ian’s (partner) relationship in comparison. Caring for her. As she revealed the changes since the stroke, there were times when Anna’s eyes appeared to redden – she looked tearful and I felt tearful too – the stroke had brought loss, reduced her world from very wide to very small – added burden and a daily need to problem solve in order to manage basic living in her home.*

Anna made a modification to Method 2, selection of the hand images (theory-generated photo elicitation). She indicated that Figure 62 was what home was like before the stroke. Figure 63 is home after the stroke. The meanings underlying the images chosen in Figure 62 are powerful, dynamic, unbounded. In comparison, home now is ‘comfort’, ‘closeness with partner/family’ and ‘being cared for/treated/needy’. Anna also indicated that ‘home’ had diminished in its size and complexity of meaning, suggesting that it is simpler now. Instead of a work and a career, the week is spent managing tasks within the home and the carefully planned bus rides to medical appointments.

There was a very close alignment of choices for the four participants whose experiences and stories shaped the case study ‘Suspended’. All four chose the photographs of the hand holding the mug, hands in a pile, shaking hands and the syringes to describe what it feels like to live in their home. The meanings attributed to the photographs are very similar: comfort, close affiliation to family, and ‘being treated/needing assistance/therapies’. One participant, Clara, did not choose the image with the syringes, and David included the image of the blankets meaning ‘warm’ and the map to mean ‘holidays’. These selections contrast significantly with the images chosen in the case of ‘Immured’. In the case of ‘Suspended’, comfort and social connection were dominant experiences. Each displayed their experience of social connection, love and comfort, which was absent in the selections and meanings from the participants whose responses shaped ‘Immured’. For the young men, these very positive qualities existed despite the wish for a place of their own.

Figure 62. Before stroke (Anna’s selections)

Figure 63. After stroke (Anna’s selections)

Clara, with a previous career as a teacher of mathematics, is 77 years of age. A stroke twelve years ago resulted in her loss of verbal communication and her physical impairment increased after a second stroke four years ago. Like Anna, Clara spoke of her experiences of home in terms of the changes that have occurred as a result of experiencing a stroke. Using the same measure as was introduced with Anna, Clara described a similar shrinking of her world outside of the home (Figure 64). The container on the left (Figure 64) demonstrates the volume before her strokes (indicated in a full glass/beaker). Ending were her volunteering roles, including a leadership role with Probus, weekly social gatherings at the golf club, as well as greatly diminished social connections (people visiting her home, phoning or emailing).

Clara raised issues of not being understood by others, that the reality of her not being able to speak was interpreted by significant others as severe intellectual impairment. Clara relayed the story of the doctor who treated her in the weeks after her stroke, declaring her intellectually impaired and likely to soon pass away. Clara explained her desperation and fear at hearing these discussions and that her own mother concurred with the doctor's thinking. She explained that her husband knew that her thinking mind was as it always had been, but she at first had no way of proving this. Eventually Clara used number sequencing to demonstrate her cognitive capacity to medical professionals, resulting in a change to her prognosis and treatment.

For Clara, like the other participants whose meanings formed a nexus of 'Suspension', the realisation of the fragile veil of security between their condition and needs and a good home hinged greatly on the ability of ageing partners and parents to persevere with the quality of care. Clara's gesturing arm indicates her husband and says 'without him'; she watches my face to confirm my understanding before her hand then slices the air in a downward shape to say 'nothing', 'there is no home' (I spoke these words aloud and received her confirmation that it was precisely what she meant). Conveyed in the interviews was a mindful awareness that the care received from loved ones (parents and spouses) is temporary due to them ageing and their declining health. This was a significant theme that contributed to the formation of the case study of these four participants.

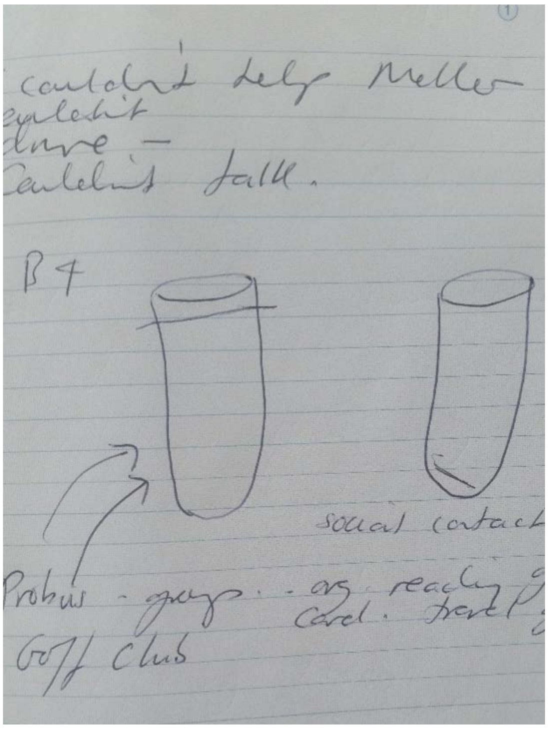


Figure 64. Scaling response – Clara

These four remaining participants of the study are either residing with parents or with partners. The young men who live with their parents would like to leave home, but could see no suitable pathway out. Both appeared to be knowledgeable about group homes and were eager to avoid this option.

David, 23, has lived full-time with his grandparents and an aunt since he was seven years old. His parents still maintain contact with him but they struggled to provide adequate care. He has thick bushy hair, uses a powered wheelchair for mobility, and is a part-time student at TAFE. (He studies from home.) David uses a hand-operated voice-output communication device. David's grandparents have nurtured his connection and participation in the world. Despite poor literacy and severe cerebral palsy, David has access to a computer and social media which he uses with assistance from his grandmother. He recently met with a disability advocate to discuss his desire to leave home.

He, like Liam, stated that he would like to move out of the family home in the near future because it is getting harder for his grandparents to help him and that he would like to live with young people that he has things in common with. 'Not just disability', he added. Later in the interview it became evident that David harboured strong fears about leaving home. He indicated that it is very hard for him to make friends and that he would love to have friends he could move in with, but does not know how he can find friends like that. Despite his loving grandparents and their friends (who are friends with him too), he revealed that loneliness is a big part of his life.

Most of the contact he has with other young people is through Facebook or by attending disability workshops. In answering the question about what is most important about a good home, the young man chose 'support workers', 'housemates' and 'body safety' and placed them next to each other. He typed into his communication device the words 'No disability home'.

Figure 65. David’s selections (Talking Mat icons)

David’s grandmother explained that they are worried about David’s long-term housing options:

> We’re all in a bit of a no-man’s land … we’ve looked around a bit but haven’t found anything really that can help him with what he needs care-wise … to let him get the care he needs, but to feel part of a real home … but help him with his daily needs and just let him be an everyday ordinary person which he is inside.

6.8 *Analysing Suspended*

In Figure 66, the hand photographs selected by one of the participants are surrounded by the objects given to him to raise his comfort and happiness in his home with his parents. Beneath this image on a background of the dark unknown is the mother (parent) figure, waist-deep in the dark unknown, working on a trajectory, a plan, a way to a good life in a future home – battling darkness with a conjured brightness. Under the span of the parent figure is the young person developing – emerging – trying to aid the parent to make this plan for the future home. Two AAC symbols float on the dark background: ‘Want’ and ‘More’.

Figure 66. Suspended

There are strong parallels between the responses made by the young men interviewed in the study and those of the young man in the pilot interview. All stories were punctuated by significant fears around moving out of the family home, due to both care needs and housing needs falling short in the community. Instead of the independence, identity and opportunities the young people are seeking, the young people and their families perceive the options available as likely to incur significant losses. During the pilot interview, the young man and his mother explained that without the right support workers there is a risk that his communication device will not be turned on.

The homes of the parents and grandparents of the participants interviewed housed loving and committed family members with knowledge of the necessary communication style; these are people who understand communication, advocacy and connection to others – other relatives, family friends, and personal friends of parents and grandparents. There is also a sense of being ‘stuck’; needing, hoping and/or having to move on to another home, their own home. Some of the participants hope to be able to live with other young people that they get along with, to not be living in a ‘disability or group home’, to become someone independent, to live life in the broader world with identity and connection to others and to feel safe and well cared for.

The stories of the two partnered women differ in that they do not desire to leave the family home to ‘spread their wings’. They, like the young men in the study, enjoy close and loving relationships with their families, but as married partners (not children of parents) they are settled, and wish to remain with their families. Their suspension is felt in the sharp curtailing of the meaning of home due to the extent of their care needs (great social loss and loss of connection to the broader world). They are also mindful of the safety net of care represented by their partner; if he cannot continue to care for them, then the options do not look good.

Nussbaum’s capabilities appear to be more nurtured within the stories described within ‘Suspended’ than for ‘Immured’. In the descriptions of ‘Suspended’, comfort and social connection were dominant experiences, qualities much less present in the stories underlying ‘Immured’. Selections made of hand images suggest closer social bonds with others and comfort. Access to the public sphere, albeit arguably shaped or mediated by or through parents, grandparents or partners, appeared to be more evident within the group ‘Suspended’. Connection to family friends, being part of a church community, help with writing emails or using Facebook are some of the examples highlighted.

The partners, parents and grandparents of the four people interviewed demonstrated loving commitment to their family member, but appeared concerned about the long-term implications of care for their loved one. These partners and parents facilitated the first contact with the study and assisted the recruitment and, in most cases, the interview process and other contact. For example, Clara’s husband typed and emailed her response to the question she wanted to answer but needed more time to formulate her response. Likewise, the participants interviewed in the study expressed a loving regard and concern for the welfare of their family.

As is the case with the themes ‘Provisioned’ and ‘Immured’, intrinsic factors emerge including psychological sub-themes such as interpersonal dependency and attachment, outlined in the summary below.

6.9 *Discussing Provisioned, Immured and Suspended*

The three art works, ‘Provisioned’, ‘Immured’ and ‘Suspended’, hang on the evolving wall of social meaning. Each symbolises different meanings as captured by the grouping of themes. The interviewing and time spent with the ten participants helped to forge the broad and distinctly different themes of ‘Provisioned’, ‘Immured’ and ‘Suspended’, reflecting specific features within each group. The participants of ‘Provisioned’ differed extensively from the rest. They live alone, access some daily support worker assistance, and have, in the past, lived in residential settings. Their capacity to communicate using speech is greater than the rest of the participants, as appears to be their access to information technology (email, social media, blogs, etc.) in combination with access technology to communicate. Their private world of home therefore supports participation and influence within the public sphere as disability advocates, with a number of roles on community boards and committees. Despite employment access barriers, these participants have created opportunities for paid work, in the establishment of private business, including work as consultants within the field of disability.

The statement from Clifford (2012, p. 12) was reflected in the home experiences of many of the participants, but not all: ‘Failure at linguistic competence threatens to result in “denied reciprocity” in which a person is no longer recognised as a free and equal citizen’. The case studies of ‘Provisioned’, ‘Immured’ and ‘Suspended’ suggest that a continuum of access to being a free and equal citizen exists for people with CCN. Emma and John, of the ten participants, have the greatest use of speech, with most of their interview responses provided verbally. I noted:

> *Although I found it quite difficult to understand and often had to check and re-check my comprehension, conversation flowed faster with more detailed explanations. Intelligence is possibly a factor (Emma and John have scholarly backgrounds), but there were other participants with similar backgrounds, but without the support of speech or writing the responses to interview questions took longer and were less detailed.*

John and Emma appear to have enough of the resources required to meet most of the capabilities outlined by Nussbaum, yet significant parts of capability 10, control over one’s environment, access to employment and owning property and goods, is impeded despite the high levels of education attained and unpaid or partially paid community work. At this point the relationship between work and home becomes clearer. There may be many reasons for this, however, it is worth revisiting the point Hallahan (2015) makes in relation to the incoming NDIS shaping inroads into resource allocation, but failing to pursue a reform agenda that focuses on community inclusion and economic participation.

Education is facilitated in the homes of Emma and John through the provision of information technology infrastructure, online access and external education, but less so employment. This is not suggesting that people with CCN should work from home; rather it points to broader implications, such as how one's home is configured, and where it is located as potentially having a bearing upon access, or not, to work. For example, Emma's access to a train (wheelchair-accessible public transport) was and continues to be an absolute necessity in relation to home. The state has provided a home which is a 48-minute train ride to the city. With the additional time taken to travel via wheelchair to the train station and back it is a significant undertaking for anyone, notwithstanding the experience of severe cerebral palsy.

As outlined earlier, intrinsic factors emerged as a topic of consideration during the study. Qualities such as resilience, spirituality and internal locus of control combine with other factors such as the expression, personality and freedom reflected in their long hair. The homes of Emma and John reflected their personalities; the colours of the town square in Warsaw, art works, collections of items,

Three of the four participants living in group homes, like John and Emma, have cerebral palsy. Their stories revealed that their lives fall short, to varying degrees, of several, if not all, of the capabilities listed by Nussbaum. One of the participants works four days a week in a sheltered workshop affiliated with the same organisation which owns and tenants his home. This participant conveyed that this work was neither good nor bad, but whether it is the kind of meaningful employment that leads to flourishing, and indeed the opportunity to possess goods and property, appeared unlikely.

The study brought to life many points raised in the literature reviewed in Chapters One and Two. The homes of six of the ten participants fit Wiesel et al.'s (2015) description below. A further two participants live with partners and, without the care they provide, they would likely also be required to live in a group home.

> Many people with disability in Australia experience housing and living arrangements which are markedly different to the rest of the population. A large proportion of people over 25 years old live with parents, in group homes or in large congregate or institutional settings. (Wiesel et al., 2015 p. 1)

There is a clear delineation between meanings of home for the group described within ‘Immured’ and those of ‘Suspended’. Issues of bodily safety for instance were raised by three of the participants of ‘Suspended’, but only in relation to what *could* happen if they went into a residential care setting, whereas two participants of ‘Immured’ disclosed that they *had* experienced serious assaults in care settings in recent years. There was also a notable difference in relation to social connection and participation, with the experiences of the ‘Immured’ participants revealing very limited social interaction with the broader world, with social events appearing to be limited to ‘day-option outings’. Loneliness, isolation and boredom were raised by several participants, particularly within this group. The point made by Light (2015) that many individuals continue to experience serious challenges participating in educational, vocational, healthcare and community environments is most noticeable with ‘Immured’.

Opportunities to have a voice or contribute to the broader public sphere appeared very limited to almost non-existent for the group ‘Immured’. An exception to this was the connection Ruby made to the government support service that targets abuse of people with disabilities. However, this connection appears to have required the facilitation of a trusted support worker and closely involved parent, resources which not all residents may be able to draw upon. The home and house distinguishes the private sphere (Laurence, 1987) and is the foundation for participation in social, economic, cultural and political life. (Hulse et al., 2011).

In contrast to both ‘Immured’ and ‘Suspended’, participants of the group ‘Provisioned’ appeared well connected to the public sphere, with ‘Suspended’ participants having a lesser degree of public access. Three of this group of participants (Suspended) use the computer (with some level of assistance) for tasks including emailing, messaging and for study or entertainment purposes. Each participant in this group of four has some level of involvement with family, family friends, and friends of parents and siblings to varying degrees. However, it was clear that social contact is very limited, as revealed in Figures and in their revelations of loneliness. Ballin and Ballandin (2007) provide some context for these findings:

> Researchers have surmised that loneliness in adults with lifelong disability may result from problems with communication (Higginbotham and Wilkins, 1999), or from difficulties in developing friendships and maintaining social relationships (Balandin et al., 2006; Ballin and Balandin, 2007), including a tendency to rely on staff as friends (McVilly, 1997). (p 316)

For the group ‘Suspended’ the connection between the private world of home and the public sphere differed for each participant. One of the four participants within ‘Suspended’ was known to have a cognitive impairment, with the others describing some partial loss of cognitive functioning in some areas, such as the loss of the ability to read and write.

As with ‘Provisioned’, education was noted within the group ‘Suspended’, with one of the participants currently completing an online course and another considering doing a course from home sometime in the future.

> *The feelings about hair and who gets to the right to have it – express themselves with it – speak with it – all became clear. Interviewing Emma and seeing her hair was like looking at some of Nussbaum’s capabilities flipping around me in the wind.*

CHAPTER SEVEN – ANALYSING METHODOLOGY AND ARCHITECTURE OF COMMUNICATION

Part A. Analysing Methodology

7.1 *Finding Meaning in the Methods*

The previous chapter centred on the case study analysis of the first two questions of the study. This chapter analyses the data concerned with discovering answers to the final two study questions: Question 3 – what are the barriers to research with people with CCN and how might AAC be experienced by both participants and researcher in the research process? – and Question 4: how might effective research practice with participants with CCN be pursued and achieved? Can AAC and visual research methods be combined to create a set of methods offering utility with participants with CCN?

Findings for the first part of Question 3, regarding the barriers to research with people with CCN, were obtained from the review of literature as outlined in Chapter Three. These include communication-related barriers due to researchers' reliance upon spoken and written language (Lloyd, 2006; Ison, 2009; Paterson, 2002). Other barriers include the budget constraints of research institutes, which affect such things as time allocated for interviewing (Castrodale, 2010), and ethical issues such as the avenues for gaining consent (Cascella, 2014; Philpin, 2005). The second part of Question 3 regarding how AAC might be experienced by both participants and researcher in the research process, and Question 4 on how effective research practice with participants with CCN might be pursued and achieved, are addressed here.

> Just below your awareness, you live in a parallel world: a world where your evolutionary heritage (loosely speaking) keeps you safe. Your inner bat listens to the spaces you occupy. Your inner rabbit listens for threats and anticipates their approach. Your inner dog allows you to determine the location of smells and your inner mouse helps you implicitly use those smells to perceive family, fertility and reproductive potential. Your inner spider allows you to feel things without directly touching them and your inner firefly helps you sync with people. Your inner monkey helps you recognise intent from faces and effectively mimic the behaviour of others.
> (Rosenblum, 2010, p. 295)

Sensory ethnography, as both methodology and method, validated and welcomed this parallel world of knowing into the science of qualitative exploration. It provided an answer to the challenge of finding a methodology capable of transcending the confines of traditional communication; one capable of building upon knowledge acquired through means other than speaking and writing. Sensory ethnography provided the methodological point of embarkation from which multiple methods of information gathering were developed. Method 1 is dedicated to the sensory experience of the researcher, with the other methods adapting elements of the senses into the approach. Photographs, icons, film and participant sensory ideas were incorporated into the study. Making space for the voices of others is particularly important in the area of disability research (Sunderland et al., 2015) and, in this vein, the study has pursued avenues for development, testing and application of these methods so as to best understand how to hear the voices of people with CCN.

The testing phase enabled an opportunity for experimentation, but it also provided reassurance that these methods might work. There were many surprising outcomes of the methods. For instance, the hand images were well received by the participants but the ‘participant-generated sensory selection’ (selecting an image, smell or sound) left several participants confused (including participants during the testing phase). It was included in the final study following the suggestion of the pilot-test participant, which was fortunate as it provided revelations from some participants about the meaning of home (Warsaw Town Square image, metaphor of fire) which would have been unlikely to have been discovered through another method. Furthermore, in formulating and asking the question, my sensory experience of ‘researcher emplaced’ was encouraged to answer this question from a personal ‘snapshot’ perspective. For instance, if I was asked what smell would sum up the experience of Ruby’s home, my answer would be disinfectant and cleaning agents, OMO in particular.

AAC, both that which was provided by the participant or by me (researcher) was a critical element of the study. The Talking Mat was used in each interview with variations of other forms of AAC, such as PODD use.

7.2 *Analysing Methods*

I begin my analysis by returning to the objectives of the study, which are: to discover the meaning of home for people with CCN; to investigate the relationship between home/place and health/wellbeing for people with CCN; to increase the understanding of best research methods for researching with people with CCN – including the benefits of and barriers to AAC – from both the perspective of the participant and the researcher; and to investigate, develop, test and implement a set of CCN-friendly research methods capable of capturing an in-depth understanding of the meaning of home and place for people with CCN.

In the study I took the opportunity to develop and investigate new methods and combine them in a single study, and in doing this, I have demonstrated the capacity for these methods to contribute to research initiatives with participants with CCN. This involved a lengthy phase of testing these methods before they were applied. Five methods were developed and used as described below.

Method 1: Sensory ethnography and the emplaced researcher. This relied upon my sensory awareness of the place and experiences as a researcher with the participants. Underlying this method were the questions: What does it feel, look, sound, smell and taste like to live in this home? What is the architecture of communication surrounding us? What does it look, sound, smell, taste and feel like?

Method 2: Theory-generated image selection (hands) used the question: Which of these photographs of hands (maximum of 3) best reflects what it is like to live in your home? Participants were asked to indicate with a single word (or more) what this image meant to them.

Method 3: Adapted image selection (Talking Mat) used the question: Which would be your top qualities of a good home? Participants were asked to choose up to five icons.

Method 4: Participant-generated sensory selection used the question: What does it look like, feel like, sound like or smell like to live in your home? Participants were asked to think of a picture, a song or sound, or a smell that can give the sense of what it is like to live in their home.

Method 5: Structured and ethnographic questioning used the following structured questions also in conjunction with general conversation: Why were you interested in participating in the study? Where have you lived in the past and what was good/not good about these places? Where do you feel most at home with your AAC and what suggestions do you have for anyone thinking about interviewing people with CCN? What suggestions do you have for anyone thinking about interviewing people with CCN?

7.2.1 *Meeting the Objectives with These Methods*

Objective 1 was to discover the meaning of home for people with CCN. This was undertaken through the application of the experience of the senses (noticing and recording) by observing, listening, smelling, touching and tasting. The use of the tools of questioning, video, photography and note taking were also instrumental in an approach founded upon triangulation. As outlined earlier, the research design was scaffolded on the process of triangulation, wherein several types of methods are used in a study in order to check the results of each subject (Rothbauer, 2008; Paton 2002). The purpose of the process of triangulation was to provide accountability in light of methods that were new and experimental, with accountability being sought from evidence of consistency in the information received and interpreted, across each of these methods.

Participants were invited to provide information about home from multiple angles: how it feels, its sensory experience, what they value about it, what ‘home’ should be, what it has been in the past, and what is most important about it. These facets were explored with participants in a way that enabled a clear dovetailing with the theoretical meanings of home as well as Nussbaum’s list of capabilities. In doing this, an assessment of the quality of home was enabled by determining the extent to which these homes conformed to the realisation of Nussbaum’s ten capabilities, as well as the theoretical notions of home, in particular: ‘identity’, ‘power in one’s environment’, ‘safety’, ‘social connection’, and ‘comfort’.

These methods afforded rich insight into the meaning of home for each of the ten participants. Three major themes, into which sub-themes were imbedded, were clarified over and over again through the consistent response to the various methods used in the study. There was an exception of one participant whose single response was woven into the case study ‘Immured’. His participation teetered on the brink of not being included in the study due to the severity of his impairments and the fragility of his health. However, his ability to convey so much information using only one of these methods (theory-generated photo elicitation – hand photographs) was evident. Testing for consistency across different methods (triangulation) was not possible because he only answered one question. Yet the act of begging to go home, using every possible means available, profoundly informed the study. Together with Method 1, for the emplaced researcher who saw, heard, smelled, touched and tasted despair with him, the decision to include his contribution was made.

Objective 2 was to investigate the relationship between home/place and health/wellbeing for people with CCN. This was supported through aligning of Nussbaum's capability theory (2010) along with some of the core qualities of home emerging from the theory (identity, safety, social connection, comfort and power in one's environment) with the information gathered through the study. This could, more or less, be achieved in a broad sense; however, the measuring of quality of life is subjective. Furthermore Nussbaum's (2006) list of capabilities are not necessarily definitive or able to be applied equally. For instance, comparing participants with severe impairments, some with significant health concerns with capability number 1 *Life*. *Living a full-length, quality life* required a disclaimer addressing the possibility of lowered life expectancy because of one's physical condition; furthermore there was some ambiguity around quality of life. However, there were other capabilities that offered an easier comparison, engendering deeper thought and consideration about home. Some flourishing qualities emerging from the meanings of home for participants were difficult to place into Nussbaum's list or home theories in general. Spirituality, God and faith were important sub-themes of the meaning of home for several participants, interwoven with intrinsic qualities such as resilience and identity. Furthermore, church going was closely aligned with community participation and the public voice, but this too appears to sit outside the literature, including Nussbaum's capabilities, that were sourced for this study.

Objective 3 was to increase the understanding of the best research methods for research with people with CCN; including the benefits and barriers of AAC from both the perspective of the participant and the researcher. This objective was tackled in a number of ways. First through literature searches which were largely unsuccessful. Thereafter, by creating and testing new methods, and then applying these methods to the study using an evaluative framework, I hoped to gain a sense of what worked well and what did not. Further still, the following structured questions used in the study asked participants where they felt most at home with their AAC; and followed with asking what suggestions they might have for anyone thinking about interviewing people with CCN. The responses to these questions were recorded and are listed below:

Response to the question: where do you feel most at home using AAC?

The individual responses to this question were:

- At home.

- Wherever my crazy self can communicate and connect with others. I can do this in a lot of places.
- At home, at church, with friends of parents, with siblings and at the football. [Liam uses little formal AAC and so the question was modified to ask where he feels ‘at home’ communicating with others.]
- Did not wish to answer this question.
- Don’t know.
- Don’t know.
- Did not answer this question (fatigue).
- At home, on the internet and with people who know me. Have quite a lot of friends, I get out but there are often problems [made an earlier note about people often asking to speak to her ‘carer’ rather than her].
- Indicated a very small circle, suggesting ‘home’ and in therapy sessions including a local rehabilitation hospital.
- Mostly just home.

From this list home appears to be the key (or only) place for participants’ use of their AAC. This aligns with the information gathered in the interviews: parents fearing that carers will be unable to support their child’s CCN/AAC; a participant revealing email and social media being a preferred way to communicate with people; and several stories of communication access barriers, including stories of people in the community refusing to speak with the person or learn about their AAC. These findings also concur with Hodge (2007) who points out that communication aids have the potential to address the extreme marginalisation that can often accompany people with CCN. Herein a transformative effect is likely for only a minority of cases because, as Hodge (2007) indicates, using a communication aid itself may serve to stigmatise an individual.

Other data supporting Objective 3 is evident in the response to the question: Do you have any suggestions to guide researchers in interviewing people with CCN (or who use AAC)? This question was introduced before interviewing participants and then revisited at the end. It served two purposes: informing the immediate approach of the current interview; but also for gathering insight to support objective 3: to increase the understanding of the best research methods for research with people with CCN, including the benefits and barriers of AAC from both the perspective of the participant and the researcher.

There were several responses to this question, all of which are listed below. Although only a short list, it offers ideas about what might be required to improve any future approaches to research with people with CCN.

- Email, Skype, social media, online forums, face-to-face interviews, no detailed writing
- Relax (meaning researcher to relax)
- Support person (trusted) to help
- Use like the hands (hand photographs)
- iPad, Google maps, Facebook
- Spend a little time with the carer.
- A sound knowledge of the subject of aphasia and dyspraxia
- Pictures like you (referring to visual images, Talking Mat and hand photographs)

Family and personal support workers also offered suggestions. These were:

- Spend time with the family. Walk in their shoes for a while.
- Wait and take time to listen for responses
- Researchers should be trained in AAC

Although obtained from a small group, these suggestions cover a broad range of ideas that might be reduced to three key themes:

- Involvement of digital tools, e.g. social media and technology
- Researcher qualities (background knowledge, communication partnering skills, ability to be comfortable, connecting effectively with participant support network)
- Use of pictures, images, symbols

Drawn from this feedback is the knowledge that in the combination of elements of a supportive methodology, methods capable of incorporating the types of suggested qualities are critical. The inclusion of digital tools and social media was highlighted. Researcher qualities were also of high significance, which has particular implications for sociologists with little or no knowledge of AAC. As Sunderland et al. (2015) outlined: ‘As researchers, we must continuously ask: who gets to speak and how? To what extent are we limiting this interaction to match our own abilities as researchers?’ (p. 54). With this comes an invitation for sociologists to extend their skill repertoire to include such things as knowledge and use of AAC as well as good communication partnering, and a willingness to expand into alternative areas of research.

Objective 4 was to investigate, develop, test and implement a set of CCN-friendly research methods capable of capturing an in-depth understanding of the meaning of home and place for people with CCN. Participants, as with the test groups, were asked to provide feedback on the methods using a scale of good/okay/not good/don't know. The study and test group responses are outlined in Table 3.

Table 3. Combined study and test group feedback about methods

	Method	n	good	okay	not good	don't know	na
TEST	PGSS	**22**	8	9	2	3	
%			36%	40%	9%	13%	
STUDY	PGSS	**10**	2	2	2	2	2
%			20%	20%	20%	20%	20%
TEST	TGPE	**22**	16	4			
			72%	18%			
STUDY	TGPE	**10**	8			1	1
			80%			10%	10%
TEST	AIS	**10**	9	1			
			90%	10%			
STUDY	AIS	**10**	6	3			1
			60%	30%			10%

The participant-generated sensory selection (PGSS) received a poor rating from the study group, with only 40 per cent, in combination, indicating that it was either good or okay. This method received a more favourable response from the test group, with a combined good/okay score of 76 per cent. This method consisted of one question: Is there an image, sound or smell that comes to mind that could show what it is like to live in your home? To provide support with answering this question, participants were provided with options, for example, using the internet, an accessible camera (Go-Pro with the wheelchair attachment) or a word bank of sounds and smells was offered. Only five of the ten participants provided a response to this question, with four choosing a visual metaphor to describe the feeling of their home. One chose two songs; however, he did not wish for these to be considered in the study because they were not quite right and he needed more time to think about it. The young man who answered these questions in the pilot also indicted his interest in this question, but stated that it would take him some time to find something.

The visual imagery chosen by participants did not appear to take very long and resulted in powerful and informative illustrations, for example, one woman used vocalisations to say ‘warm open fire’. Using eye-gaze technology (in which eye movements substitute for the use of a mouse or a keyboard to operate a computer) one participant controlled a search on the internet, selecting a photograph of the town square in Warsaw. These were very positive exceptions to a method that was not well received by the majority of participants. Two other participants provided images; one was ‘a yellow shrine of ornaments’ from his bedroom window (however, this was a suggestion made by his mother which he subsequently agreed with, rather than an answer he developed himself). The other participant later provided her response via her husband, who sent an email to indicate that the story ‘Goldilocks’ was how her home currently felt: ‘just right’, but also a little insecure. It is interesting to note that the responses from John and Emma (and the theme of ‘Provisioned’) appeared to emerge without difficulty, but these too, were limited to a visual description. Perhaps, with more time, preparation and explanation, descriptions using other sensory corridors might be possible.

My view of this method is mixed. Overall, it failed to translate across senses, and appeared confusing, with most participants expressing difficulty in responding to it. Yet this method afforded great insight into the meaning of home for Emma and John. For John, it was discovered that home exists in more than one place. It also showed a sense of how ‘homeliness’ can be brought into a space through colour and décor to connect these meanings together. From this perspective, it is difficult to consider this method completely unsuccessful. Without further testing it is difficult to clearly determine why John and Emma’s responses were more easily provided, and also why other sensory channels were not used to answer this question.

In responding to the adapted image selection (AIS, using the Talking Mat), the participants were asked to select (in their opinion) approximately five of the most important qualities of ‘home’ for them. Nine of the ten participants answered this question; Carl did not due to frailty. All of the 21 options were selected at least once. The average number of cards selected was 5.5 with the card selected most frequently being ‘Support Workers’, selected by six of the nine participants. ‘Comfort’ and ‘Being Myself’ followed, with five participants selecting ‘Comfort’ and four choosing ‘Being Myself’. The selections from this method matched the information gathered in other methods. For example, for Emma and John the same or similar themes arose about their home, and for Ruby and George, most of their selections for this method contrasted with the reality of what home is. Ruby’s ‘reality’ (hand photograph selections) versus what she thinks a home ‘should be’ (Talking Mat icons) were precisely opposite, affirming consistency and thus accountability for these methods. Furthermore, a few of the respondents were not using communication aids, instead relying on a close support to interpret their requests. The Talking Mat provided an opportunity to directly understand and clarify the thoughts of participants.

It was interesting to compare these results with the videoed behaviour of participants as they made selections. Three of the participants selected ‘Support Workers’ before making any other selections, and two persons who had placed their selections in priority order (unrequested) had the ‘Support Workers’ card at the top of an unrequested priority pyramid. Furthermore, two of the nine persons who responded to this question relied upon their partners to provide support or care, and as such this card was likely to be less relevant. When seen in its context, the selection of the ‘Support Workers’ card provided a strong indication of the critical role that good care plays in the making of a quality home. This aligns with notions presented earlier of care provision being a major factor in housing for people with disability (McLoughlin and Tually, 2012; Bleasdale, 2006).

From this method, and in context with the overall interviews, it is possible to identify five core qualities of greatest importance for a good home (in order of importance): the quality of support work as the most significant, with Comfort and Being Myself (identity) being of next highest significance for this study, with Choice, Safety, Relationships and Housemates following from there.

Furthermore, the video recordings of the interviews revealed long periods of ‘word silence’ (a term I developed to distinguish AAC from sound-dependent communication of speech). There were many periods of ‘word silence’ between the researcher and the participants, but the silence was full of communication: image selection, gestures, laughter, etc. There were many moments where the need to clarify and re-clarify meaning interrupted the flow of the participants’ messages; however, every person patiently accommodated this and all appeared to be engaged with (with several appearing to enjoy) the experience of selecting cards (even those for whom ‘home’ was not good). It did not appear to be onerous or confusing for any of the nine participants who answered this question.

The adaptation of the Talking Mat as both a research tool and communication device contributed greatly to the study. It was primarily implemented as a method; however, it was also used as a communication device, helping to capture more detailed information but sometimes just to chat with a participant. It was easy to use, versatile and supported a variety of communications with participants (clarifying points, assisting with understanding scale, and with the process of gaining consent, as well as general thoughts, feelings and conversation with people with CCN). Furthermore, as a research tool, it was well received by the test cohort (participants without CCN). One test participant exclaimed ‘I love this – if research was presented like this I’d put my hand up to answer questions’. From here it is possible to imagine the benefits of including AAC as normalised practice within general research; breaking down communication barriers while raising ‘status enhancement’ (Wolff, 2009) of AAC. The Talking Mat (available in physical or digital form) comes with both workshop and online training in support of its use. Overall the development of new ways of adapting the mat to serve qualitative research purposes offers the field of sociology an exciting opportunity for discovery.

My view on this method was that it was effective for the following reasons: the Talking Mat itself could be readily adapted as a research tool, bringing with it the utility of its communication aids of colourful icons that could also be adapted to suit the research. The method was well received by participants. This was evident both in direct feedback, and in later observations of the behaviour of participants in the video: leaning forward, interested faces, thought and engagement in the task, and two participants placing cards in priority order (adding value to the method).

The theory-generated photo elicitation (hand images), was very well received, as reflected in participant feedback. It offered considerable information directly related to the key research question. The preparation of the theory-generated photo elicitation (hand photographs) was lengthy; however, the images are likely to have ongoing use in any qualitative study seeking to identify the relationship between an individual and their experience of social goods such as power, freedom, social connection and agency. Furthermore, due to the evocative use of images, this method enabled participants to arrive at a deeper level of meaning than if they were limited to a verbal response. Essentially it provided a ‘shortcut’ to meaning that may be useful in other settings such as therapeutic work, and for people with or without CCN.

From my perspective as the researcher, this method, in combination with the sensory ethnography of the emplaced researcher, could have stood alone in answering the first two questions of the study, with some additional clarification (using the Talking Mat). The first question – what is the meaning of home for research participants with CCN? – could have had further detail included through a clarification process after the selections were made. This could have taken the form of questions like: What has it been? What is it now? What could/should it be? These images were founded upon Nussbaum’s capabilities and core elements of home theory, wherein the selections of certain images, alongside the process of clarification provided a good indication of what home means. In this way the second question – how is the participants’ experience of home related to and promoting (or not) of communication access and Nussbaum’s list of capabilities? – was pursued. This is evident when referring back to each of the participants’ responses. There were two participants for whom further, more detailed clarification of the choices they made would have been necessary, but overall this method, in combination with the sensory ethnographic information, would have sufficed.

The time and effort it took to develop the hand images requires consideration. In comparison, the other methods were not particularly onerous or time consuming to develop. Yet this method was arguably the most successful as it captured a deep level of insight about the meaning of home and required very little use of spoken or written language. It involved the creation of new images with four phases of testing images before the final 13 photographs were identified. When considering the point raised by Castrodale (2010) about pragmatism as a barrier to research, this amount of experimental testing is unlikely to be supported in many research settings. Herein lies the question of the extent to which those hand images might have utility for other research questions, particularly those focussed on quality of life issues. If the use of these hand images proves to be transferable, then this problem may be resolved.

7.3 *Reflections on the Emplaced Researcher*

Sensory ethnography and the focus on the embodied sensory experience of time spent with participants was as emotionally powerful as it was insightful. Because sensory ethnography entails the embodied experience of the researcher in being with a participant (Pink, 2011), it required a new kind of analytic orientation that would bring to the fore the sensory aspects that commonly go unnoticed (Valtonen, 2007). This meant paying attention to sensory information present during time with the participant through experiences such as the use of AAC, interactions with support staff and the locking of doors. There was new, different, deeper information in these sounds, smells and images. Conscious sensory awareness, journaling and video were tools used to capture this information, but it was the ‘noticing in the moment of being there’ that wielded the greatest power and insight.

> *a few hours after leaving the home of George and Carl, I walked into the laundry and could smell it – one of the cleaning products from their home. I opened the laundry cupboard, then lifted the lid of the washing powder bucket that was Omo – the smell that was stuck with me – Omo. I took the bucket outside to the carport and poured the contents into the bin.*
>
> *… I sensed imprisonment. Heard the latch go on the door (can’t be reached from the wheelchair). The shaved heads sent my mind to the book ‘Man’s Search for Meaning’ by Viktor Frankl.*

These notes made after spending time with participants reveal some of the impact of this approach. After leaving the home of George and Carl, I found it difficult to detach the re-sensing of what I had experienced. The smell remained with me, as did the images and the sound of the latch on the screen door (something I probably would not have consciously noticed without the insight of sensory ethnography). There was too much information, the content of which raised anger inside of me. It was a dreadful experience, mixed with the memory of Carl’s plea to ‘go home’. I decided momentarily that sensory ethnography was ‘too difficult’. I also wondered about vicarious trauma in a situation that requires a full opening of the senses, instead of what may have been; a defensive position of ignoring, overlooking, or rationalising a situation as somehow being ‘okay’.

‘It would be impossible to provide an answer to the question of “how” to carry out a sensory ethnography analysis. Indeed, no standard procedure exists’ (Pink, 2009, p. 120). However, Pink (2009) makes some important distinctions between traditional and sensory ethnographic analysis, in that sensory ethnographic analysis ought to extend beyond simple content analysis in such a way as to consider it, itself, as a sensory experience and ‘should be situated in relation to the phenomenological context of the production of the materials’ (Pink, 2009, p. 121). I noted:

> *I see myself looking at the video and I remember my thoughts at the time: ‘The video will never be able to capture what I’m experiencing right now’ – smells, cleaning agents. But in contradicting this thought, only now, from this video am I noticing that the TV (in the shared lounge space) never stopped humming – I could hear it from all corners of the group home. Somehow I didn’t notice it at the time. As George and Neil told the stories of the smallness of home, this television told of one-way communication.*

I noted at one point that the embodied experience can raise personal and interpretive biases due to its subjective nature, which compelled the approach to be managed in such a way that these risks were not realised. As described in Chapter Four, reflexive testing ensured an awareness of my situatedness, not only in relation to myself as a person, but also with an insight into my own meaning of home. Being able to separate my own personal meaning of home from that of others was important. For example, my own home is messy – like Emma’s, John’s and Anna’s homes, it has piles of cluttered stuff. I like it that way. Homes that are kept in clean ‘show home’ condition feel uncomfortable to me. Herein was the risk of me walking into the group homes that were in tip-top cleanliness and clutter-free and deciding that ‘this is not a comfortable home’ and imposing this meaning based on my sensory experience of such cleanliness. By declaring and noting down this subjectivity, I was able to balance my response to my sensory experience of clean, empty surface areas in these homes. Herein was a need to maintain an open, questioning mind about my judgement on all aspects of the study.

By highlighting the experiences of participants, sensory ethnography got under my skin at times. Throwing out a bucket of perfectly good laundry powder because I was associating it with the 'Immured' stories of the group homes gives testament to the influence of the senses, but I found it to be an incredibly powerful approach to learning about others. As such, no matter what methods I find myself applying in any future research, I cannot imagine ignoring the embodied, sensory information that will encase me. I have learned that sensory ethnography is not something you can pick and choose as a method because it is now part of me; I cannot walk into a space of another and pretend it is not there. While months have passed since I completed the field research, I have this residual heightened sensory awareness when being in the spaces of others. While at times during the study this led to some painful (as well as good) feelings while being with participants, my skills in communication have increased, widening the doorway to such things as understanding and empathy in everyday life.

7.4 *Using AAC in Research*

AAC was used in two major parts of the study. Firstly, it was integrated into, and indeed shaped, the nature of the interview questions. Secondly, it was used to propel general chatting and conversation with participants, as well as to elicit more detail about participants' answers.

There were no known studies outlining the use of AAC in sociological (and non-AAC specific) research, so reflections on its efficacy are limited. I found the use of AAC critical to the success of every interview; not just in answering the questions, but the entire experience of being with the participants in an environment that supported (or not) their communication methods. I have been using AAC every day for twelve years and have attended training and workshops in a variety of AAC methods (although not all of the AAC used by participants was known to me). This overall familiarity is likely to have been an influential factor in the success I experienced in incorporating AAC into the methods, building rapport and conversation with participants, and in obtaining more detailed responses. Perhaps even more influential was the enthusiasm of the participants to patiently teach me the complexities of their communication approaches. Messages stating things like 'It's okay to keep asking me for clarification', 'Shows you are trying to really know what I'm saying – not just pretend you do', 'Don't be so hard on yourself', and 'Relax – it's okay' were commonly conveyed to me during times when I simply did not understand what participants were trying to tell me. This not only made the interviewing easier, it served as a reminder that the participants are the experts on their lives and I was there to learn.

Using the different forms of AAC was not only a learning experience, but was very interesting, enjoyable and successful in both the amount and depth of information captured. With some training in the use of AAC, and specifically in the use of the Talking Mat, researchers who are keen to understand others, and are willing to step outside the restrictions of spoken and written language, have much to gain. Furthermore, CCN is not necessarily limited to participants. Two of the participants I interviewed were from research backgrounds. While the concept of a researcher who relies upon AAC conducting research with participants who use typical speech sits outside the parameters of this study, it is a concept worth pursuing.

The study was not without notable shortfalls. The methods were successful but it was only by luck that the cohort did not include persons with sensory impairments. With vision being only one sense, it brings to mind the need to develop other forms of sensory-based research methods. Greater thought and investigation is needed here.

Part B. Architecture of Communication

7.5 *A New Way to Think about Communication*

The ‘architecture of communication’ is a concept generated through the study to explore the factors, structure and dynamics of communication arising between the participant and their home (space). As a by-product of the study, so to speak, it refers to the framework supporting the communication of the inhabitants of a space or place.

Imagining the wheelchair user in Wolff’s (2009) quotation as having CCN and using AAC, and then applying this perception in relation to communication access helped spark a range of ideas underpinned by the notion of architecture as not only physical, but also constructed in communicative and communico-sensory forms. Figure 67 was created as part of a poster presented at the 2014 ISAAC conference in Portugal.

It includes two symbols relevant to communication. The communication symbol (upper left of figure 67) developed by an Australian agency, SCOPE, has emerged, in very recent years, as the universal symbol of communication access. The other symbol (bottom right) is one of a number of symbols indicating the availability of electricity for disability-related electronic devices (powered wheelchairs, but also electronic communication devices). At this time I had only conceived the architecture of communication as physical elements in the environment – furniture that enabled a wheelchair to sit together with other chairs, symbols alerting the public to communication access services (similar to interpreter services), etc. It was not until I met participants in their homes, and approached these experiences from the perspective of sensory ethnography, that the compelling evidence of communication as broad and multi-sensory; as architectural, was manifested to me.

Figure 67. Experimenting with communication as architecture

Over the course of the study, I pondered the concept of the architecture of communication, taking myself on several journeys of communication architecture appreciation. For instance, I noted in my journal (on a walk back from the University Hub to my desk in the Health Sciences building):

> *I stood in line and ordered my coffee, describing exactly how I have it, then sat down on the new yellow chairs to arrange my things for the walk back to the office. Really like the layout of the yellow chairs – people can sit in whatever structure suits them – groups to eat or chat or work. Said hi to the person next to me who made space for my gear, she said 'Hi' back and laughed 'You've got your hands full'. As I approached the door into the Health Sciences building I called to the person in front to please hold the door. The guy from computer support was already there waiting for me. We sat down at my desk and I explained to him the problems I was having with my computer.*
>
> *I did this walk again in my mind and imagined I was one of the participants I had earlier interviewed. Even without CCN, if I was a person in a wheelchair, I wouldn't have been able to reach the counter to order my coffee. If I had CCN (and could reach the counter), there was a list from which I could have eye-gazed or gestured my choice, but it was not visible to the person serving me. I doubt if the person who served me would have understood my request. There was a line – it was rushed – how would this have been managed if I had CCN? The new yellow seating would manage my wheelchair very well. It would support communication – but then I noted there were no power points among the chairs from which I might charge the battery in my communication device. If I needed to charge it, I would have to sit on the other side of the hub next to the sink. The main door to the Health Sciences building is not automated, I must wait until someone else enters and leaves so I can get into the building. It's obvious to the person who comes by that I need to get in and the door is swung open with a 'let me help you'. This opens up an opportunity for communication, but it is also sometimes a frustrating wait. The computer man greets me and follows me to my desk – there is no room for us to sit side by side – I must back my chair into the hallway.*

Figure 68. New hub at Flinders University demonstrating communication-supportive furniture.

Communication architecture can be anything from the arrangement of seating, to the training received by employees who work on the reception desk of a building and their subsequent familiarity with AAC, to an available power point from which one's communication device can be recharged. At the outset of this study, the nature and role of communication in the shaping of the many facets that make 'home' was under-researched and opaque. Furthermore, and perhaps even more significant, was the discovery of the concept of the architecture of communication, its ability to be measured and therein its potential to be utilised as a measurement tool for wellbeing.

I began searching for signs of communication architecture in different spaces, including my own home. When attending the different homes and settings of participants, I engaged in this search as part of my embodied experience. However, my display of this 'knowing' has been presented more as 'content data', reflecting a pragmatic purpose which will be discussed further on. Another, very different form of sensory ethnographic analysis that I implemented was to interpret and display findings through art. The themes arising from my sensory experience were merged with the responses to questions provided by participants.

Many sources provided information to support the understanding of the architecture of communication which can be categorised in two ways. The first is that which is inherently meaningful (either consciously or unconsciously) to the participant (as a cultural grouping).

The anthropological term ‘emic’ can be applied here: ‘The emic approach investigates how local people think’ (Kottak, 2006). The second category, the ‘etic’ approach, is forged by the description of the scientific observer from the outside. The Merriam-Webster (2017) defines it as ‘of, relating to, or involving analysis of cultural phenomena from the perspective of one who does not participate in the culture being studied’. Sensory ethnography, it can be argued, blends these approaches, and in the case of this particular study, my personal experience of CCN, albeit removed from actual bodily experience, contributes to this blend. Nevertheless, it is a worthwhile exercise to find whatever distinctions might exist between participant communication experiences and researcher observations.

7.6 *Analysing the Architecture of Communication*

Emic data in relation to the architecture of communication was present in each interview, either as either indicated or described by the participant or through their (or their close support’s) use of such communication. It included indicators such as use of communication devices, communication prompts, key support workers’ use of AAC, the number of and type of electronic packages, internet and social media access, etc.

The etic data was drawn largely from my notes about my embodied experience of visiting participants in their homes and included the location of the person, the neighbourhood, the style and look of the home, and the décor and furniture in the home. These emic and etic indicators are tabled below. From recruitment through to the completion of interviews, I was actively sensing the architecture of communication. However, I was not conscious of all of this information at the time. The question of how each home works to facilitate communication or to ameliorate barriers to communication accompanied my sensory experience. Yet it was later, as I wrote reflections of my experience, typed transcripts and watched the videos of the interviews, that much of this detail revealed itself. The following indicators were created and, where possible, linked to theory, for example, the use of communication prompts in residential settings of people with dementia (Santo Pietro and Boczko, 1997). Using the information gathered by the study, the following indicators were developed to help inform the study of patterns of communication access for participants.

Table 4. Communication architecture: emic and etic communication indicators

Emic	Etic
Verbal communication – including dysarthric speech, single word utterances, etc.	*Information access*– other than TV (internet, word-of-mouth, friends/visitors/supports, radio, written material)
Participant attitude toward communication devices	*Conversation starters* – front yard (e.g. house design, paintwork, garden, statues, etc.)
Communication partners – number and quality of (e.g. family/friends/support familiar with participant's AAC/neighbours).	*Conversation (identity) starters* – inside the home (e.g. photographs, art, pets, décor, etc.)
AAC aids/prompts– in most/all rooms (e.g. calendars, symbols/icons/Post-it notes displayed, low- or high-tech devices at hand?)	*Furniture/settings for communication* –does the home accommodate visitors (e.g. private place to talk – not bedroom, couch, comfortable chairs, spare room, can offer tea/coffee/meals, etc.)?
Marks on paper – single words, letters, symbols, signature	*Key support person's attitude toward communication device*
Key support person's use of AAC – were the support people present able to communicate effectively with the participant?	
Phone access – including facilitated	
Internet access – email, Skype, etc.	
Social media access – is the participant connected to others via social media?	
Spiritual/God – prayer communication	
Communication with pets	

This is not a complete list, but it represents those noted and understood by me as the researcher of the study. Participants may add to this list. Furthermore, the list omits an assessment of the researcher's ability to communicate with the participant and likewise the researcher's assessment of her communication with the participant. Many of the indicators were also etic in that they were also observed or experienced by the researcher. For example, I observed Emma talking to her cat, from which she commented, 'I talk to him and he understands me'. However, insights such as communication with God, and participants' attitude to using communication devices, were only known due to participant disclosure.

The embodied experience of meeting with participants in their homes enabled some appreciation of these indicators of communication in the home, an assessment of which is described below (Table 5). This is a subjective assessment based upon my witnessing or learning of the items, interactions and emic and etic information provided during the interviews with the purpose being to apply a communication access analysis alongside these experiences of home.

This evaluation is limited by the number of occasions of being with the participant (no more than twice) and is therefore a snapshot. In relation to some of the communication indicators, ‘unknown’ is recorded when the indicator was not learned, but this does not necessarily mean that it does not exist. A reflection of the quality and/or intensity of the communication indicator is described by allocating a scale of H = high level, M = medium level, S = slight level, or N = not evident. Individuals within each case study were allocated a score against the communication access indicator. In the grouping of ‘Provisioned’, wherein there are only two participants, this score was doubled to reflect the grouping of four participants in each of the other case studies. The allocation of N (as distinct from Unknown) was provided when it was clear that the indicator does not exist in the home described. For example, regarding access to social media, ‘High’ was considered to be frequent/weekly or more access, ‘Medium’ was fortnightly through to a few times a year, and ‘Some’ indicated that they may have social media accounts, but do not access/maintain them very often.

Despite the limitations of this study, this analysis provides a verification of the patterns which emerged in findings and helped form the case studies. The following analysis was undertaken within the context of the three case studies, comparing the quality of indication across the ten participants, not with the general community. Each participant was given a score related to how strongly that particular indicator was evident during the interviews. For example, both participants from the case study ‘Provisioned’ scored ‘High’ for verbal communication, despite dysarthric speech (and the common, often extensive, experience of communication barriers). Yet the use of dysarthric sentences enabled greater communication access than one- or two-word utterances made in isolation. This was evident by 1) the participant choosing to use speech to answer questions (e.g. one of the participants who could speak one- or two-word utterances would often not speak – instead he would point to single-word symbols on his tray or indicate to his support worker to provide a detailed response to the question); and 2) through my receptive appreciation of what was being said. This indicator also illustrates the combined emic and etic nature of the analysis.

While the indicators were assessed individually, the overall assessment (frequency of scores) was analysed within the case study groupings. Because case study ‘Provisioned’ had only two and not four participants (as was the case with ‘Immured’ and ‘Suspended’), numerical comparison was limited; nevertheless it was still possible to appreciate patterns. For example, within ‘Provisioned’, there was a strikingly large number of ‘High’ indicators in comparison with ‘Immured’, even though the numbers of participants in ‘Provisioned’ was half that of ‘Immured’.

The scores for ‘Unknown’ and ‘Not Evident’ are important findings. Taking into consideration that the case study of ‘Provisioned’ had only two participants, the ‘Suspended’ and ‘Immured’ case studies reflect a disproportionately higher score for ‘Unknown’. From a research perspective, this suggests differences in the efficacy of the study across the groupings. Put simply, information was more readily obtained from some participants than others, and communication access was likely to be implicated in this outcome.

In relation to the ‘Not Evident’ scores there was a striking difference between the groups ‘Provisioned’ and ‘Suspended’ in comparison to the case study ‘Immured’, with ‘Provisioned’ scoring 0, ‘Suspended’ 5 and ‘Immured’ 20. ‘Not Evident’ scores differ from ‘Unknown’ in that there was evidence that these were not likely to be in place outside of the interview. Examples were communication starters outside and inside the home, and available computers (including accessible technology) in areas utilised by participants. This score indicated the extent of paucity of communication access for the participants of ‘Immured’.

Table 5. Comparative assessment of individual architecture/s of communication indicators. H = high level, M = medium level, S = slight level, N = not evident, U = unknown, and na = not applicable

Emic indicator	Provisioned 2 persons	Immured 4 persons	Suspended 4 persons
Verbal communication – dysarthric speech (M), single/two-word utterances (S)	M M	S S N N	N S S N
Communication partners present were effectively using AAC with participant	S na	M S S S	U x 4
Participant access to AAC if desired	H H	S M N U	M M S H

AAC aids/prompts	H S	N S M S	M M M H
Key support person’s use of AAC	H U	H M S U	H U x 3
Internet access	H H	N x 4	H N M S
Social media access	H H	N x 3 U	H N U U
Marks on paper – single words, letters, symbols, signature	H H	N N U U	N U H H
Information access	H H	U x 4	U U M M
Phone access	U U	N N S U	M M U U
Spiritual/God	M M	U x 4	U x 4
Communication with pets	H H	N N U U	M U x 3
Score	H = 14 N = 0 M = 4 U = 3 S = 2 na = 1	H = 1 N = 15 M = 4 U = 18 S = 10 na = 0	H = 7 N = 5 M = 11 U = 21 S = 4 na = 0
Etic indicator	**Provisioned 2 persons**	**Immured 4 persons**	**Suspended 4 persons**
Conversation starters outside	M H	N N S S	M H M S
Conversation starters inside	M M	S S N S	M M H M
Furniture/settings	M M	S S S N	M M M S
Support person’s positive attitude toward AAC	U U	S N U U	S H M S
Score	H = 1 N = 0 M = 5 U = 2 S = 0 na = 0	H = 0 N = 5 M = 0 U = 2 S = 7 na = 0	H = 3 N = 0 M = 9 U = 0 S = 4 na = 0
Combined score	**H = 15 N = 0 M = 9 U = 3 S = 2 na = 1**	**H = 1 N = 20 M = 4 U = 20 S = 17 na = 0**	**H = 10 N = 5 M = 20 U = 21 S = 8 na = 0**

7.7 *Case studies, communication and architecture*

What this study has demonstrated, albeit unintentionally, is that communication does not simply ‘just happen’. It is not necessarily a phenomenon that can be taken for granted. There are many powers and processes which affect the existence of communication which go well beyond the use of writing, speech or body language, or access to a phone. It was through the embodied experience of standing in the front yard and searching for a comment to ‘break the ice' with the person I was about to meet, that I realised that the power of communication can be contained in the story one's garden tells. This extended to the objects displayed in one's home, the style of clothing and the individuality of one's hairstyle, engagement with pets, the communication skills of the people surrounding them, and undoubtedly more factors which sit outside the learning of this study.

The results obtained reveal the marked differences in the architecture of communication across each case study. Furthermore, these results concur with the results of the interviews. 'Provisioned' afforded the closest alignment to the realisation of Nussbaum's (2006) capabilities, with 'Suspended' to a lesser extent, and 'Immured' receiving relatively low outcomes both in relation to Nussbaum's (2006) list and in the scoring of communication indicators. This provides another form of validation of my decision to follow the natural or organic data so as to create these three distinct case studies. From here it can also be posited that a tacit but powerful relationship exists between communication access and the attainment of capabilities for the participants interviewed. Without communication access, capabilities like social affiliation, control over one's environment, practical reason and bodily health have very little opportunity to flourish. With inadequate communication access, the pursuance of capabilities flounders.

CHAPTER EIGHT – WRANGLING ART NON FINITO

8.1 *The Strength and Limitation of Art as Scientific Conversation*

Art has provided more than a metaphor for this study; it has facilitated an opening into the participants' worlds. Together with sensory ethnography, it enabled a creative, interpretive and imbedded expression of the lived experience of both the participants and the 'researcher with participants'. Combined with the use of AAC and some traditional ethnographic questioning, the study was able to move outside the norm of the written and spoken word. As outlined in Patton (2002), art presents alternative criteria for judging the quality and credibility of qualitative inquiry. The collaged works 'Provisioned', 'Immured' and 'Suspended' captured the many complex themes from the interviews and allowed these to speak of core meanings of home. Of course, these stories could have been told without the images, but the collages tell of other, more subconscious qualities that may have not been told through text. For instance, the clean, ordered lines of the roster in the background of 'Immured' combine with the symbolism of medical/clinical blue; the anonymous figure with a shaved head offers a glimpse of how it was; the fisted hand represents the 'resistance' and 'defiance' meanings attributed to it by the participants, and re-enacts the movement made by a participant as he called out in anger. These collaged images sit below the architecture of communication as expressed in the passive, one-way communication of the television antenna.

Yet from a sensory ethnography perspective, visual art alone fails to reveal all the nuanced facets of the case study, such as the sound of the front screen door being repeatedly unlocked and locked, the hum of the television, the sharp edges of laminated communication symbols that scratch against writhing hands, the smell of disinfectant, the taste of tablets held in the mouth – not swallowed – the taste of loneliness.

The ethnographer's task is often not simply to represent, but to convince. She or he seeks to invite empathetic engagements, and in doing so to invoke a sense of intimacy and sympathy in the viewer/reader/user. This task involves not only engaging audiences in ways that enable their sense of knowing, in some embodied way, about what it was like to be with – or even to be – the people who participated in the research. It also involves a theoretical narrative through which this knowing informs scholarly knowledge, and that convinces an audience through an established form or method of intellectual argument (Pink, 2007, p. 153).

Reflexive practice in combination with sensory ethnography provided me permission to use what I know; the knowing of the participants 'stories, but also combining this with my own knowings and influences. Art theory was my introduction to philosophy. Before commencing a Master's degree and learning about Jurgen Habermas, I was intrigued by another German: Josef Beuys. He was an installation artist, sculptor, academic, humanist, political activist and philosopher. As with Habermas, I found myself on a local search to discover more about the art of Beuys, a person who pushed the boundaries of what constitutes art. Aesthetics was not the goal; art was a vehicle to express the conceptual. He declared everyone to be an artist and coined the term 'social sculpture' to encapsulate his anarchic approach to transforming society (Antliff, 2014). I could identify with this approach and his left-wing politics, and was fascinated by his use of symbolic objects and performance as art. Walters, in a 2012 biography of Beuys, quotes the artist:

> When I use language, I try to induce the impulses of this power … the power of evolution. But language is not to be understood simply in terms of speech and words. … Beyond language as verbalization lies a world of sound and form impulses, a language of primary sound without semantic content, but laden with completely different levels of information. (2012, p. 180)

In Dusseldorf in 1965 Beuys presented a performance art piece titled *How to Explain Pictures to Dead Hare* (Figure 69). It is described on the Art Gallery of NSW website (2016):

> The invited public arrived at the gallery to find the doors locked. Through the glass front of the gallery they saw Beuys sitting in a chair with his face covered in honey and gold leaf, cradling a dead hare in his arms. Slowly he got up and wandered around the exhibition, as if explaining each work to the hare.

Figure 69. Joseph Beuys' 1965 performance art piece titled 'How to Explain Pictures to Dead Hare'. Image has been removed due to copyright restrictions.

In August 2015, the findings of this study were exhibited as art works produced for this study, but there were many limitations. As stated in a blog article by a Flinders University journalist, '*The artworks in Betty-Jean Dee-Price's SALA exhibition don't set out to be pretty*' (Gent, 2015) (see Appendix A). The exhibition was conceptual, not aesthetically focussed. Yet art has remained a supportive adjunct to the study, not the radical protest, the disturbing voice that it could have been. Just as this thesis is primarily writing, the images in the exhibition were captioned or 'propped up' by words. The audience, arguably, was invited to think about communication. There was some evoking of the experiences of participants, and a display of the hand photographs and symbolism presented the themes. But rather than leading the viewer through an experiential process as I had imagined, the invitation could have ventured further. For instance, Pink (2007) reveals the need for researchers to convince audiences through the duel vehicles of an embodied sense of knowing and scholarly argument. From here it is possible to imagine the thesis transcending the containment of bounded pages, and instead contained by the rooms and walls of a gallery or a space or a 'home'. I can imagine visitors to the thesis, not flicking through chapters, but rather experiencing the movement between rooms and spaces, surrounded by the architectures of communication, of watching performance art, feeling, smelling, seeing, hearing an open fire, a television, a hair clipper humming its drone through parts, a diversity of beautiful threads being chopped for utility, smelling disinfectant, tasting wine in one room, having it not allowed in the next. But the reality of the exhibition was a predictable arrangement of frames with images, captions, speeches and university posters. In its own way the ‘conforming’ (written) thesis alongside the ‘shortfalls’ of the attempt to present findings in a non-traditional manner has reinforced the compelling power of written and spoken communication.

8.2 *Necessity, Invention and Method*

The power of written and spoken communication, however, was challenged in the methods developed by the study. The video material from the interviews reveals many quiet periods where a participant was engaged in silent contemplation of the images and choices before them; where answers were selected from communication devices, icons selected, buttons pressed, eyes were directing their communication partner towards pictorial messages, heads were turned up to the ceiling to say ‘I don’t know’.

Methodological findings were a major outcome of the study. There were significant barriers particularly in relation to gaps in prior research and the methodological challenges of gathering data from people without the assumed resource and ‘norm’ of written and spoken words. This made it necessary to move outside common research practices and look for alternative options. Overcoming communication barriers to find accessible methods, therefore, became as much a part of the study as the original intent to learn about the meaning of home for people with CCN. Sensory ethnography, as both method and methodology, opened a doorway into other forms of knowing; experience, not from listening to and recording someone’s verbal account, but through the sensory information gathered in being present in the space/world of the participant. Combining sensory ethnography with AAC and visual research methods such as photo elicitation, and linking these to broad choices, enabled opportunities for learning about the experiences of a diverse group of people with CCN. Important too was the embracing of the varied forms of AAC used by participants, beginning with such things as the way in which each person conveys ‘yes’ and ‘no’, when and how they direct support from a communication assistant, and how they operate AAC devices. This enabled more detail to emerge about the choices made by participants.

The hand images provided a way to capture the relationship between the participants' homes and their experience of Nussbaum's capabilities (2006). These images appeared to resonate very well with participants both in using them to indicate their experiences of home, and also in their feedback. It is not entirely known why the hand images were successful, and whether or not different types of images would work. Further investigation is needed to understand this and to determine the capacity of these types of images to work with different research questions, as well as their ability to be adapted to different theories, not just Nussbaum's capabilities (2006). My sense is that this is highly likely to be due to the seemingly endless arrangement of hand shapes and gestures (along with the addition of simple props) that can be created. This type of method would require the researcher's ability to translate aspects of theory into single images; however, with further studies and more examples, this process will be better supported. In the current study, this translation of theory into images was done loosely so as to allow different or more individualised interpretations of capabilities. In other research, these images may be required to be more directly representational of, for example, Nussbaum's capabilities (2006) or other types of theoretical positioning.

The Talking Mat, as both a research tool and communication device, contributed to the study in such a way as it is now difficult to imagine conducting any human research, particularly within the field of disability, without a device such as this. Currently there are no guidelines, ethical standards or legislation compelling research practice to make these types of supports available to the community.

8.3 *The Relationship between Communication and Home*

Chapter One introduced the framework of the study and the importance of communication as part of daily life and central to human function (Threats, 2010).

> Having an effective communication system influences the success of our personal interactions, our involvement in activities, and our ability to make decisions. These can range from everyday decisions, such as which shirt to wear, to life-changing decisions, such as where to live. (Queensland Department of Communities, Child Safety and Disability Services, 2009, pp. 3–4)

Chapter One also described some of the nuanced textures of CCN, and its relative absence within the disability justice debate, and in the discourses surrounding disability housing issues in Australia.

Theories of home were described in Chapter Two, with ‘home’ being central to such human needs as identity, safety, power and control, and social connection, all of which dovetail with Nussbaum’s list of capabilities (2006) in understanding what is necessary for a good life. Communication determines how well one might access these qualities of a good home and live a valued life. Closely related to this is the Habermasian lifeworld of private discourse, imbedded in and feeding into the public sphere of a rationality-building society.

It is evident from the disparity of the case studies, reinforced by the findings about the architecture of communication surrounding the individual case studies, that a significant relationship exists between communication access and living in a home which supports the development of capabilities. What is unclear, at this point, is how this influence manifests. Is it the home which supports communication access, or the creation of communication access which helps individuals to identify, advocate, shape and meet their needs? Further research is required to unravel these types of questions.

There were other important findings, such as the secondary analysis of ABS data which showed the prevalence of people with CCN residing in residential care settings, which not only informed the study, but coincided with the major findings. All of the people living in the three residential settings that I visited (including people who were not participants of the study) had CCN. This requires further investigation; however, at this early point it would appear that there is a relationship between CCN and being ‘housed’ in formal care settings such as group homes. The implications of this are considerable, potentially affecting a range of areas across tiers of disability housing. It raises questions such as: who is responsible for ensuring that communication access is effectively established in residential settings? This is particularly important in the context of constant changes in support staff, as was described by Afford (2009, p. 183). What are the training needs of staff? How is AAC established to best support participation in the broader community? Further still, if communication access was improved, would people with CCN still need to be cared for in residential settings such as group or nursing homes?

Returning to the question that was asked of participants: where do you feel most at home using AAC? The list of responses is, once again, displayed below. Only six of the ten participants answered the question, with five of those responses locating home as primarily/mostly the place where they felt most at home, and three of the responses suggesting that home is close to the only place in which they feel comfortable using AAC.

- At home.
- Wherever my crazy self can communicate and connect with others. I can do this in a lot of places.
- At home, at church, with friends of parents, with siblings and at the football. [L uses little formal AAC and so the question was modified to ask where he feels ‘at home’ communicating with others].
- Did not wish to answer this question.
- Don’t know.
- Don’t know.
- Did not answer this question [fatigue].
- At home, on the internet and with people who know me. Have quite a lot of friends, I get out but there are often problems [made an earlier note about people often asking to speak to her ‘carer’ rather than her].
- Indicated a very small circle – suggesting ‘home’ and in therapy sessions, including a local rehabilitation hospital.
- Mostly just home.

These responses suggested a significant containment or restriction of the participants’ communication – limiting their participation and ‘voice’ to the private sphere and significantly diminishing access to the capabilities that Nussbaum (2006) outlines. To select just one facet of a capability (capability 10, control over one’s environment, and the right to employment), without communicatively accessible and flexible workplaces as well as communicatively accessible processes of job advertising, recruitment and interviewing, it is difficult to imagine how people with CCN might share their knowledge and skills. With a communication that is either silenced (as in many aspects of the case study ‘Immured’), diminished, mediated by others (as was discovered in parts of ‘Suspended’), or not adequately supported in the public sphere (such as in employment), as was evident in all of the case studies, home risks becoming ‘the small world of everything’. The constant hum of the television is no longer surprising in this ‘small world of everything’ because it provides a connection to the outside world, albeit one deficient in the realisation of f Nussbaum's capabilities (2006).

8.4 *Non Finito*

A conclusion, in some sense, is like the artist who steps back from the canvas for the last time, drops the brush into the water and declares the work finished. Perhaps there is relief, satisfaction, and a sense of completeness. Alternatively, the work may be left *non finito* – an unfinished work, unresolved and open-ended. This study is a little of both; there are clear findings, but in concluding there is also a great sense of the unknown and unresolved.

The study contributes a variety of findings of potential value to the fields of sociology, disability and housing. This included discoveries obtained through the gathering of literature and background information, the estrangement of persons with CCN from research participation, and the relationship between formal residential settings (group homes, nursing homes, etc.) and people with CCN as indicated through a secondary analysis of ABS data.

The study was required to create a type of 'fork in the road of inquiry' by dovetailing an investigation of methodology and methods alongside the core theme of meaning of home. This resulted in several discoveries. Sensory ethnography AAC could be integrated as both communication tool and method. A mixed-methods approach of adapted visual research methods combined with AAC, and guided by sensory ethnography, provided a successful alternative to interviewing people. Deeply insightful, accountable, demonstrable and often detailed information was obtained using these methods. The hand images provided an effective way to capture Nussbaum's capabilities (2006) and core aspects of home theory without the need for verbal or written communication.

Arguably, my lived experience and training in AAC was critical to the orchestration, and moreover the application, of these methods. Yet, like any other social phenomenon, one does not need to directly experience it in order to integrate it into one's world of skill and knowledge. However, it does require enough understanding to enable researchers to be willing to reach beyond an established realm of comfort. Researcher training in CCN and AAC is likely to be a critical component in future research, with the resource cupboard of sociology including tools such as the Talking Mat. Important too is the tenacious heart and mind of the 'person researcher' in pursuing 'knowing' through different corridors.

The meaning of home for the ten people interviewed highlighted many themes which could be analysed within three core case studies, ‘Immured’, ‘Suspended’ and ‘Provisioned’. Within each of these case studies there are clear parallels between the living of home and the living of Nussbaum’s capabilities (2006). Furthermore, communication access can be broken down into multiple pieces of architecture, which support each human being in their connection to the world, and these pieces of architecture can be analysed for their presence and quality.

Although the study questions were answered, many more questions arose along the way. These were home and housing-related questions such as why there is a relationship between CCN and residential care settings, and what the implications might be for communication access in different types of home settings. This brings to mind the role of housing across multiple roles (policy, research, management, landlord) in the building of communication architecture in homes (and other) settings. It also brings to mind the significance of health and allied health services, amongst other community supports and services, to ensure communicatively competent (accessible) service delivery.

The study outcomes beckon further inquiry into the field of sociological research. This include methodological questions such as: How might methods be adapted to ensure the participation of people with CCN and vision impairment? Why were the hand images so successful? Could these research methods be applied across different fields of qualitative research? Or in reverse by researchers with CCN? Further methodological testing is required to answer these questions and to promote greater inclusive research practice(s).

The need for further investigation of the ‘architecture of communication’ as an idea and concept has also arisen from this study. Not only does this hold implications for services across different settings to understand and improve the dynamism of communication access for many people with CCN, but there is an impetus to consider how all people may indeed benefit from a conscious awareness of communication as architecture.

These questions paint a picture of an unfinished study.

References

Abercrombie, N., Hill, S. and Turner, B. (2006). *The Penguin dictionary of sociology*. London: Penguin.

ABS (Australian Bureau of Statistics) (2012) *Disability, Ageing and Carers Survey*, Australia, Cat. No. 4430.0.

ABS (Australian Bureau of Statistics) (2009a) Disability, *Ageing and Carers Survey*, Australia, Cat. No. 4430.0.

ABS (Australian Bureau of Statistics) (2003) *Disability, Ageing and Carers Survey*, Australia, Cat. No. 4430.0.

ABS (Australian Bureau of Statistics) (2009b) *Disability, Ageing and Carers Survey User Guide,* Australia, Cat. No. 4430.0.

ABS (Australian Bureau of Statistics) (2012) *Disability, Ageing and Carers, Australia: Summary of Findings,* Australia, Cat. No. 4430.0.

Afford, D.J. (2013) *My life on wheels*. 2nd edn.

AGOSCI (2009) *Home*. Available at: https://agosci.wildapricot.org/ (Accessed: 1 February 2017).

Alm, N., Dye, R., Gowans, G., Campbell, J., Astell, A., & Ellis, M. (2007). A Communication Support System for Older People with Dementia. *Computer*, *40*(5), 35-41.

Alston, M. and Bowles, W. (2012) *Research for social workers: An introduction to methods*. 3rd edn. Canberra, ACT, Australia: Allen & Unwin.

American Speech-Language-Hearing Association (1997) *Audiologists*. Available at: http://www.asha.org/ (Accessed: 1 February 2017).

Angry Cripple Column, Ramp Up, 10 Aug 2011, Australian Broadcasting Commission (ABC).

Apel, K.-O. (1999) *The response of discourse ethics to the moral challenge of the human situation as such and especially today: (Mercier lectures, Louvain-la-Neuve, march 1999)*. Leuven: Peeters Pub & Booksellers.

Arild Holt-Jensen (1999). Geography. History and Concepts: A Student's Guide (fourth edition). *Singapore Journal of Tropical Geography*, *32*(2), 267-268. http://dx.doi.org/10.1111/j.1467-9493.2011.00425.x

Arthurson, K., Worland, P., & Cameron, H. (2007) A Place to Call My Own: Identifying Best Practice in Housing and Mental Health, State of Australian Cities National Conference 2007, Adelaide, South Australia

Australian Government, Disability Discrimination Act 1992, *Federal Register of Legislation.*

Australian Government, Productivity Commission (2011). *Disability Care and Support*, No. 54, Inquiry Report Volume 1.

Baker, K., Carrillo, D. and Stanton, F. (2011) ‘200 A day the easy way: Putting it into practice’, *Perspectives on Augmentative and Alternative Communication*, 20(4), p. 125. doi: 10.1044/aac20.4.125.

Balandin, S. (2002) ‘Message from the President’. *The ISAAC Bulletin, 67,* p. 2

Balandin, S., Hemsley, B., Sigafoos, J. and Green, V. (2007) ‘Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs’, *Applied Nursing Research*, 20(2), pp. 56–62. doi: 10.1016/j.apnr.2006.03.001.

Ballin, L. and Balandin, S. (2007) ‘An exploration of loneliness: Communication and the social networks of older people with cerebral palsy’, *Journal of Intellectual and Developmental Disability*, 32(4), pp. 315–326. doi: 10.1080/13668250701689256.

Banks, M. (2001). *Visual Methods in Social Research.* London. Sage.

Barnes, C., Mercer, G. (1999) *Exploring disability: A sociological introduction.* Polity Press.

Barton, L. (2005) ‘Emancipatory research and disabled people: Some observations and questions’, *Educational Review*, 57(3), pp. 317–327. doi: 10.1080/00131910500149325.

Batterbury S (2012) Language justice for sign language peoples: the UN Convention on the Rights of Persons with Disabilities. *Language Policy.* 11(3) 253-272

Batterbury S (2007) Sign Language Peoples as indigenous minorities: implications for research and policy. *Environment and Planning* 39, 2899-2915.

Baum, F. (1999) ‘Social capital: Is it good for your health? Issues for a public health agenda’, *Journal of Epidemiology & Community Health*, 53(4), pp. 195–196. doi: 10.1136/jech.53.4.195.
Baum F, MacDougall C, Smith D. (2006) Participatory action research. *Journal of Epidemiology & Community Health* 2006;**60:**854-857.

Beer, A. Faulkner, D. (2009) The housing careers of people with disabilities and their carers. *AHURI - Research and Policy Bulletin. Issue 107.*

Beer, A. Faulkner, D. Gabriel, M. (2006) *21st century housing careers and Australia’s housing future: Literature review*. National research venture 2, research paper 1. Australian Housing and Urban Research Institute.

Bell, D.S. (2009) ‘The Sage Encyclopedia of qualitative research methods’ In Lisa M. Given. The Sage Encyclopedia of qualitative research methods. Thousand Oaks, CA: Sage Publications 2008.

Bendix, R. (2000) The Pleasures of the Ear: Toward and Ethnography of Listening. *Cultural Analysis,* Vol 1.

Beukelman, D.R. and Mirenda, P. (2012) *Augmentative and alternative communication: Supporting children and adults with complex communication needs*. 4th edn. Baltimore: Brookes Publishing Co.

Beukelman, D.R. and Mirenda, P. (1998) *Augmentative and alternative communication: Management of severe communication disorders in children and adults*. 2nd edn. Baltimore, MD: Brookes Publishing Co.

Bigby, C., & Beadle-Brown, J. (2016). Culture in Better Group Homes for People With Intellectual Disability at Severe Levels. *Intellectual And Developmental Disabilities, 54*(5), 316-331.

Bigby, C., Bould, E., & Beadle-Brown, J. (2016). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 1-11. http://dx.doi.org/10.3109/13668250.2016.1253051

Bigby, C., Frawley, P. and Ramcharan, P. (2013). Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities,* 27(1), pp.3-12.

Bigby, C. and Frawley, P. (2010). Reflections on doing inclusive research in the "Making Life Good in the Community" study. *Journal of Intellectual & Developmental Disability,* 35(2), pp.53-61.

Blackstone, S., Williams, M., & Wilkins, D. (2007). Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication*, *23*(3), 191-203. ://dx.doi.org/10.1080/07434610701553684

Bornman, J., & Bryen, D. (2013). Social Validation of Vocabulary Selection: Ensuring Stakeholder Relevance. *Augmentative and Alternative Communication*, *29*(2), 174-181.

Bryen D-Na Cohen K Ja Carey A (2004) Augmentative communication employment training and supports (ACETS) Some employment related outcomes. *Journal of Rehabilitation* 70(1): 10–19.

Bleasdale, M. (2006). Supporting the housing of people with complex needs. *Australian Housing and Urban Research Institute (AHURI).* Positioning paper No. 89

Boczko, F., & Santo Pietro, M. (1997). *The COMFI Scale: Communication Outcome Measure of Functional Independence*. Speech Bin.

Bostock, L., Gleeson, B., McPherson, A. and Pang, L. (2004) 'Contested housing landscapes? Social inclusion, Deinstitutionalisation and housing policy in Australia', *Australian Journal of Social Issues*, 39(1), pp. 41–62. doi: 10.1002/j.1839-4655.2004.tb01162.x.

Bridge, C. Kendig, H. Quine, S. Parsons A. (2002). *Housing and care for younger and older adults with disabilities*. Australian Housing and Urban Research Institute. Sydney Research Centre.

Brown, C. (1999) *My left foot*. Cyprus: Burlington Books.

Bryen, D. Carey, A. Frantz, B. (2003) 'Ending the Silence: Adults who Use Augmentative Communication and their Experiences as Victims of Crimes'. *Augmentative and Alternative Communication* 19(2), 125-134.

Bryen D-N, Cohen K J, Carey A (2004) Augmentative communication employment training and supports (ACETS) Some employment related outcomes. *Journal of Rehabilitation* 70(1): 10–19.

Butler, T. and Robson, G. (2001) 'Social capital, Gentrification and neighbourhood change in London: A comparison of Three south London Neighbourhoods', *Urban Studies*, 38(12), pp. 2145–2162. doi: 10.1080/00420980120087090.

Carbaugh, D., & Boromisza-Habashi, D. (2015). ‘The Ethnography of Communication’. In *The International Encyclopedia of Language and Social Interaction*, Edited by Tracy, K. Sandel, T, Ilie, C..

Caron, J., & Light, J. (2015). ‘“Social Media has Opened a World of ‘Open communication”: experiences of Adults with Cerebral Palsy who use Augmentative and Alternative Communication and Social Media’. *Augmentative and Alternative Communication, 32*(1), 25-40.

Carlson, F. (1981). A Format for Selecting Vocabulary for the Nonspeaking Child. *Language Speech And Hearing Services In Schools*, *12*(4), 240. http://dx.doi.org/10.1044/0161-1461.1204.240

Cascella, P.W. and Aliotta, F. (2014) ‘Strategies to enhance the informed consent process for communication disorders researchers’, *Communication Disorders Quarterly*, 35(4), pp. 248–251. doi: 10.1177/1525740114524589.

Castrodale, M., & Crooks, V. (2010). The production of disability research in human geography: an introspective examination. *Disability & Society*, *25*(1), 89-102.

Chew, Ka Lip; Iacini, T., Tracy J. (2009) Overcoming Communication Barriers: Working with Patients with Intellectual Disabilities. *Australian Family Physician* 38(1/2)

Clapham, D. (2005). *The meaning of housing*. Bristol: The Policy Press.

Clapton, J. (2009). *A tranformatory ethic on inclusion*. Rotterdam: Sense Publishers.

Clifford, S. (2011) ‘Making disability public in deliberative democracy’, *Contemporary Political Theory*, 11(2), pp. 211–228. doi: 10.1057/cpt.2011.11.

Cohen, K., Bryen, D. and Carey, A. (2003) ‘Augmentative communication employment training and supports (ACETS)’, *Augmentative and Alternative Communication*, 19(3), pp. 199–206. doi: 10.1080/07434610310001595678.

Collier, B., Blackstone, S.W. and Taylor, A. (2012) ‘Communication access to businesses and organizations for people with complex communication needs’, *Augmentative and Alternative Communication*, 28(4), pp. 205–218. doi: 10.3109/07434618.2012.732611.

Collier, B., McGhie-Richmond, D. and Self, H. (2010) ‘Exploring communication assistants as an option for increasing communication access to communities for people who use Augmentative communication’, *Augmentative and Alternative Communication*, 26(1), pp. 48–59. doi: 10.3109/07434610903561498

Commonwealth of Australia (2014). Senate Inquiry, Community Affairs References Committee. *Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia*. Report.

Commonwealth of Australia. National People with Disabilities and Carer Council. (2009). *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*. National Disability Strategy Consultation Report.

Commonwealth of Australia. *Disability Services Act* (1986).

Crossley, R. and McDonald, A. (1980) *Annie’s coming out*. United Kingdom: Penguin Books.

Davidmeme (2007) *Jürgen Habermas interview*. Available at: https://youtu.be/jBl6ALNh18Q.

Davis, A. (1989). *From where I sit*. London: Triangle.

Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) (2007). Social Policy Research Centre, UNSW.

Dietz, A., Hux, K., McKelvey, M.L., Beukelman, D.R. and Weissling, K. (2009) 'Reading comprehension by people with chronic aphasia: A comparison of three levels of visuographic contextual support', *Aphasiology*, 23(7-8), pp. 1053–1064. doi: 10.1080/02687030802635832.

Duchan, J.F. (2006) 'Providing a place in the new history of disabilities for communication access', *Disability Studies Quarterly*, 26(2). doi: 10.18061/dsq.v26i2.675.

Earle, Sarah (2003) 'Disability and stigma: an unequal life'. *Speech & Language Therapy in Practice* pp. 21–22.

Emerson, E., Madden, R., Graham, H., Llewellyn, G., Hatton, C. and Robertson, J. (2011) 'The health of disabled people and the social determinants of health', *Public Health*, 125(3), pp. 145–147. doi: 10.1016/j.puhe.2010.11.003.

Epstein, I., Stevens, B., McKeever, P., Baruchel, S. (2006) Photo Elicitation Interview (PEI): Using Photos to Elicit Children's Perspectives. *International Journal of Qualitative Methods* 5 (3).

Finkelstein, V. (1993) Disability: An Administrative Challenge? In Swain, J., French, S., Barnes, C., & Thomas, C. *Disabling barriers – enabling environments*.

Fine, M. (2005). Individualization, risk and the body. *Journal of Sociology*, *41*(3), 247-266. http://dx.doi.org/10.1177/1440783305057077

Flynn, R.J. and Nitsch, K.E. (1980) 'Normalization, social integration and community services', *International Journal of Rehabilitation Research*, 3(4), p. 605. doi: 10.1097/00004356-198012000-00031.

Forster, S. and Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual & Developmental Disability*, 33(2), pp.137-147.

Foucault, M. (1973) *The order of things: An archaeology of the human sciences*. New York: Vintage Books USA.

Fox, L. (2007). *Conceptualising home: theories, laws and policies*. Portland, or: Hart.

Frankl, V.E. (1997) *Man's search for meaning*. New York: Washington Square Press.

Fried-Oken, M., Beukelman, D.R. and Hux, K. (no date) 'Current and future AAC research considerations for adults with acquired cognitive and communication Impairments', 24(1).

Gent, C. (2015). Home truths from people without voices. *In Daily*, Adelaide's Independent News. Flinders University.

Gleeson, B. (2000) 'Disability, geography and ethics', *Philosophy & Geography*, 3(1), pp. 65–70. doi: 10.1080/13668790008573695.

Glennen, C. (2014) ‘Valid States of Inclusion’. Presentation. Community Housing Industry Association.

Goggin, G. (2014). Communication rights and disability online: Policy and technology after the World Summit on the Information Society. *Information, Communication & Society,* 18(3), pp.327-341.

Goggin, G. and Newell, C.J. (2004) *Disability in Australia: Exposing a social apartheid*. Sydney: NewSouth Publishing.

Government of South Australia, *Disability Justice Plan 2014-2017*. Prepared by the Attorney General’s Department.

Goyen, W. (1975) *The house of breath*. 2nd edn. New York: Random House Trade.

Grbich, C. (1998) *Qualitative research in health: An introduction*. Sydney, Australia: Allen & Unwin.

Gunter, T.C. and Bach, P. (2004) ‘Communicating hands: ERPs elicited by meaningful symbolic hand postures’, *Neuroscience Letters*, 372(1-2), pp. 52–56. doi: 10.1016/j.neulet.2004.09.011.

Habermas, J. (1990). *Moral Consciousness and Communicative Action*. Cambridge, UK: Polity Press

Habermas, J. (1984). *The Theory of Communicative Action. Vol. 1: Reason and the Rationalization of Society*. Cambridge, UK: Polity Press

Habermas, J. (1987). *The Theory of Communicative Action. Vol. 2: The Critique of Functionalist Reason*. Cambridge, UK: Polity Press.

Habermas, J. (1970) ‘Towards a theory of communicative competence’, *Inquiry*, 13(1-4), pp. 360–375. doi: 10.1080/00201747008601597.

Hallahan, L. (2016). Disability policy in Australia: a triumph of the scriptio inferior on impotence and neediness? *Australian Journal of Social Issues*, *50*(2), 191-208.

Hallberg, L., Mellgren, E., Hartelius, L., & Ferm, U. (2011). Talking Mats in a discussion group for people with Huntington’s disease. *Disability and Rehabilitation: Assistive Technology*, *8*(1), 67-76.

Hanagan, K. (1992) ‘Let’s keep real AAC users in studies about AAC users: Comments on Doss et al. (1991)’, *Augmentative and Alternative Communication*, 8(3), pp. 251–251. doi: 10.1080/07434619212331276243.

Harnacke, C. (2013). Disability and Capability: Exploring the Usefulness of Martha Nussbaum’s Capabilities Approach for the UN Disability Rights Convention. *The Journal of Law, Medicine & Ethics*, *41*(4), 768-780. http://dx.doi.org/10.1111/jlme.12088

Harper, D. (2002) ‘Talking about pictures: A case for photo elicitation’, *Visual Studies*, 17(1), pp. 13–26. doi: 10.1080/14725860220137345.

Hauge, A. L. (2007) ‘Identity and place: a critical comparison of three identity theories’, *Architectural Science Review.*

Hauschild, B. M. (1998) *Revealing the hidden city*. (1999). Adelaide.

Hemer, S. R and Dundon, A. (2016). *Emotions, Senses, Spaces*. University of Adelaide Barr Smith Press.

Hemphill, E. and Kulik, C. (2016). Shaping attitudes to disability employment with a national disability insurance scheme. *Australian Journal of Social Issues*, 51(3), pp.299-316.

Hemsley, B., Balandin, S., & Togher, L. (2008). 'I've Got Something to Say': Interaction in a Focus Group of Adults with Cerebral Palsy and Complex Communication Needs. *Augmentative and Alternative Communication*, *24*(2), 110-122. http://dx.doi.org/10.1080/07434610701830579

Henman, P. and Foster, M. (2015) 'Models of disability support governance: A framework for assessing and reforming social policy', *Australian Journal of Social Issues*, 50(3), pp. 233–252. doi: 10.1002/j.1839-4655.2015.tb00348.x.

Hepworth, D.H., Rooney, R.H. and Larsen, J.A. (2001) *Direct social work practice: Theory and skills*. 6th edn. United States: Brooks/Cole-Thomson Learning.

Hermant, D. (2016). 'The National Disability Insurance Scheme (NDIS) faces a huge shortfall in disability housing when it is fully rolled out in 2020'. *ABC News Website*.

Hidecker, M.J.C., Paneth, N., Rosenbaum, P.L., Kent, R.D., Lillie, J., Eulenberg, J.B., Chester JR, K., Johnson, B., Michelsen, L., Evatt, M. and Taylor, K. (2011) 'Developing and validating the communication function classification system for individuals with cerebral palsy', *Developmental Medicine & Child Neurology*, 53(8), pp. 704–710. doi: 10.1111/j.1469-8749.2011.03996.x.

Higginbotham, D.J. and Wilkins, D.P. (1999). Slipping through the timestream: Time and timing issues in augmentative communication. In J. Duchan, D. Kovarsky & M. Maxwell (eds.), *The social construction of language incompetence,* Lawrence Ehrlbaum Publisher. pp 49 – 82.

Hodge, S. (2007) 'Why is the potential of augmentative and alternative communication not being realized? Exploring the experiences of people who use communication aids', *Disability & Society*, 22(5), pp. 457–471. doi: 10.1080/09687590701427552.

Housing, A. and Institute, U.R. (2016) *Australian housing and urban research institute*. Available at: http://www.ahuri.edu.au/ (Accessed: 2 February 2017).

Howes, D. (2005) *Empire of the Senses: The sensual Culture Reader.* Oxford.

Hymes, D.H. (1966). 'Two types of linguistic relativity'. In Bright, W. *Sociolinguistics*. The Hague: Mouton. pp. 114–158.

Ignatieff, M. and Ignatieff, M. (1994) *The needs of strangers*. London: Vintage Books.

Imrie, R. (2004) 'Housing quality, disability and domesticity', *Housing Studies*, 19(5), pp. 685–690. doi: 10.1080/0267303042000249143.

Imrie, R. and Edwards, C. (2007) 'The Geographies of disability: Reflections on the development of a sub-discipline', *Geography Compass*, 1(3), pp. 623–640. doi: 10.1111/j.1749-8198.2007.00032.x.

Iacono, T., Balandin, S., & Cupples, L. (2001). Focus group discussions of literacy assessment and world wide web-based reading intervention. *Augmentative and Alternative Communication*, *17*(1), 27-36. http://dx.doi.org/10.1080/aac.17.1.27.36Irigaray, L. (2004).

International Society for Augmentative and Alternative Communication (2011) *ISAAC – home*. Available at: https://www.isaac-online.org/english/home/ (Accessed: 1 February 2017).

Introduction to Kate and the unspoken project (2015) Directed by Kate Caryer.

Irigaray, L. London: Continuum.

Ison, N.L. (2009) 'Having their say: Email interviews for research data collection with people who have verbal communication impairment', *International Journal of Social Research Methodology*, 12(2), pp. 161–172. doi: 10.1080/13645570902752365.

ISAAC (2009) Factsheet on Accessibility for People with Communication Disabilities, developed by Barbara Collier and Sarah Blackstone

Jackson, M. (2011). Cluster housing a valid choice for people with disabilities

Johnson, G., Natalier, K., Mendes, P., Liddiard, M., Thoresen, S., Hollows, A., & Bailey, N. (2010). *Pathways from out-of-home-care* (AHURI Final Report No. 147). Melbourne: Australian Housing and Urban Research Institute

Thomas, P. N. (2011) Negotiating communication rights: Case studies from IndiaThomasPradip Ninan, Negotiating communication rights: Case studies from India. New Delhi: Sage, 2011, 284 pp., ISBN: 9788132106364. *Global Media and Communication*, 8(2), pp.187-188.

Keane, J. (1995). Structural transformations of the public sphere. *The Communication Review*, *1*(1), 1-22. http://dx.doi.org/10.1080/10714429509388247

Kellner, D. and Habermas, J. (1992) 'Moral consciousness and communicative action', *Contemporary Sociology*, 21(2), p. 278. doi: 10.2307/2075511.

Krey, P. (2004) Habermas' Life-World and the Two Systems Expanded. Scholardarity website (Peter Krey): Available at https://peterkrey.wordpress.com/2007/07/27/habermas-life-world-and-the-two-systems-expanded-nov-8-2004/. (Accessed 6th July 2017).

Khader, S. (2008). 'Cognitive Disability, Capabilities, and Justice,' *Essays in Philosophy*, 9(1), Article 1.

Kittay, E. F. (2011). The Ethics of Care, Dependence, and Disability. *Ratio Juris*, *24*(1), 49-58. http://dx.doi.org/10.1111/j.1467-9337.2010.00473.x

Kittay, E.F. (2009) 'The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield', *Metaphilosophy*, 40(3-4), pp. 606–627. doi: 10.1111/j.1467-9973.2009.01600.x.

Kottak, Conrad. (2006), *Mirror for Humanity*, New York, NY: McGraw Hill.

Krogh, K., & Lindsay, P. (1999). Including people with disabilities in research: implications for the field of augmentative and alternative communication. *Augmentative and Alternative Communication*, *15*(4), 222-233. http://dx.doi.org/10.1080/07434619912331278765

Lapenta, F. (2011) 'Some theoretical and methodological views on photo elicitation'. In *The SAGE Handbook of Visual Research Methods*. SAGE, pp. 201-213.

Levin, K. (2013). *The Communicative Participation of Adults with Cerebral Palsy*. PhD, Stellenbosch University.

Levitas, R. (1998). *The inclusive society?* Basingstoke: Palgrave Macmillan.

Liamputtong, P. (2007) *Researching the vulnerable: A guide to sensitive research methods*. London: Sage Publications.

Light, J. (1989) 'Toward a definition of communicative competence for individuals using augmentative and alternative communication systems', *Augmentative and Alternative Communication*, 5(2), pp. 137–144. doi: 10.1080/07434618912331275126.

Light, J. (1997) '"Communication is the essence of human life": Reflections on communicative competence', *Augmentative and Alternative Communication,* 13(2), pp. 61–70. doi: 10.1080/07434619712331277848.

Light, J. and McNaughton, D. (2014) 'Communicative competence for individuals who require Augmentative and alternative communication: A new definition for a new era of communication?', *Augmentative and Alternative Communication*, 30(1), pp. 1–18. doi: 10.3109/07434618.2014.885080.

LLC2017StataCorp (1996) *Data analysis and statistical software*. Available at: http://www.stata.com/ (Accessed: 1 February 2017).

Lloyd, V., Gatherer, A. and Kalsy, S. (2006) 'Conducting qualitative interview research with people with expressive language difficulties', *Qualitative Health Research*, 16(10), pp. 1386–1404. doi: 10.1177/1049732306293846.

Mackay, M & Murphy, J. (2017) Will anyone listen to us?: What matters to young people with complex and exceptional health needs and their families during health transitions. *Communication Matters Journal 31*(1) 23-25.

Mallett, S. (2002). Understanding Home: A Critical Review of the Literature. *The Sociological Review*, *52*(1), 62-89. http://dx.doi.org/10.1111/j.1467-954x.2004.00442.x

Manzi, T. (2005) 'Fact and fiction in housing research: Utilizing the creative imagination', *Housing, Theory and Society*, 22(3), pp. 113–128. doi: 10.1080/14036090510011595.

McCarthy, T. (1984). *The critical theory of Jurgen Habermas*. Cambridge: Polity.

McDonald, A. (1992)

McIntyre, A. (2008). *Participatory action research*. Los Angeles: Sage Publications.

McLoughlin, P. and Tually, S. (2012) *Being a Social Landlord in the 21st Century: Insights from Tenant and International Experience. Final Report*. Centre for Housing, Urban and Regional Planning (CHURP), Adelaide.

McMahon, J. (1996) Cognitive Disability, Misfortune, and Justice. *Philosophy and Public Affairs,* 25(1) pp. 3-35.

McNaughton Nicholls, C. (2010). Housing, Homelessness and Capabilities. *Housing, Theory and Society*, *27*(1), 23-41. http://dx.doi.org/10.1080/14036090902764588

McVilly, K. (1997). Residential Staff: How They View Their Training and Professional Support. *British Journal of Learning Disabilities*, *25*(1), 18-25. http://dx.doi.org/10.1111/j.1468-3156.1997.tb00004.x

Merleau-Ponty, M., Smith, C.J. and Smith (1981) *Phenomenology of perception*. London: Humanities Press International.

Midtlin, H., Næss, K., Taxt, T., & Karlsen, A. (2014). What communication strategies do AAC users want their communication partners to use? A preliminary study. *Disability and Rehabilitation*, *37*(14), 1260-1267.

Miles, M. (2011) ‘The “Social Model of Disability” Met a Narrative of (In)Credulity: A Review’, *Disability, CBR & Inclusive Development,* 22(1). doi: 10.5463/dcid.v22i1.14.

Mohnen, S., Groenewegen, P., Völker, B., & Flap, H. (2011). Neighborhood social capital and individual health. *Social Science & Medicine*, *72*(5), 660-667. http://dx.doi.org/10.1016/j.socscimed.2010.12.004

Montaigne, M. and Frame, D. (2003). *The complete works*. New York: A.A. Knopf.

Morris, J. (1991). *Pride against prejudice*. London: Women’s Press.

Morrison, Z. (2010). ‘On Dignity: Social Inclusion and the Politics of Recognition’. Brotherhood of St Laurence. Online article.

Mostert, M., & Kavale, K. (2001). Evaluation of research for usable knowledge in behavioural disorders: Ignoring the irrelevant, considering the germane. *Behavioural Disorders*, *27*(1), 53-68.

Muenchberger, H., Ehrlich, C., Kendall, E., & Vit, M. (2012). Experience of place for young adults under 65 years with complex disabilities moving into purpose-built residential care. *Social Science & Medicine*, *75*(12), 2151-2159. http://dx.doi.org/10.1016/j.socscimed.2012.08.002

Murphy, J., & Cameron, L. (2008). The effectiveness of Talking Mats®with people with intellectual disability. *British Journal of Learning Disabilities*, *36*(4), 232-241. http://dx.doi.org/10.1111/j.1468-3156.2008.00490.x

Nelson Bryen, D., Carey, A. and Frantz, B. (2003) ‘Ending the silence: Adults who use Augmentative communication and their experiences as victims of crimes’, *Augmentative and Alternative Communication*, 19(2), pp. 125–134. doi: 10.1080/0743461031000080265.

Nicholls, C.M. (2010) ‘Housing, homelessness and capabilities’, *Housing, Theory and Society*, 27(1), pp. 23–41. doi: 10.1080/14036090902764588.

Nind, M. (2014). Inclusive research and inclusive education: why connecting them makes sense for teachers’ and learners’ democratic development of education. *Cambridge Journal of Education*, 44(4), pp.525-540

Nind, M. (2008) *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. National Centre for Research Methods. UK.

Nirje, B. (1980) The normalization principle. in R.J. Flynn, K.E. Nitsch (Eds.), *Normalization, social integration and community services*, University Park Press, Baltimore, MD.

Noddings, N. (2012). The caring relation in teaching. *Oxford Review of Education*, *38*(6), 771-781. http://dx.doi.org/10.1080/03054985.2012.745047

Nussbaum, M.C. (2006) *Frontiers of justice: Disability, nationality, species membership*. Cambridge, MA: Belknap Press of Harvard Univ. Press.

Nussbaum, M.C. (2011) *Creating capabilities: The human development approach*. Cambridge, MA: Belknap Press of Harvard University Press.

Nussbaum, M.C. (2012) *Philosophical interventions: Book reviews, 1986-2011*. New York: Oxford University Press.

Oliver, M. (1990). *The politics of disablement*. London: Macmillan Education.

Oudshoorn, A., Ward-Griffin, C., & McWilliam, C. (2007). Client nurse relationships in home-based palliative care: a critical analysis of power

Oxford Wordlist (2008) Available at: http://www.oxfordwordlist.com/pages/search.asp (Accessed: 1 February 2017).

Pappas, C., & Williams, I. (2011). Grey Literature: Its Emerging Importance. *Journal of Hospital Librarianship, 11*(3), 228-234. http://dx.doi.org/10.1080/15323269.2011.587100

Parliament of Australia. (2016). *Access to real learning: the impact of policy, funding and culture on students with disability.*

Parliament of Australia. (2015). *Senate report into the violence, abuse and neglect against people with disability in institutional and residential settings, including gender and age-related dimensions, and the particular situations of Aboriginal and Torres Strait Islander people with disabilities, and culturally and linguistically diverse people with disabilities*

Paterson, B. and Scott-Findlay, S. (2002) ‘Critical issues in interviewing people with traumatic brain injury’, *Qualitative Health Research*, 12(3), pp. 399–409. doi: 10.1177/104973202129119973.

Patton, M.Q. (2015) *Qualitative research & evaluation methods: Integrating theory and practice*. 3rd edn. Thousand Oaks, CA: SAGE Publications.

Patton, M., & Patton, M. (2002). *Qualitative research and evaluation methods*. Thousand Oaks: SAGE Publications.

Pennington, L., Marshall, J. and Goldbart, J. (2007) ‘Describing participants in AAC research and their communicative environments: Guidelines for research and practice’, *Disability and Rehabilitation*, 29(7), pp. 521–535. doi: 10.1080/09638280600902794.

Pepper, J., Weitzman, E., Manolson, A.H. and Staff, H.C. (2004) *It takes two to talk: A practical guide for parents of children with language delays*. 3rd edn. Toronto, Ont.: Hanen Program.

Perry, A., Reilly, S., Cotton, S., Bloomberg, K. and Johnson, H. (2004) ‘A demographic survey of people who have a disability and complex communication needs in Victoria, Australia’, *Asia Pacific Journal of Speech, Language and Hearing*, 9(3), pp. 259–271. doi: 10.1179/136132804805575804.

Petersen, A.J. (2011) ‘Research with individuals labeled “other”: Reflections on the research process’, *Disability & Society*, 26(3), pp. 293–305. doi: 10.1080/09687599.2011.560413.

Philpin, S., Jordan, S., & Warring, J. (2005). Giving people a voice: reflections on conducting interviews with participants experiencing communication

Pietro, M. J., & Goldfarb, R. (1985). Characteristic patterns of word association responses in institutionalized elderly with and without senile dementia. *Brain and Language****,*** *26*(2), 230-243. doi:10.1016/0093-934x(85)90040-9

Pink, S. (2015) *Doing sensory ethnography*. 2nd edn. Sage Publications.

Pink, S. (2013) *Doing visual ethnography*. 3rd edn. London: Sage Publications.

Pink, S. (2009) *Doing sensory ethnography*. Thousand Oaks, CA: Sage Publications.

Pink, S. (2006) *Doing visual ethnography: Images, media, and representation in research*. Thousand Oaks, Calif: Sage Publications.

Pomeroy, C. (2004) *Redefining Public and Private in the Framework of a Gendered Equality*. Web Report. Serendip.
http://serendip.brynmawr.edu/sci_cult/courses/knowbody/f04/index.html

Proshansky, H.M., Fabian, A.K. and Kaminoff, R. (1983) ‘Place-identity: Physical world socialization of the self’, *Journal of Environmental Psychology*, 3(1), pp. 57–83. doi: 10.1016/s0272-4944(83)80021-8.

Pullin, G., Treviranus, J., Patel, R., & Higginbotham, J. (2017). Designing interaction, voice, and inclusion in AAC research. *Augmentative and Alternative Communication*, *33*(3), 139-148. http://dx.doi.org/10.1080/07434618.2017.1342690

Queensland Department of Communities, Child Safety and Disability Services (2009) *Complex Communication Needs booklet*.

Quenouille, M.H. (1949) ‘Approximate tests of correlation in time-series 3’, *Mathematical Proceedings of the Cambridge Philosophical Society*, 45(03), p. 483. doi: 10.1017/s0305004100025123.

Quinlivan, S. (2012) ‘The United Nations convention on the rights of persons with disabilities: An introduction’, *ERA Forum*, 13(1), pp. 71–85. doi: 10.1007/s12027-012-0252-1.

Randell, M., & Cumella, S. (2009). People with an intellectual disability living in an intentional community. *Journal of Intellectual Disability Research*, *53*(8), 716-726. http://dx.doi.org/10.1111/j.1365-2788.2009.01181.x

Reid, S.M., Carlin, J.B. and Reddihough, D.S. (2012) ‘Survival of individuals with cerebral palsy born in Victoria, Australia, between 1970 and 2004’, *Developmental Medicine & Child Neurology*, 54(4), pp. 353–360. doi: 10.1111/j.1469-8749.2012.04218.x.

Reinders, L., & Van Der Land, M. (2008). Mental Geographies of Home and Place: Introduction to the Special Issue. *Housing, Theory and Society*, *25*(1), 1-13. http://dx.doi.org/10.1080/14036090601150998

Robeyns, I. (2010). The capability approach. *The Philosophers' Magazine*, (50), 92-93. http://dx.doi.org/10.5840/tpm20105073

Rosenblum, L.D. (2011) *See what I’m saying: The extraordinary powers of our five senses*. New York: W W Norton & Co.

Ruben, R.J. (2000) ‘Redefining the survival of the fittest: Communication disorders in the 21st century’, *The Laryngoscope*, 110(2), pp. 241–241. doi: 10.1097/00005537-200002010-00010.

Ryan, S. and Reynolds, A. (2015) *New housing options for people with significant disability: design insights*. Summer Foundation Report. Analysis Policy Observatory (APO).

Saugeres, L. (2010) ‘(Un)accommodating disabilities: Housing, marginalization and dependency in Australia’, *Journal of Housing and the Built Environment*, 26(1), pp. 1–15. doi: 10.1007/s10901-010-9201-x.

Seale, J., Nind, M., Tilley, L. and Chapman, R. (2015). Negotiating a third space for participator research with people with learning disabilities: an examination of boundaries and spatial practices. *Innovation: The European Journal of Social Science Research*, 28(4), pp.483-497.

Sella, A., & Muller, M. (2011). É possível a ética do discurso de HABERMAS para pessoas com deficiência?. *Revista Brasileira De Educação Especial*, Is HABERMAS’S discourse ethics possible for people with disabilities?.*17*(2), 181-194. http://dx.doi.org/10.1590/s1413-65382011000200002

Sen, Amartya and Nussbaum, Martha (1993). *The Quality of Life.* Oxford, England, New York: Clarendon Press.

Sendak, M. (1982) *Where the wild things are and other stories/cassette/CP 1835*. New York: Caedmon.

Seymour, W. (1999) ‘Remaking the body: Rehabilitation and change’, *Choice Reviews Online*, 36(10), pp. 36-5991–36-5991. doi: 10.5860/choice.36-5991.

Shakespeare, T. (2006) *Disability rights and wrongs revisited*. New York: Taylor & Francis.

Shakespeare, T., Barnes, C. and Mercer, G. (1999) *Exploring disability: A sociological introduction*. Malden, MA: Polity Press.

Shaw, M. (2004) ‘Housing and public health’, *Annual Review of Public Health*, 25(1), pp. 397–418. doi: 10.1146/annurev.publhealth.25.101802.123036.

Somerville, P. (1998) ‘Explanations of social exclusion: Where does housing fit in?’, *Housing Studies*, 13(6), pp. 761–780. doi: 10.1080/02673039883056.

Stock, B. (2011). Mixed Messages: Validity and Ethics of Facilitated Communication. *Disability Studies Quarterly*, *31*(4). http://dx.doi.org/10.18061/dsq.v31i4.1725

Sunderland, N., Chenoweth, L., Matthews, N. and Ellem, K. (2015) ‘1000 voices: Reflective online multimodal narrative inquiry as a research methodology for disability research’, *Qualitative Social Work*, 14(1), pp. 48–64. doi: 10.1177/1473325014523818.

Taylor, R., & Thomas-Gregory, A. (2015). Case study research. *Nursing Standard*, *29*(41), 36-40. http://dx.doi.org/10.7748/ns.29.41.36.e8856

Teachman, G. and Gibson, B. (2018). Integrating Visual Methods With Dialogical Interviews in Research With Youth Who Use Augmentative and Alternative Communication. *International Journal of Qualitative Methods*, 17(1), p.160940691775094.

Tenny, C. L. and Hill, K. J. (2011) Lecture (Aug 8-9) Think Tank for the Intersection of Linguistic Research and Augmentative and Alternative Communication (AAC). University of Pittsburg, Pittsburg Pennsylvania.

Thill, C. (2009). Courageous listening, responsibility for the other and the Northern Territory Intervention. *Continuum*, *23*(4), 537-548.

Thijssen, P. (2016). *New Public Spheres*. Routledge.

Todman, J. and Rzepecka, H. (2003) ‘Effect of Pre-utterance pause length on perceptions of communicative competence in AAC-aided social conversations’, *Augmentative and Alternative Communication*, 19(4), pp. 222–234. doi: 10.1080/07434610310001605810.

Truxler, J., & O’Keefe, B. (2007). The effects of phonological awareness instruction on beginning word recognition and spelling. *Augmentative and Alternative Communication, 23*(2), 164-176. http://dx.doi.org/10.1080/07434610601151803

Tuan, Y. (1974). *Topophilia*. Columbia University Press.

Turner, B.S., Hill, S. and Abercrombie, P.N. (1984) *The Penguin Dictionary of Sociology*. Edited by Nicholas Abercrombie. London: Penguin Books.

Turner, V. (1967). *The forest of symbols*. (2014 ed). Ithaca, NY: Cornell Univ. Pr.

Valtonen, A., Markuksela, V. and Moisander, J. (2010) ‘Doing sensory ethnography in consumer research’, *International Journal of Consumer Studies*, 34(4), pp. 375–380. doi: 10.1111/j.1470-6431.2010.00876.x.

Vannini, P (2008) ‘Situatedness’ in Given, L. M. (ed.) (2008) *The Sage Encyclopedia of Qualitative Research Methods*. Sage.

VÁSQUEZ, C. and KULAVUZ-ONAL, D. (2012). Netnography: Doing Ethnographic Research Online by KOZINETS, ROBERT V. *The Modern Language Journal*, 96(1), pp.147-148.

Vincent, K. (Hon MLC) (2016) Budget Analysis speech at the Annual Scientific Meeting for the Australian and New Zealand Spinal Cord Society, November 16th 2016.

Walters, V. (2010). Working ‘in the Opposite Direction’: Joseph Beuys in the Field. *Anthropological Journal of European Cultures***,** *19***(**2). doi:10.3167/ajec.2010.190203

Wehmeyer, M. and Schwartz, M. (1997) ‘Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities’, *Exceptional Children*, 63(2), pp. 245–255. doi: 10.1177/001440299706300207.

Werner, E. (2000). Protective Factors and Individual Resilience. In *Handbook of early childhood intervention*. Cambridge University Press.

Wiesel, I. and Bigby, C. (2015). Movement on Shifting Sands: Deinstitutionalisation and People with Intellectual Disability in Australia, 1974–2014. *Urban Policy and Research*, 33(2), pp.178-194.

Wiesel, I. and Habibis, D. (2015) *NDIS, housing assistance and choice and control for people with disability*, AHURI Final Report No. 258, Australian Housing Institute Limited.

Wiesel, I., Laragy, C., Gendera, S., Fisher, R., Jenkinson, S., Hill, T., Finch, K., Shaw, W. and Bridge, C. (2015) *Moving to my home: housing aspirations, transitions and outcomes of people with disability*. Australian Housing and Urban Research Institute, University of New South Wales, AHURI Final Report No. 246.

Whyte, W. (1991). *Participatory action research*. Newbury Park: Sage.

Williams, M, Krezman, C., & McNaughton, D. (2009). “Reach for the Stars”: Five Principles for the Next 25 Years of AAC. *Augmentative and Alternative Communication*, *24*(3), 194-206

Winkler, E. (2012) *Understanding language: A basic course in linguistics*. 2nd edn. London: Continuum.

Wolff, J., & De-Shalit, A. (2013). *Disadvantage*. Oxford: Oxford University Press.

Wolff, J. (2009). Disability, Status Enhancement, Personal Enhancement and Resource Allocation. *Economics and Philosophy*, *25*(01), 49.

Wolff, J. (2002). Addressing Disadvantage and the Human Good. *Journal of Applied Philosophy*, *19*(3), 207-218.

Yong, S (2018) In: *Handbook of Research Methods in Health Social Sciences pp 1-17| Cite as Netography: Researching Online Populations Authors and*

Webpages cited

ABC News Website. Available at http://www.abc.net.au/news/2016-06-12/ndis-racing-to-meet-demand-for-disability-housing/7501622. (Accessed 7th June 2016).

AGOSCI. Available at https://www.agosci.org.au/. (Accessed the July 2017).

American Speech Language Hearing Association (ASHA). Available at http://www.asha.org/. Accessed October 3rd 2015.

Anne McDonald Centre. Available at http://www.annemcdonaldcentre.org.au/right-communicate-0. (Accessed 1st May 2017).

Art Gallery of NSW Available at https://www.artgallery.nsw.gov.au/collection/works/434.1997.9/). (Accessed 18th October 2016)

Australian Government, National Health and Medical Research Council. National Statement on Ethical Conduct in Human Research (2007) (Updated May 2015)

Australian Network for Universal Housing Design. ANUHD (2016) Available at: https://anuhd.org/ (Accessed: 2 February 2017).

Anne McDonald Centre. (no date) *Homepage*. Available at: http://www.annemcdonaldcentre.org.au/ (Accessed: 2 February 2017)

Centre for Disability Studies. Available at https://cds.org.au/. (Accessed 12th February 2016).

Communication rights Australia (no date) Available at: http://www.caus.com.au/ (Accessed: 1 February 2017).

Flinders University News (2016) Available at http://news.flinders.edu.au/blog/2016/02/18/art-helps-to-break-the-silence/ (Accessed 5th July 2017).

Inclusive Press. Toronto Canada. Available at http://www.inclusion.com/ (Accessed 7th January 2017).

In-Daily Independent News (2015) Available at http://indaily.com.au/news/2015/08/07/images-of-home-from-people-without-voices/ (Accessed 5th July 2017).

Less silence more safety project. Available at: http://www.hcscc.sa.gov.au/less-silence-more-safety-project/ (Accessed: 1 February 2017).

Merriam-Webster online. (1998). Choice Reviews Online**,** 35 (08), 35-4218-35-4218. doi:10.5860/choice.35-4218

National Disability Insurance Scheme (NDIS). Available at http://www.ndis.gov.au/ (Accessed Dec. 2nd 2015).

National Disability Insurance Scheme (NDIS): Strategic Plan. Available at http://www.ndis.gov.au/about-us/information-publications-and-reports/Strategic-plan-2013-16. (Accessed Dec. 2nd 2015).

National Stroke Foundation Australia, Facts and Figures about Stroke. Available at https://strokefoundation.com.au/ (Accessed Dec 20th 2015).

People with Disabilities (PWD). Available at http://www.pwd.org.au/. (Accessed 19th February 2017).

South Australian Curriculum Standards and Accountability Framework. (2009) http://www.sacsa.sa.edu.au/splash.asp

Talking Mats. Available at http://www.talkingmats.com/. (Accessed August 21st 2015)

The interest group on the intersection of linguistic research and Augmentative and Alternative Communication (2011). Available at http://www.linguist.org/AAC.html (Accessed 18 November 2015).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 19. Available at https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html. (Accessed 22nd May 2017).

World Health Organization (2017) *International classification of functioning, disability and health (ICF)*. Available at: http://www.who.int/classifications/icf/en/ (Accessed: 2 February 2017).

Youngcare. Available at https://www.youngcare.com.au/. Accessed May 1st 2014).

Appendices

Appendix A

CONSENT FORM TO PARTICIPATE IN THE RESEARCH PROJECT -

The meaning of home and place for people with complex communication needs

Name of participant ……………………………………………………………

What communication method has been used to complete the consent form?

☐ Electronic signature

☐ Hand written signature

☐ AAC – researcher to describe below the AAC methods that will be used, including how the participant conveys 'yes', 'no' and 'undecided/neutral'.

Description of AAC methods that will be used by participant in this research, and how the participant conveys – 'yes' 'no' 'neutral'.

………………………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

If AAC is used to provide consent, it will require the involvement of a trusted friend or advocate (and skilled communication partner) of, and chosen by, the participant to witness the consent process. This role of this person is to witness the demonstrated capacity of the researcher to communicate satisfactorily with the participant.

Name of friend or advocate

………………………………………………………………………………

Relationship to participant

……………………………………………………………………………..

CONSENT FORM TO PARTICIPATE IN THE RESEARCH PROJECT -

The meaning of home and place for people with complex communication needs

1) Please indicate yes, no, or neutral (not sure, undecided) for the following.

Is it fully your decision to participate in this study?	YES	NEUTRAL	NO
I understand -			
what the study is about and its' purpose and how research findings will be used.			
what the study involves and what is expected of me.			
the possible risks and discomforts that could arise for me from the study.			
that although identifying names etc. will not be used the study cannot guarantee my confidentiality and anonymity.			
that my participation is voluntary. I don't have to answer any questions that I don't want to and can withdraw from the study at any time.			
that the interview may involve some videoing or photographs taken of me or of aspects of my home.			

2) My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Yes ☐

No ☐

Neutral ☐

3) I am satisfied that the researcher can communicate with me.

Yes ☐

No ☐

Neutral ☐

____

Name of Participant

____

Signature of Participant (where applicable) Date

____

Name of Witness

____

Signature of Witness Date

____

Name of Researcher

____

Signature of Researcher

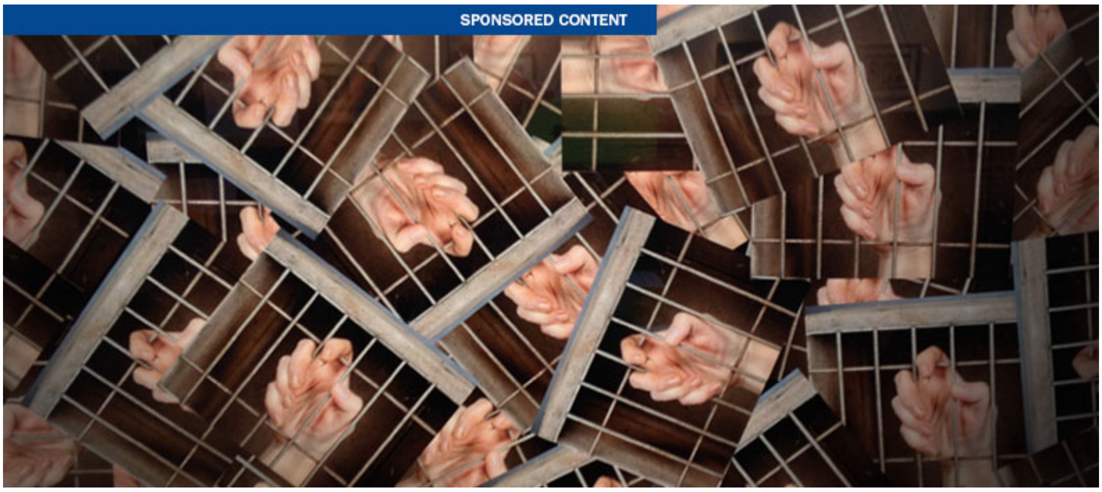
Appendix B

http://indaily.com.au/news/2015/08/07/images-of-home-from-people-without-voices/

Home truths from people without voices

Friday August 07, 2015

NEWS



The artworks in Betty-Jean Dee-Price’s SALA exhibition don’t set out to be pretty.

‘The Meaning of Home and Place for People with Complex Communication Needs’, which opens at the North Adelaide Community Centre in Tynte Street today at 5.30pm, is a show that will provoke and confront because it speaks on behalf of people whose disabilities severely affect their ability to communicate.

Many of them, says Ms Dee-Price, live lives of unimaginable isolation, frustration and powerlessness.

Ms Dee-Price, a doctoral student in the Southgate Institute of Health, Society and Equity at Flinders University, is part curator, part artist of the SALA exhibition: more importantly, she says, the art acts as a conduit to communicate something of the lives and experiences of the 10 people she interviewed as the basis for the exhibition.

“Most are people without voices, who are nearly completely hidden from view,” Ms Dee-Price says.

Appendix C

http://news.flinders.edu.au/blog/2016/02/18/art-helps-to-break-the-silence/

Art helps to break the silence

Art will help show the way for a group of counsellors, psychologists and social workers in learning new ways to communicate with clients with complex communication needs (CNN).

For the past two years, Flinders public health PhD researcher Ms Betty-Jean 'B-J' Dee-Price has been working with people with CNN, people whose ability to communicate through speech has been severely affected by a range of conditions that include such as cerebral palsy, stroke, autism and multiple sclerosis.

Drawing on interviews conducted for her thesis research, Ms Dee-Price has mounted an exhibition of art works that uses images of hands chosen by the participants, and also employs 'sensory ethnography' and augmentative and alternative communication in the creative process.

Her SALA exhibition in 2015 and the methodology behind it caught the attention of a professional group of family therapists and counsellors, and at their request Ms Dee-Price will make a 45-minute presentation this Friday (7pm) at the ***Tin Cat Café*** *in Kent Town, where her remounted and updated exhibition is on show.*

As counselling is traditionally heavily dependent on speech, Ms Dee-Price, who has a background in counselling and groupwork, said professionals need to look beyond language for alternative methods of communication.

Ms Dee-Price said some of her interviewees relied on gestures, eye movements or communication devices to make their answers known.

She says said she is thrilled at the interest shown by the Family Therapy Network.

"The whole point of my work is to encourage greater understanding and interest in addressing the gulf of awareness about communication access barriers," Ms Dee-Price said.

"Most people take for granted the opportunities to access services such as counselling and support, but for people with CCN this is often not the case."

Ms Dee-Price was recently awarded an Emerging Research Travel Award by the International Society for Augmentative and Alternative Communication, which will take her to Canada to present a conference paper on her research.